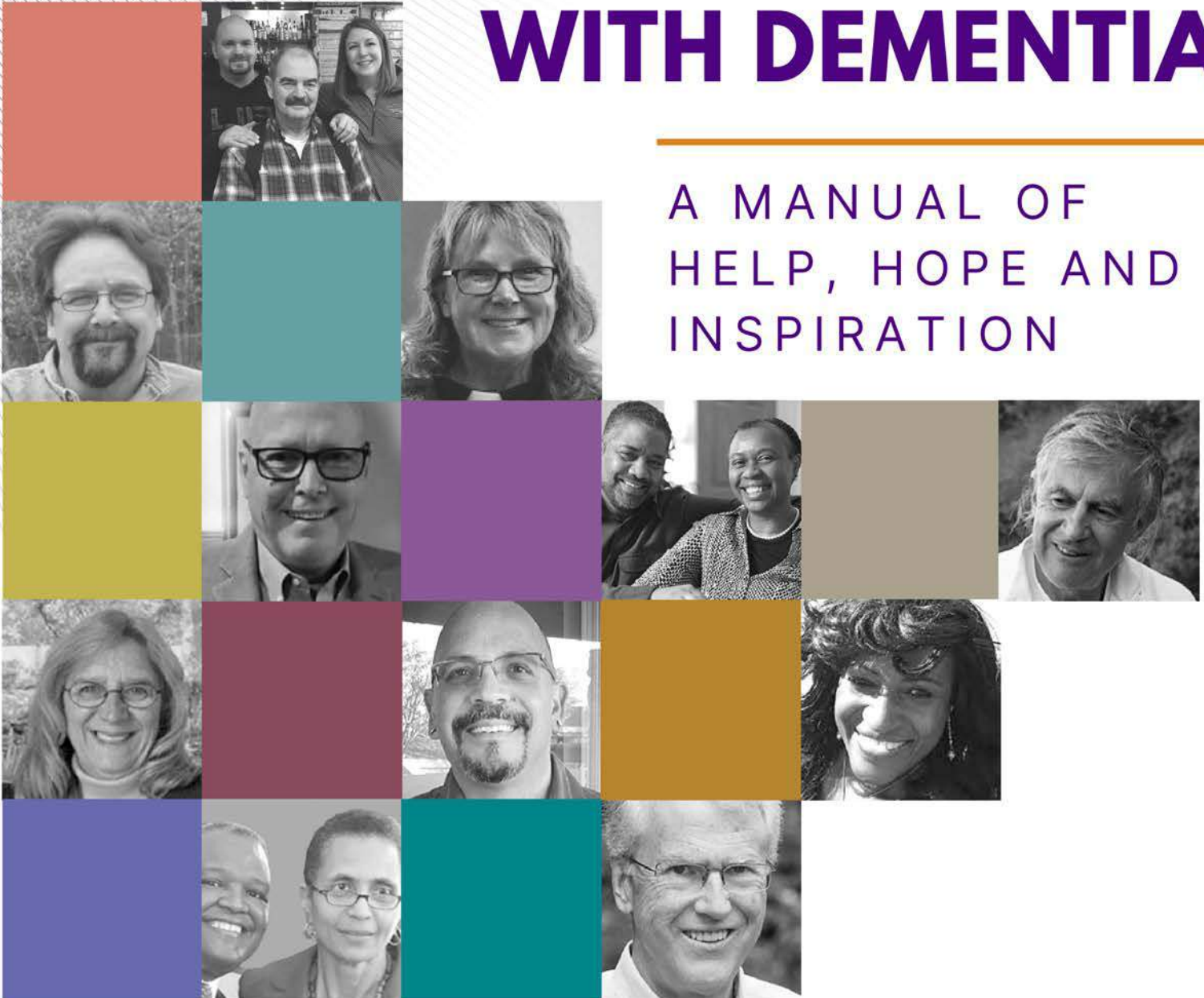


# PATHWAYS TO WELL-BEING WITH DEMENTIA

A MANUAL OF  
HELP, HOPE AND  
INSPIRATION



**Essential information by  
people living with dementia,  
care partners and leading  
dementia specialists.**

Developed by:



Dementia Action Alliance

Creating a better society in  
which to live with dementia

**We are thankful to the following for their grant and donation support for the manual.**



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# **PATHWAYS TO WELL-BEING WITH DEMENTIA:**

## A MANUAL OF HELP, HOPE AND INSPIRATION

**BY:**

**Beth Baker, Writer/Editor**

**Karen Love**

**And by 48 Contributors Who Are Living with Dementia,  
Care Partners, and Leading Dementia Specialists**



, 2022

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The belief that it takes a village is foundational to the development of this manual. The content has been written by many contributors who reflect the broad diversity of the dementia community. The decision to use the Creative Commons copyright was purposeful to recognize and celebrate the broad authorship.

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**Sherrie All, PhD; Jan Bays, PT; Jennifer Carson, PhD;  
Cyndy Luzinski, MS, RN; LeeAnn Mandarino, MA; Jim Mann;  
Daniel C. Potts, MD, FAAN; and Julia Wood, OTR/L.**

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# PATHWAYS TO WELL-BEING WITH DEMENTIA:

## A MANUAL OF HELP, HOPE AND INSPIRATION

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## I.1 About This Guide

If you search for “books on dementia” on [amazon.com](https://www.amazon.com), 30,000 entries appear — from *Alzheimer’s and Dementia for Dummies* to *The Picture Book of Kittens: A Gift Book for Alzheimer’s Patients* to *When Your Aging Parent Needs Help*. So why another book?

Most of the books about dementia are written for the care partner audience. While care partners are indeed a valuable part of the lives of individuals living with dementia<sup>1</sup>, they are not the only ones affected. As diagnostics for detection improve and more doctors understand the importance of giving people an early diagnosis, there is a growing number of people learning they have dementia while living with early symptoms. They need to know how to live proactively with and manage the symptoms of dementia.

You can have a significant positive impact on your health and well-being by being actively involved in your self-care, building coping mechanisms and resilience, and learning ways to adapt. You will need new strategies for changing abilities. Those who care about you can help by being supportive, empowering, and enabling of proactive practices. Living with dementia is only one aspect of your life and there is still much life to live!

You need a guidebook to help you live proactively. This manual is a comprehensive resource and reference written as a collaborative effort by many, including people living with dementia, to provide you with a wide spectrum of insights, expertise, information grounded in science, and inspiration.

---

<sup>1</sup> This manual is meant primarily for people who are experiencing some cognitive changes, have been diagnosed with mild cognitive impairment, or who have been diagnosed with a form of dementia. Instead of writing cognitive impairment/dementia throughout the manual, we use the term “dementia” for brevity to mean any type of cognitive change.

Ten people living with dementia and four care partners serve as your Guides throughout the manual to inform and inspire you. All are living proactively and productively. You will also gain insights from the many contributors who are dementia specialists or have expertise to share. The manual is not intended to be read from beginning to end but, rather, to be used as a resource and reference to be used as needed.

The manual is written primarily for the person living with dementia as the gold standard for person-centered practices. The manual is also useful to a much wider audience, including care partners, family, friends, neighbors, advocates, community supporters, faith groups, service providers, healthcare practitioners, policymakers, researchers, and academics.

We want to thank the Davis Phinney Foundation for its excellent book, *Every Victory Counts*, for people living with Parkinson's Disease. The book was an inspiration to us as we set out to prepare our own Manual.

When people with dementia and their care partners make living well a priority, they undergo a transformation. Apathy becomes determination. Disablement becomes enablement. Hope becomes real! You are not alone. We are part of a large community supporting you.

*Karen Love, CEO, Dementia Action Alliance;  
Manual Project Writer and Director*

*Beth Baker, Manual Writer and Editor*

Steering Committee Members

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*Cyndy Luzinski, MS, RN*

*Julia Wood, OTR/L*

## 1.2 Welcome



*Jim Mann, Manual Guide*

I remember how it felt when the doctor said to me — “You have dementia.” Some people have referred to this moment as a *punch in the stomach*. Others have expressed relief that what they have been experiencing has a name. So, you are probably thinking, now what?

This can be the start of a period of uncertainty, which is unsettling and disorienting. And that’s the purpose of this Manual. It is indescribably helpful to have a trusted resource of information provided by people who are living with dementia, their care partners, and other dementia specialists who want to support and help you live well with dementia.

The manual is not intended to be read all at once, but rather to be used as a resource as needed. Pick it up when you have a burning question or are puzzled by something. The pages are filled with valuable insights and information throughout the course of living with dementia.

It is often said that if you have met one person with dementia, you have met one person with dementia. We all have different backgrounds, different experiences at home, at work, and culturally, so every person diagnosed with dementia will encounter different challenges and opportunities.

Hearing directly from someone who is living with dementia will be an eye opener, in a positive way. You will gain immeasurable insights, know that you are not alone, and learn some of the strategies they have learned to accommodate cognitive changes.

I was diagnosed in 2007 at the age of 58. The experiences, the conversations I’ve had, and the reactions I’ve heard have all added to the richness of my life. Some have been heartwarming, and some have been jaw-droppingly surprising.

There is widespread misunderstanding around Alzheimer’s and other dementias, and there is certainly a stigma around the condition. I have been touched by what Jonathan Evans, MD, a geriatrician, said in the *Person-Centered Matters* video produced by Dementia Action Alliance:

*“Even though dementia is something that affects the brain, dementia does not equal or result in a loss of intelligence. On the contrary, people use their intelligence to overcome some of the impairments that dementia causes.”*

I especially valued his comment that, “*Dementia doesn’t rob you of your ability to experience joy or to be happy.*”

I now invite you to take a look around **your** Manual. Become familiar with its content and keep it handy for later today, next month and even next year. It’s a resource of help, hope, and inspiration!

## 1.3 You are Not Alone on this Journey



*Rev. Dr. Cynthia Huling Hummel, Manual Guide*

Many years ago, I was traveling abroad and ended up stranded at JFK International Airport because of bad weather in Rochester, NY. The delay made me miss my international flight. Aargh. I wasn't alone! Nearly all of my fellow passengers who were traveling on that flight missed their connections as well. It was a dark and stormy night both inside and outside the airport. We had gotten in so late that all the kiosks were closed up tight for the night. All the airport hotels were full and the rental car folks had already gone home. So there we all were — weary travelers, strangers with our plans disrupted and trips ruined in a place we didn't want to be. Many of us felt angry, lost and alone.

We may have been strangers to each other, but not for long. Something wonderful began to happen. Folks started helping one another by sharing what they knew and what they had. Passengers offered their cell phones so that fellow travelers could make calls to loved ones and to book new flights. A maintenance worker brought out cases of water and distributed snacks to us. A flight attendant appeared with a box of blankets and folks helped to pass them out with comforting and encouraging words. Passengers helped one another to arrange chairs to make beds for the children. Strangers offered to hold babies to give parents a break. A man handed out flattened boxes that would become our beds for the night. And as the lights were dimmed, and as we said good night to one another, I think we all realized that we were not alone on this journey — that we were in it together, that there were folks who cared and folks who, despite their own difficult situations, wanted to help.

Some who are living with a dementia diagnosis may find themselves (ourselves!) identifying with the poor travelers who were suddenly stranded in the airport terminal. Perhaps, like the frustrated travelers, you are thinking, "This was NOT in my plans" or "Why me? This is not where I want to be." For those reading who are care partners, you may be wondering what lies ahead, and how a dementia diagnosis will change your life and the life of your loved one. Some readers may be waiting for results of tests or waiting for a diagnosis for themselves or for someone they love. It's hard to wait in uncertainty, unsure of what do next — and what "next" will even look like.

Whoever you are. Wherever you are. Stop. Take a deep breath because YOU are not alone on this journey. The Dementia Action Alliance (DAA) is here to help. DAA created this manual, this guide of resources that have been written by THE experts: people living with dementia, care partners, physicians, social workers, clergy, and others to help you on this dementia journey. So take a deep breath. You might just be surprised to find unexpected joy in this journey of friendships made, resources shared, and people you can lean on and count on when you are weary. We are here to help guide you, encourage you, and offer our support. Remember, you are NOT alone.

— Blessings, Cynthia



## I.4 Words Matter

When advocate John-Richard Pagan was invited to participate at a forum at the National Academy of Sciences, he was pleased to be there. But one incident marred the day.

“I didn’t like that someone from the National Institute on Aging used the word *demented* in describing people living with dementia. I spoke up. ‘How dare you use that word? I am not demented. I am living with dementia. It’s a condition that affects my life but I’m still living.’”

John-Richard is one of the Guides in this manual whose experiences and wisdom you will hear throughout. They care deeply about being seen as individuals striving to live as fully as possible, even though they have been diagnosed with dementia. One recurring theme is that the words our culture uses to talk about dementia can greatly contribute to people’s fears, sorrows, and despair. For John-Richard, the sting of being called “demented” is still with him. Words matter!

The Dementia Action Alliance has taken this to heart. As you will see, we use the term “living with dementia” to stress that a diagnosis is not a death sentence, and that individuals indeed are still living. We also recognize that your diagnosis does not define you. Advocates in the field of dementia have taken lessons from those living with developmental disabilities who reject labels and use “people-first” language. So, for example, “people with an intellectual disability” rather than “the retarded” became the norm. (In fact, President Obama in 2010 signed “Rosa’s Law” that replaced the term “mental retardation” with the term “intellectual disability” in federal documents.)

Another term we use is “care partner” rather than “caregiver.” Individuals living with dementia are agents of their own lives for as long as possible. They are not mere recipients of care. They need support, not pity or control. They also continue to give to others. Relationships are reciprocal even as they change over time.

In contrast to language that conveys hope and dignity, our culture, including the media and some advocacy organizations, has adopted the “tragedy narrative” to define living with dementia. The British organization DEEP (The Dementia Engagement and Empowerment Project), in its guide on language [[www.innovationsindementia.org.uk/wp-content/uploads/2018/03/DEEP-Guide-Language-4.pdf](http://www.innovationsindementia.org.uk/wp-content/uploads/2018/03/DEEP-Guide-Language-4.pdf)] urges people to avoid “curl up and die” words, specifically:

- ◆ words that make people physically flinch when they hear or read them!
- ◆ words that send out the message that a life with dementia is not worth living, that people are helpless and have nothing to contribute!
- ◆ words that are negatively attached to the person rather than the condition of dementia
- ◆ words that create stereotypes

Examples are referring to people living with dementia as “sufferers,” “zombies,” “erased” or “shells.” Or dementia viewed as a tragedy or tsunami of misery. This is not to downplay the challenges and pain that dementia can cause, but rather to recognize that after the dementia diagnosis, people typically live many years having fun, learning new things, volunteering, participating in life. Being hit over the head repeatedly with grim words and images of vacant people slumped in wheelchairs is not helpful.

We encourage everyone to join us in pushing back against the tragedy narrative, embracing language of dignity, hope, and possibility. Words do matter.

## 1.5 Meet Your Manual Guides

The following people are your Guides throughout the manual. They are people who have many years of experience living with dementia, as well as a few care partners. You will hear their stories and viewpoints, and learn from their experiences and insights. We are deeply grateful for their honesty and openness, and for their willingness to share with you their stories.

### Rushern Baker and Christa ‘Cis’ Beverly

Christa Beverly was a force to be reckoned with. She was a lawyer for the underdog, including those on death row. “If anyone was done wrong, she’d elevate it to her cause,” says her husband, Rushern Baker III. “She would not let injustice go by.”

Christa, known to friends and family as Cis, was a steadfast wife and mother to their three children.

She was also her husband’s chief political advisor, speechwriter, and campaigner.

The couple met at Howard University in Washington, D.C., and even then, her peers recall, she was dressed professionally and mentored other students. She was interested in public policy, but not the business of politics. “I was always running for something,” her husband says. “I wanted to go into politics. She tolerated the idea, hoping I’d grow out of it.” He went on to win two terms as County Executive of Prince George’s County, the second most populous county in Maryland.

Meanwhile, Cis was beginning to change. At first it was little things, but steadily it grew worse. The day she got lost on her way to pick up their daughter from high school was



a wake-up call. She went to physician after physician, including four neurologists. She had such a deep well of intelligence and organizational skills that she kept passing the cognitive tests, according to her husband. After four years, though, she was diagnosed with younger onset Alzheimer's disease.

Rushern sought to shield her from the public spotlight. He even hid it from their two daughters, telling only their son, the oldest child. Rather than show up for expected public appearances, she stayed at home, gardening, cooking, and taking care of their youngest child. The family stopped going to church, a huge part of Cis's life. Hiding her disease, Rushern now realizes, was a mistake. Part of his concern was the stigma, especially in African-American communities. "I didn't want people judging or feeling sorry for us," he says. "We were not unhappy. We had challenges."

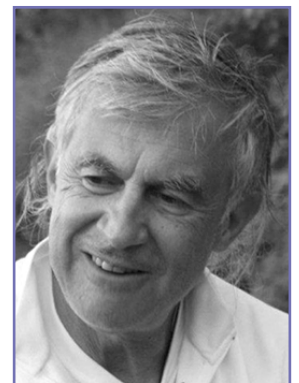
Eventually, though, the family decided to go public, appearing on a local television news show. The response was overwhelmingly positive. Appreciative people shared their own stories of family members living with dementia. "Once we went public the world opened up," he says. "Her line [sorority] sisters who were concerned about her kicked into hyper gear." He was able to continue his career as a prominent elected official with the help of friends, family, and paid care partners. The family also became outspoken supporters of those living with dementia.

And instead of being isolated at home, whenever possible Cis was at her husband's side. The final ten years of her life, when she lived with the disease, was in many ways the best, Rushern says. "It forced me to really listen, to pay attention," he says. "I had to focus completely on her."

Cis died in September, 2021, at the age of 61. Announcing her death, Rushern Baker said, "Today I lost the love of my life, my best friend, and the source of all my strength. She was our rock — the absolutely best mother to my kids and wife to me. She spent her life fighting injustice, inequities and, for the last decade, illness with grace and grit."

## Dave Baldrige

Dave Baldrige of Albuquerque, New Mexico, has worked on behalf of Native elders for more than 25 years. After leading the National Indian Council on Aging, he co-founded the International Association for Indigenous Aging (IA2) in 2003, an organization that he still directs. In recent years, IA2 began to focus on dementia, an area that historically had received scant attention. "There is a lot of denial and a great lack of education [about dementia] in Indian Country," he says.



As he was leading the effort to raise dementia awareness, in 2020, at the age of 73, Dave got a call that left him feeling “overwhelmed by the irony.” (See [Staying Positive with an Unexpected Diagnosis](#), Section 2.4, page 120.) He was diagnosed with progressive supranuclear palsy (PSP), a rare neurological disease, sometimes confused with Parkinson’s. Hallmarks of the disease include loss of executive function and balance, and depression is common. “Dealing with that diagnosis is extremely challenging,” he says.

Since sharing the news with his staff, he has been gratified by how understanding and supportive they have been. “They’re not asking me to do detailed budgeting, but they’re still making room for me to contribute. In the end, that’s all that any of us can do. I try to keep up the highest level of professional performance, but the challenges grow incrementally and imperceptibly.”

His balance is severely compromised now, so he has had to make accommodations that can be especially challenging for someone like him who lives alone. So too is managing his depression. “It’s very difficult to deal with decline when you’re used to being a performer,” he says. “Keeping that depression at bay is an effort towards not ruminating, staying in the moment, not being carried away by the negatives or the potential of it. Being as present as we can.”

He is buoyed by a network of supportive friends and colleagues, as well as his daughter, who lives across the country in New York. He also has two dogs who are a source of companionship and care. “The two passions in my life are Indian elders and search-and-rescue dogs,” he says. He has been on dozens of missions with his dogs, looking for missing people, many of whom had dementia.

One lesson he has learned through his experience: “People with dementia are still people who can contribute a great deal in their life and in our lives. It doesn’t make them less of a person. It is an aspect of [our] behavior, and it doesn’t diminish anything that we can contribute.”

## The Carson-Arand Family

Ray Arand, 77, spent his life working in law enforcement, first as a Deputy Sheriff and later as a Correctional Sergeant before his retirement in Port Angeles, Washington, a rural community on the Olympic Peninsula. “I was in law enforcement for 40 years,” he says. Following in his father’s footsteps, his son Dave Arand is also a police officer, as is Dave’s wife, Katie, and Dave’s late uncle,



Ray's brother. Now Dave's younger son, Tom, 17, hopes to be the next generation to work in law enforcement. Dave's older son, Ray, 19, serves in the United States Marine Corps.

Dave and Katie chose to live very near both sets of parents in Port Angeles. Also part of this close-knit family is Ray's daughter Jennifer Carson, who is a dementia specialist at University of Nevada, Reno.

Jennifer first became aware of her father's cognitive challenges in 2016 when her mom expressed concerns about Ray having difficulty managing their finances. His driving too was a little erratic. Jennifer went into problem-solving mode, encouraging her father to get a comprehensive cognitive assessment. But then the family had a terrible shock. "I lost my mom," Jennifer says. Her mother died suddenly from a heart attack.

Added to Ray's grief and growing cognitive problems was a serious diabetes-related foot infection. This landed him in the hospital and rehab for more than a month, later in 2016.

Once he was discharged, his children wanted to support his wish to live on his own for as long as possible. "We started to realize there were more things he needed help with," says Dave. "We realized we were dealing with dementia." At first, Ray was misdiagnosed with Alzheimer's and vascular dementia. But as Jennifer observed her father's symptoms over time, she thought it looked like Lewy body dementia and suggested another comprehensive cognitive assessment to ensure an accurate diagnosis. Sure enough, a new diagnosis of Lewy body and vascular dementia was confirmed in 2019.

For a time, Ray continued to live on his own, aided by four hours a day of home care. That was all he could afford out of pocket, but it wasn't enough. Dave's family found themselves going to Ray's house frequently, after a long day's work, to make sure he was doing okay. Even though they lived only five minutes away, it was still stressful. After some dementia training from Aunt Jennifer, grandsons Tom and Ray and a couple of their buddies took turns spending the night with Ray in case he needed anything during the night. But the situation was not sustainable.

Ray was adamant he did not want to move into a care facility. His wife had been a nurse in a nursing home, and her experience did not inspire confidence in the long-term care system. So, the family came up with a creative solution: Dave and his wife would sell their home and buy Ray's. The three generations of family would live under the same roof. "The moving process was super stressful, but we made it work," says Dave. "Everybody participated and pitched in to make it happen."

With the proceeds from selling his house to Dave, Ray now has enough to pay for more home care while Dave's family is at work and school. "It's been great," says Ray. "I was by myself for several years. Now I have the satisfaction of being safe."



Ray participates in interviewing and hiring the homecare aides. "I have home care five days a week," he says. "They come in at 8:00, make sure I'm up and still breathing, and then they fix my breakfast. If I have a doctor's appointment, they take me to it. They even go in with me and take notes. I'm very fortunate, I got two right now that are lovely people." They also take him on scenic drives, to a paved waterfront trail for walks, and grocery shopping. In addition, they prepare lunch and put it in the refrigerator for him when he's hungry.

Ray often eats supper with Dave's family — if he likes what they're having. When the family eats out, they find places that are accessible, quiet, and calm for Ray.

The living arrangement is working, says Dave, in part because they have always had a family culture of being direct and open. There have been hard conversations around such things as driving and gun ownership.

"Dad may think we're overzealous in wanting to help," says Jennifer. (Ray agrees.) "But I'm grateful to Dad for appreciating that these decisions are also for us to be able to sleep better at night, knowing everything is safe and taken care of. I appreciate Dad's respect for shared decision making. Any decision one of us makes affects the others."

## Rev. Dr. Cynthia Huling Hummel

Rev. Dr. Cynthia Huling Hummel grew up in New Jersey, the oldest of six children. Always an achiever, she was in the first class of women at Rutgers College. After a stint in the Peace Corps in Jamaica, she was hired by Dun and Bradstreet, where she worked for 15 years in technical support. Married with two children, the family became active in their church. Her life changed when her pastor urged her to explore a call to ministry.



Cynthia went on to complete her seminary studies, earned her MDiv, and became the 15th Pastor of the First Presbyterian Church in Lyons, New York. "Life was good," she says. She was leading a very busy church, working on her DMin, and raising two teenagers. In the midst of all that, she began to have memory problems. She forgot people's names and faces. "I forgot what people had shared with me," she recalls, a serious problem when you are expected to hold congregants' confidences and be praying for them.

Because she was only 49 and highly functional, her diagnosis was a long time coming. Doctors blamed her symptoms on stress, menopause, depression, and a previous head injury. After eight years, she was finally diagnosed with amnesic mild cognitive impairment due to Alzheimer's disease. Because others in her family had had Alzheimer's, she says, "It wasn't a surprise, but it was a sadness."

Unable to continue as a full-time pastor, she moved to Elmira, a place she had never lived. Her marriage had ended, and she felt alone. “Who was I, if I wasn’t Pastor Cynthia?” she wondered. But brick by brick, she began to build a new life. She enrolled in a large-scale study, the Alzheimer’s Disease Neuroimaging Initiative, to do her part in fighting the disease. Passionate about research, she has served on prestigious national boards, including the National Advisory Council on Aging and committees of the National Academy of Sciences and the National Alzheimer’s Project Act. Contributing to scientific research “is part of my new ministry,” she says.

A lifelong learner, Cynthia has audited 40 classes — and counting — at Elmira College. She also is spiritually nourished by artistic pursuits, including mask-making and music. Ten of her masks of living with dementia were displayed at the National Gallery of Art in Stockholm, Sweden. She is retired from ministry but continues to fill in at the Lyons church and other churches in her area, and sometimes recycles sermons that she preached in the past, refreshing them to reflect current events.

Cynthia feels the disease progressing, and she continues to develop new strategies to compensate for new losses. When asked how she feels, she answers, “Blessed! It took me a while to accept and reframe these changes. Look at all I’ve found — I’ve had so many amazing opportunities, I’ve met so many wonderful people, and I have a new purpose, a new ministry that God’s given me. Yes, it’s been a huge blessing in a strange sort of way.”

## Jim Mann

Jim Mann of Vancouver, British Columbia, had a 25-year career with Canadian Airlines, including eight years as the Director of Government Affairs. His career honed his communications and advocacy skills, which he has since put to good use on behalf of people like him who are living with dementia. “Diagnosed with Alzheimer’s in February 2007 at the age of 58, I ‘advocate to educate’ focusing on living positively with dementia, reducing stigma and shattering stereotypes,” he writes.



Jim had been a care partner to his mother, who had Alzheimer’s Disease, and he saw through her experience how deeply held the cultural stigma was towards people living with dementia. He became a leading advocate in Canada and beyond, educating the public and policymakers about the full life that many with cognitive challenges continue to enjoy.

He has been particularly interested in research and the importance of including in studies those who are living with dementia. In this regard, he has become an authority on medical

ethics and is a mentor to dementia researchers. He has contributed to three books, co-authored some two dozen published research papers, and given many Podcasts.

Among his many accomplishments: he served a three-year term on the federal Minister of Health's first Advisory Board on Dementia, which was focused on developing a National Dementia Strategy for Canada.

In 2020, he was awarded an honorary Doctor of Laws degree from the University of British Columbia for his advocacy efforts. The University noted, "He has been acknowledged as the single-most influential person in Canada for countering negative stereotypes and promoting an inclusive society in which persons with dementia can make an active and meaningful contribution."

Jim serves on the Steering Committee for this manual.

## Chuck McClatchey

Chuck McClatchey grew up in rural Paradise, California. He recalls the beauty of the forests there, and said it was heartbreaking to see the terrible wildfires that have swept through in recent years.

He went from the quiet of the forests to a career of adventure, beginning with 21 years in the Air Force as a flight engineer on C-41 transport aircraft. He traveled to 56 countries, including doing "an air drop on the South Pole on the 4th of July. That was an experience, I tell you."

After retiring from the military, he spent 16 years working for the Arizona Department of Transportation as a traffic signal technician, before landing his dream job in Dallas, as superintendent of maintenance for a construction group with the Texas Department of Transportation. That was when he noticed something was amiss.

First it was not remembering how to program equipment and other operations that he used to teach others how to do. He only lasted at his new job for six weeks and ended up working in the plumbing and electrical department at a Lowe's. "People would come in and describe what they were doing, and I was giving them the wrong parts," he says. The last straw was when his wife, Bobbie, brought home a little red desk that needed a simple assembly, a task that would normally have taken him 30 minutes. He couldn't figure it out and grew increasingly frustrated. She sat him down and told him that something wasn't right, and he needed to see a doctor. After considerable testing, he was told he had Alzheimer's disease. "It was a 100 percent nightmare," he says. "My darkest point was when I thought I was totally alone." He was 61.



After intense anxiety attacks and fear of what the future might hold, Bobbie gave him the shove he needed when she said, "This is not who you are." He began seeing a therapist and joined a support group where he met people who had been living with dementia for many years. He soon became a national advocate, initially for the Alzheimer's Association, and then on the DAA Advisory Board.

Eight years later, he co-leads Dementia Conversations, a weekly support group, with Jennifer Carson, through Dementia Friendly Nevada, and hosts a DAA podcast, *This Dementia Life*. "It opens your eyes, to see the joy you can get in being around people who understand what you are going through," he says. "To me, humor is essential to get through this."

## Terrie Montgomery

Terrie Montgomery took a few detours along the way, but her strong work ethic and quick mind led her to a full and varied professional life. Her mother had fervently hoped that Terrie would be the first in the family to graduate from college. But at 18 Terrie married her high school sweetheart and had a baby. Having learned administrative skills at the vocational high school she attended in Chicago, she soon landed a job at a downtown insurance company.



She learned how to do billing and general accounting and went on to work in a hospital. Her father, who saw she was good in math, encouraged her to take a tax course, and she went on to become a tax consultant. By then, she and her husband had divorced and she had three daughters. She sold insurance as a way to supplement her income, allowing her to raise her family in a thriving community. In her 40s and remarried, she eventually found her way to college, taking an accelerated adult program and receiving a bachelor's degree.

Drawn to being with elders, she volunteered to visit people in the hospital who were terminally ill. She also became a family caregiver when both her mother and her husband had cancer at the same time. Those experiences led her to become a social worker. "I landed the best job, to help those who were low income to become independent. I didn't make much money, but I loved what I did," she says.

But over time, she noticed she was forgetting her clients' names. Then she lost her wallet and her passport. Always a very neat person, she became a packrat and her apartment filled with purchases she didn't need. In 2015, at 58, she was diagnosed with Alzheimer's disease. She soon became an advocate, initially with the Alzheimer's Association, for legislation to help people living with dementia. She was thrilled to discover the Dementia Action Alliance, with people like her in leadership. She joined the advisory board and stays busy as an advocate. "The opportunity of being here with DAA gives us hope,

it keeps us busy, where you say 'let me check my calendar.' Of course we may have a moment — 'where IS my calendar?'"

Even after having to be treated for breast cancer, Terrie maintains a positive attitude and a determination to make a difference. "I speak up for those in the African-American community, because there are not enough of us who share what's going on with us."

## John-Richard Pagan

John-Richard Pagan spent many years on a spiritual quest before becoming a contemplative Christian, based in the Episcopal Church. He has found a home with the Community of the Gospel, who are dedicated to spiritual growth and nurturing love and compassion. "I've gone in and out of faiths and struggled with acceptance for a very long time," he says. "The Episcopal Church became a haven for acceptance for who I am."



John-Richard is also a busy advocate, leading several support groups, helping to establish dementia-friendly airports, and working with a dementia and sobriety group to help people like him who live with dementia and are in recovery.

Before being diagnosed with Lewy body dementia, he lived in Southern California, working in the travel industry, then as a network administrator, followed by four years as a coffee shop owner, and finally a marriage and family therapist. He also served in the military and was working on his Ph.D. when he began to experience cognitive problems, including speech and balance issues. He went through many doctors before finding the right one, who diagnosed him with Lewy body dementia.

As his abilities changed, he decided to return to his parents' home in Virginia. John-Richard, who is gay, notes that gay people are less likely to be married with children and may have a harder time finding care partners. His parents, in their late 70s, have their own cognitive challenges. "There are times we can laugh about it," he says. "Other times we get frustrated with ourselves or with each other."

As part of his Lewy body symptoms, John-Richard has vivid hallucinations, which he knows are not real even as they are occurring. "I still drive locally," he says. "I know if I see, which I have, a six-foot tall beaver waving at me, it's time to pull over and call my dad." Many times, hallucinations aren't scary, he adds. "My friend lives with a purple rooster and she's happy as can be."



He finds joy in new pursuits. He is gardening for the first time and loves spending time in the backyard. He is pursuing a second bachelor's degree, one course at a time, in religious studies. "I have dreams that I used to put off for when I retire. Now I look at how soon can I get them in." One was to go to Disney World, and he treated his mom to four days at the theme park. "We had a blast," he says.

## Kim and Robert Reid

Kim and Robert Reid grew up in Hopkinsville in southwestern Kentucky, where they met in seventh grade and became sweethearts. Two years later, Robert's mother died, and he moved to Georgia to live with his father. After Kim graduated from Western Kentucky University, she joined him there.



Meanwhile, Robert's own education had been interrupted when he became a care partner to his grandmother. He eventually got a degree in Architectural Drawing, and he and Kim were married in 1989. They now live in Hampton, Georgia, and have two children in their 20s, who live with them.

Kim worked in logistics for many years, tracking freight shipments from around the nation. At first, when she noticed something wasn't quite right, she assumed it was stress from her job. She was having trouble keeping up with the multi-tasking that was required. "I knew something was wrong, but I couldn't say what," she says.

Robert had not yet noticed anything was amiss. Kim's primary care physician assured her it was probably just menopause. But the problems persisted. Eventually, Robert went with her to an appointment, and he asked the doctor to investigate Kim's concerns. After she was referred to a neurologist and a neuropsychologist, "That's when we got on the road for the diagnosis of early onset Alzheimer's," says Robert. Although getting the diagnosis was difficult, "in some ways it was a relief. I did want to know what the heck was going on," says Kim. "I thought my brain was going crazy."

They received little guidance from their healthcare providers. "It really wasn't until we got involved ourselves in different organizations that we started getting more support and understanding," says Robert.

They also receive help from family and friends. "Everybody in the family has been pretty helpful," says Kim. "They know I've got some issues going on. We have really good kids, they're on up in age, they can help. Everything's working out pretty good."

Their faith has also been foundational for them. "Our faith has given us hope that we can live through this, that we can make it, that it's going to be alright," Kim says.

Robert, who is a deacon at Live Oak Baptist Church, says he is proud of Kim's decision to be open about sharing her diagnosis with their church family. "She has been an advocate and not ashamed to speak about it, even from the original diagnosis," he says. "The ladies of the church made a special effort to pick her up and take her out to lunch. There has been support all around."

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## Laurie Scherrer

Laurie Scherrer had worked her way up the career ladder and enjoyed the challenges of the business world. Her positions included Training Supervisor, Marketing Supervisor, Human Resources Manager, Vice President, and Director of Information Systems at a bank. "I had a knack for almost any computer programming and for bringing projects from conception to success."

When she grew tired of management, she left the bank and turned to sales where she found her true career passion. "I had a knack for it," says Laurie. "I made good money and enjoyed it immensely."

But then things changed. She found she could no longer add and subtract. And always a "bubbly motivational" person who thrived on social interaction, she found that being around people often agitated her.

In 2013, at age 55, she was diagnosed with Frontotemporal dementia (FTD). For the first few months, she was depressed. But her natural positivity soon emerged, and she became an advocate for others living with dementia. A board member of DAA, she mentors others



and organizes dementia discussion groups, helping people living with dementia through their challenges. In 2021 she organized a festive Thanksgiving gathering over Zoom, with 75 people attending. Among her other volunteer jobs: helping coordinate conference planning for DAA and serving on the technology committee and the right-to-die committee. She has been interviewed often including by AARP, the New York Times, PBS, and the South Africa Times, and has spoken in eight countries.

“You have to have a reason to get out of bed and make you smile,” she says. “The Dementia Action Alliance has become a huge part of my purpose to keep pushing.”

She comes from a close-knit family with five siblings who often buoy her spirits. Laurie, who also writes a blog ([dementiadaze.com](http://dementiadaze.com)), believes laughter is key to her well-being, along with a devoted husband and their companion pet, Lil Dawg, and support from her family. Since her diagnosis, she and her husband have been scuba diving, hiking, kayaking, and parasailing in South Africa. They have also vacationed in 32 states in their motor home. They recently moved to Alabama from Pennsylvania to live in a warmer climate, due to her husband’s health.

“I’m blessed that God has given me a purpose,” she says. “I’m so thankful that I’m able to touch people’s lives.”

## Mark Timmons

Mark Timmons was an accounting whiz. Working for Ernst and Young in Arizona, he maintained 4,000 trust accounts for a bank client, including preparing all the tax forms. “I don’t like to boast, but I have to say I was good at what I did,” he says.

But in one year he went from being the top consultant in the firm to being at the bottom. His attention to detail, his accounting skills, seemed to have vanished. Then he noticed he had post-it notes stuck everywhere, reminding him of details he used to commit to memory. Clients would ask him routine questions, and he’d put off answering them. Eventually, he was diagnosed with younger onset Alzheimer’s disease. He was 48 years old.

With that news, he packed up his little red pick-up truck, and he and his dog headed east, camping at National Parks along the way. In three weeks, he was back in his native New England. He bought a house “in the middle of nowhere” in Maine, and for a while enjoyed the remote lifestyle. But his driver’s license was taken away, and without being able to drive, rural living was impossible. “I needed to get back to civilization,” he says.



He now lives in Massachusetts in his hometown, where he has reconnected with many old friends. Although living alone has its challenges, "People who know me are very supportive," he says. He has faced a lot of loss in his life, including the deaths of his immediate family and two wives. Still, he tries to "live each day to the fullest in whatever capacity I can."

Mark is determined to reduce the stigma and stereotypes people have about dementia. "I don't let dementia define who I am," he says. "It is slowing me down somewhat. There are things I can't do that I used to, but it's all about adapting to whatever symptoms I have. Today I may seem fine to you, but you might see me tomorrow and see a different me. Sometimes the symptoms change."

He has found new purpose as both a photographer and an advocate. "Dementia has severely compromised the analytical side of my brain, but the creative side of me is blossoming as a result," he says. He has a website for his photographs, and he exhibits in shows.

When he discovered DAA, he soon became an advocate, leading discussion groups and co-administering the Memory Warriors Facebook page, a group exclusively for people living with dementia. He serves on the speaker's bureau and the DAA Advisory Board, which benefits from Mark's experience managing nonprofits. "Now that I'm on the board, I have something I can really sink my teeth into," he says. Knowing of his love for music, DAA also asked him to co-host with Laurie Scherrer a weekly "Music Beat and Trivia" virtual program. "Saying 'yes' to that was a great decision," he says. "We have a great time."

## I.6 Contributors



**Sherrie All, PhD**, is an international keynote speaker, writer, licensed clinical neuro-rehabilitation psychologist, brain health expert, and the owner and director of the Centers for Cognitive Wellness. She is passionate about empowering people to use their brains to live better, lead better, and love better. She is the author of *The Neuroscience of Memory: Seven Skills to Optimize Your*

*Brain Power, Improve Memory, and Stay Sharp at Any Age.*

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**Anne Basting, PhD**, is Professor of English at the University of Wisconsin-Milwaukee, where she is Director of the Center for 21st Century Studies. She is author/editor of multiple books, including her latest, *Creative Care: A Revolutionary Approach to Dementia and Elder Care*, as well as *The Penelope Project*, and *Forget Memory*. She is founder of and a Creative Strategist

for the award-winning non-profit TimeSlips Creative Storytelling, an alliance of artists and care partners bringing meaning and joy to late life through creative engagement. In 2016 she became a MacArthur Fellow (known as the MacArthur Genius Award).

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**Dr. Jill Bjerke**, B.S., D.C., Certified Aging in Place Specialist, has 40 years' experience as a healthcare executive. She is passionate about creating a safe home environment for seniors. In 2005 she founded her business, Home Transition Solutions Group LLC. She is the creator of the first aging-in-place, senior safety home check mobile app, Silver Spaces, first released in

2015 and being re-released in 2022 as a highly expanded and detailed home assessment tool. She is a physician, international author, and aging-in-place keynote speaker and consultant.

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**Stacie L. Bonenberger, MOT, OTR/L**, is a program manager at the Jewish Healthcare Foundation (JHF) and Pittsburgh Regional Health Initiative. She is one of the statewide coordinators for Dementia Friends Pennsylvania, a global initiative that is changing the way people think, act, and talk about dementia. She is an active member of the Dementia-Friendly Greater

Pittsburgh leadership work group. Ms. Bonenberger is also a member of the Pennsylvania Alzheimer's Task Force. Prior to joining JHF, she was the assistant facility director of occupational therapy at UPMC Passavant and has 17 years of clinical experience as an occupational therapist in Pennsylvania and Colorado.



**Pam Brandon** is the Founder and CEO of AGE-u-cate Training Institute. Drawing on 25 years of personal and professional experience as a family care partner and developer of caregiver training for families and professionals, she is passionate about person-centered strategies and approaches. Pam is the creator of the Dementia Live® sensitivity awareness

experience and program, transforming people's understanding of and empathy for persons living with dementia.



**Jennifer Carson, PhD**, is a gerontologist and the Director of the Dementia Engagement, Education, and Research (DEER) Program in the School of Public Health at the University of Nevada, Reno. She has a strong commitment to partnerships and participatory approaches to research and practice and works to improve the inclusion and well-being of persons living with

dementia. Dr. Carson is the Project Director of the Dementia Friendly Nevada initiative, is the author and facilitator of Bravo Zulu: Achieving Excellence in Relationship-Centered Dementia Care, a comprehensive, 12-hour dementia education program developed in partnership with the Nevada Department of Veterans Services.

[daanow.org/board-of-directors/](http://daanow.org/board-of-directors/)





**Sherry Dupuis, PhD**, is professor in the Department of Recreation and Leisure Studies and Co-Director of the Partnerships in Dementia Care (PiDC) Alliance at the University of Waterloo, Waterloo, Canada. She is also a Research Scientist of the Schlegel-University of Waterloo Research Institute for Aging and the former Director of the Murray Alzheimer Research and Education Program.

She uses critical participatory action research and arts-based methodologies to prompt personal transformation and more humane, compassionate, and relational care practices and policies in dementia and long-term care.

[the-ria.ca/researcher/sherry-dupuis-phd/](http://the-ria.ca/researcher/sherry-dupuis-phd/)



**Carla Eben** is the Numaga Senior Services Director at the Pyramid Lake Paiute Tribe in Nevada. After reaching out to the University of Nevada, Reno Sanford Center on Aging, she began arranging training sessions to educate her elders, her community, and local departments. In 2018 she received the Dementia Friendly Nevada Grant "Pesa Soaname." She hosted the Nevada Tribal Summit

on Brain Health and Dementia drawing 113 attendees with 14 tribes represented. She continues to educate her people. The Numaga Senior Services Program operates under 12 different Grants for the Elders of Pyramid Lake. Carla's efforts have been recognized and is featured in the CDC Alzheimer's Association Roadmap to Services across Indian Country.

[iasquared.org/brain-health/brain-health-leadership/carla-eben-pyramid-lake-paiute/](http://iasquared.org/brain-health/brain-health-leadership/carla-eben-pyramid-lake-paiute/)



**Angela Edney, MSA, OTR/L**, is a National Director of Clinical Services for Aegis Therapies. She provides field support for the company's Clinical Specialists and Advanced Practice Specialists. She also serves as a clinical resource for speech language pathology, occupational therapy, and physical therapy. She has over 30 years of experience in rehab and approximately 25 years

of experience as a clinical director in post-acute care. She has co-authored several resources for therapists, including an article on falls prevention for patients with cognitive impairments. She is also a certified "Dementia Capable Care" instructor with Dementia Care Specialists.



**Anne Ellett, MSN, NP**, is a certified nurse practitioner with extensive experience in all aspects of dementia care and the founder of Memory Care Support. She established the company to provide access to quality resources, educational products, and services to improve the health and quality of life for older people, as well as those charged with their care. Recent projects include developing the Best Life Approach for the Green House Project and the LEAP memory care training program. In addition, she is a national speaker on culture change and how misperceptions about people living with dementia perpetuate institutions locked into outdated care practices. Her book, *Dementia Care, Why It Matters* will be published by HPP press in 2023.

[memorycaresupport.com/about/](http://memorycaresupport.com/about/)



**Molly Fisher** is a clinical social worker who has worked in the field for over 15 years. As a psychotherapist, she provides quality general mental health psychotherapy services to adults, specializing her work with individuals living with a parent or person with dementia. Molly is a content expert on Alzheimer's disease and dementia-related illnesses, working nationally with nonprofits, educational institutions, and residential care facilities teaching and training staff and family on best practices in dementia care. Molly is an adjunct faculty member at New York University, where she received her master's degree in Social Work. Molly received her bachelor's degree in Criminal Justice from American University in Washington, DC.

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**Emily Franke, LSW, MSW**, is a Licensed Social Worker with extensive experience in grief recovery, end-of-life decision making, caregiving strategy, and sex and sexuality education. These skills were honed through her various roles in community mental health, inpatient hospital, and private practice. Emily earned her dual bachelor's degrees in Psychology and Gender,

and Sexuality & Women's Studies from the University of Pittsburgh, where she went on to graduate with her master's degree in Social Work. Currently, Emily's work focuses on serving the diverse older adult population with a specific focus on LGBTQIA+ older adults.





**Amy Goyer**, author of *Juggling Life, Work and Caregiving*, is a consultant and serves as AARP's national family and caregiving expert. A passionate champion for caregivers, she has been one her entire adult life, caring for her grandparents, parents, sister, and others. Amy has more than 35 years of experience working in the field of aging. She shares her caregiving journey and actionable tips for caregivers in her columns and videos. She is a sought-after speaker and moderates AARP's Facebook Family Caregivers Discussion Group ([facebook.com/groups/aarpfamilycaregivers](https://facebook.com/groups/aarpfamilycaregivers)). Find more caregiving at: [www.aarp.org/caregiving](http://www.aarp.org/caregiving)

Connect with Amy: [twitter.com/amygoyer](https://twitter.com/amygoyer) (Twitter), [facebook.com/AmyGoyer/](https://facebook.com/AmyGoyer/)(Facebook), [linkedin.com/in/amygoyer](https://linkedin.com/in/amygoyer) (LinkedIn), and [amygoyer.com](http://amygoyer.com) (website)



**Jason Karlawish, MD**, is a Professor of Medicine, Medical Ethics and Health Policy, and Neurology at the University of Pennsylvania and Co-Director of the Penn Memory Center, where he cares for patients. He researches and writes about issues at the intersections of bioethics, aging, and the neurosciences. He is also the author of *The Problem of Alzheimer's: How Science, Culture, and Politics Turned a Rare Disease into a Crisis and What We Can Do About It* and

the novel *Open Wound: The Tragic Obsession of Dr. William Beaumont*, and has written essays for numerous publications.

[www.jasonkarlawish.com/about](http://www.jasonkarlawish.com/about)



**Pia Kontos, PhD**, is a Senior Scientist at KITE Research Institute, Toronto Rehabilitation Institute-UHN, and a Professor in the Dalla Lana School of Public Health, University of Toronto. She is committed to drawing on critical participatory and arts-based (visual arts, music, theatre, film) methodologies to challenge stigma associated with dementia and to promote inclusion, relationality,

and the possibility of growth for everyone living with, and impacted by, dementia.

[kite-uhn.com/scientist/pia-kontos](http://kite-uhn.com/scientist/pia-kontos)



**Nancy Emerson Lombardo, PhD**, is Co-Founder of the Alzheimer's Association and Alzheimer Disease International. She is an Adjunct Research Assistant Professor of Neurology at Boston University School of Medicine and on faculty of BU's Alzheimer's Disease Center. An internationally recognized expert and researcher on brain healthy lifestyles with over 35 years

of experience, Dr. Emerson Lombardo is President of the Brain Health and Wellness Center and HealthCare Insights LLC in Acton, Massachusetts. Much of the work at BHWC is focused on the sought after, evidenced-based, nutrition program, Memory Preservation Nutrition.

[thriveglobal.com/authors/nancy-b-emerson-lombardo-ph-d/](https://thriveglobal.com/authors/nancy-b-emerson-lombardo-ph-d/)



**Angela Lunde, M.A.**, is an Associate in Neurology at Mayo Clinic. Her interests and research focus are in the emotional and quality of life factors experienced in those living with dementia and care partners. Ms. Lunde is involved in efforts to address stigma, improve well-being, and support the inclusion of persons living with dementia into everyday community life. Ms. Lunde

co-authored the book, *Mayo Clinic on Alzheimer's Disease and Other Dementias* and has published research and written numerous articles. She has professional training in mindfulness-based therapies, grief and loss, Dignity Therapy, and Yoga.

[mcpres.mayoclinic.org/healthletter/cultural-shift-underway-in-addressing-alzheimers-disease/](https://mcpres.mayoclinic.org/healthletter/cultural-shift-underway-in-addressing-alzheimers-disease/)



**Cyndy Hunt Luzinski, MS, RN**, is an advanced practice nurse and the first accredited SPECIAL<sup>®</sup> (pronounced "speckle") practitioner in North America, credentialed by the Contented Dementia Trust in England. Cyndy enjoys sharing SPECIAL strategies which make "living well with dementia" the expectation, not the exception. Cyndy's nursing background ranges from critical

care to community case management. In honor of her dad, she founded and currently serves as executive director of Dementia Together, a nonprofit organization in Northern Colorado which offers education, enrichment, and hope, while cultivating joy and building stronger connections for people living with dementia, their care partners, and the community.



**Sara Masoud, MPH**, is a Community Outreach Senior Coordinator of the UT Health San Antonio. In this role, she collaborates closely with community partners to offer free events and resources to families living with dementia. She hosts monthly Memory Cafés and initiated the Texas Memory Café Network to support other memory cafés. She is the Project Lead on a Patient-Centered Outcomes Research Institute award to connect with Latino families impacted by dementia in South Texas to identify community-driven priorities for dementia care research. Sara is completing her PhD in translational science toward becoming a community-engaged researcher in dementia and caregiving.

[www.uthscsa.edu/academics/biomedical-sciences/student-profiles/sara-masoud](http://www.uthscsa.edu/academics/biomedical-sciences/student-profiles/sara-masoud)



**John McFadden, M.Div.**, is an ordained minister of the United Church of Christ who served in parish ministry for 34 years and is now Pastor Emeritus at First Congregational Church, Appleton, WI. In 2012 he and his wife Susan McFadden co-founded Fox Valley Memory Project, a nonprofit organization in northeast Wisconsin that provides many programs serving people living with dementia and their care partners. With Susan, he co-authored *Aging Together: Dementia, Friendship, and Flourishing Communities* (2011, Johns Hopkins University Press).

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**Susan McFadden, PhD**, is Professor Emerita of Psychology, University of Wisconsin-Oshkosh. Susan retired from the University in 2012, and with John, now volunteers in many capacities for Fox Valley Memory Project. Her most recent book is *Dementia-Friendly Communities: Why We Need Them and How We Can Create Them* (2021, Jessica Kingsley Publishers). She continues to write and give lectures on how communities can include people with dementia in community life and overcome the stigma associated with the condition.

[uwosh.edu/psychology/faculty/mcfadden/](http://uwosh.edu/psychology/faculty/mcfadden/)



**Alka Mehra OTR, CLT, RAC-CT**, received her Occupational Therapy Degree from Delhi, India, in 1986 and has practiced in a variety of settings including hospital, acute rehabilitation, home care, outpatient, and long-term care. She has worked with Aegis Therapies since September 2013, as a Clinical Specialist for Minnesota, Wisconsin, and Iowa.

She provides patient care in multiple facilities as well as continuing education courses in dementia/cognitive management, fall prevention/balance management, mental health management, geriatric strength training, pain management, and complex disease management. She has been an active member of the American Occupational Therapy Association, as well as the OTA state associations in Minnesota and Wisconsin.



**Jodi Melius, RN, BS**, is Nurse Study Coordinator at the Mayo Clinic Alzheimer's Disease Research Center in Rochester, Minnesota. In addition to research study coordination, she facilitates caregiver support groups, and develops and presents education for professionals, community stakeholders, and families. Her focus is on understanding dementia and the diseases that

cause it, with a primary goal of decreasing the stigma that is associated with dementia. She is also a community organizer and advocate of living well with dementia. Her work is in honor of her father, who lived with Lewy body dementia.



**Barney Nelson**, from Portland, OR, spent two decades working for a global technology company, then became an entrepreneur and ran a very successful business. In 2018 he noticed he was beginning to feel overwhelmed. It was more difficult to multitask and keep up with the pace of his business. He also started to experience tremors and hallucinations, leading

to a Lewy body dementia diagnosis in early 2019. He is now a Dementia Advocate and serves on the Dementia Action Alliance Board of Directors, Advisory Board, and Speakers Bureau, and is a PAC Core Team Member with Teepa Snow's Positive Approach To Care Organization.



**Anneliese Perry, MS, NHA**, is a program manager at the Jewish Healthcare Foundation (JHF) in Pittsburgh, PA. She is one of the state-wide coordinators for Dementia Friends Pennsylvania, a movement to change the way people think, act, and talk about dementia. She is an active member of the Dementia-Friendly Greater Pittsburgh leadership work group.

Prior to joining JHF, Ms. Perry worked in both home and community-based services as well as long-term care where she served as a Nursing Home Administrator.



**Daniel Potts, MD, FAAN**, is a neurologist, author, educator, and champion of those living with dementia and care partners. Selected by the American Academy of Neurology as the 2008 Donald M. Palatucci Advocate of the Year, he also has been designated an Architect of Change by Maria Shriver. Inspired by his father's transformation from saw miller to watercolor artist in the

throes of dementia through dignity-promoting care and the expressive arts, Dr. Potts makes similar programming available through his foundation, Cognitive Dynamics, started in his father's memory. He lives with his wife and daughters in Tuscaloosa, Alabama.



**Tia Powell, MD**, is the Director of the Montefiore Einstein Center for Bioethics and of the Einstein Cardozo Master of Science in Bioethics program. She holds the Trachtenberg Chair in Bioethics and is Professor of Epidemiology, Division of Bioethics, and Psychiatry. She focuses on bioethics issues related to public policy, dementia, end of life care, the LGBTQ+ community, and public

health disasters. She has worked on many projects for the National Academy of Medicine and chaired the Decadal Survey on Behavioral and Social Science research on Alzheimer's disease. Her 2019 book, *Reimagining Dementia — Building a Life of Joy and Dignity from Beginning to End* from Penguin Random House, was featured on numerous media outlets.

[lrw.rit.mybluehost.me/about-tia/](http://lrw.rit.mybluehost.me/about-tia/)





**Allen Power, MD**, is an internist, geriatrician, and an international educator on transformational models of care for older adults, particularly those living with changing cognitive abilities. Dr. Power's book, *Dementia beyond Drugs: Changing the Culture of Care*, was named a 2010 Book of the Year by the American Journal of Nursing. His second book, *Dementia Beyond Disease: Enhancing Well-Being*, was released in June 2014, and new editions of both books were released in 2017. He is currently working with Dr. Jennifer Carson and Patricia Sprigg on a new book about creating inclusive communities for people living with dementia.



**Joanne Rader, RN, MN**, has helped pioneer key advances in reducing the use of restraints and finding conflict-free ways of bathing in long-term care. She is the author of two books that received the American Journal of Nursing Book of the Year awards: *Individualized Dementia Care: Creative, Compassionate Approaches* and *Bathing Without a Battle*. Joanne is also one of the founders of the Pioneer Network.



**Rachael Redman, MS Ed., CCC-SLP**, is a speech-language pathologist for Aegis Therapies in southwestern Wisconsin. Rachael received her Master of Education in Speech-Language Pathology from Old Dominion University after receiving her Bachelor of Science in Communication Sciences and Disorders with an emphasis in geriatrics and dysphagia from the University of Wisconsin-Madison. Rachael has been the State Advocate for Medicare Policy for the Wisconsin Speech-Language Pathology and Audiology Association since 2017. She has published research on traumatic brain injury rehabilitation in the *Journal of Brain Injury*, *Archives of Physical Medicine and Rehabilitation*, and *Journal of Head Trauma Rehabilitation*. Rachael enjoys mentoring clinical fellows and working on education programs.



**Pat Snyder** received bachelor's and master's degrees at University of North Carolina-Chapel Hill, taught school, worked as a certified paralegal in her husband's law office, and is a church deacon. She was the primary care partner of her husband, John, who was diagnosed with Lewy body disease in 2007 and who died in 2015. She authored *Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease*. She founded the Wake Forest Dementia Caregiver Class and has served on the UNC Cognitive Disorders Clinic Caregiver Team. She received the 2018 LBDA Volunteer of the Year Award and 2021 Dr. Daniel Kaufer Outstanding Service Award by Dementia Alliance of NC.

YouTube Channel: [www.youtube.com/channel/UCrjzZYVyeopBjasIMmCLH3g](https://www.youtube.com/channel/UCrjzZYVyeopBjasIMmCLH3g)

Playlist: [www.youtube.com/playlist?list=PLjwUqITKKiMqXfcxLYYmo6F-O72DyHE\\_z](https://www.youtube.com/playlist?list=PLjwUqITKKiMqXfcxLYYmo6F-O72DyHE_z)



**Beth Soltzberg, MSW, MBA**, directs the Alzheimer's/ Related Disorders Family Support Program of Jewish Family and Children's Services. Beth's work includes facilitating the JF&CS Memory Café and Balancing Act group in Waltham, and coordinating the Percolator Memory Café Network, a resource for those starting and sustaining memory cafés across Massachusetts and nationally. Beth leads the Dementia Friends public awareness program for Massachusetts and is a member of the leadership team for Dementia Friendly Massachusetts. She holds an advanced credential in hospice and palliative care social work.



**Steve Sonnenberg, MD**, started his practice of Psychiatry in 1985 after completing residency at the University of Washington, where he also obtained a Master's degree in Philosophy. For the past ten years, he has focused on Geriatric Psychiatry. Retiring from full-time practice in 2019, Dr. Sonnenberg has since taught psychiatry to counseling students, medical interns, and psychiatric residents in Thimphu, Bhutan and facilitated a spirituality group for the Dementia Action Alliance. He is completing the Buddhist Chaplaincy Training program with the intention of pursuing further research into the experience of dementia from a Buddhist perspective and the application of a Mindfulness-based approach to living with dementia.



**Pat McHenry Sullivan** is a mentor, writer, and speaker for people who want to live and work with integrity, purpose, joy, and creativity. She is the author of *Work with Meaning, Work with Joy: how to bring spirit to any job* and the creator of a legal education workshop for the California Bar Association, *From Stress, Burnout and Exhaustion to Energy, Resilience and Insight*. Pat and her

husband John often write and speak about how they thrive with his dementia. Contact Pat through [www.Visionary-Resources.com](http://www.Visionary-Resources.com) or [pat@visionary-resources.com](mailto:pat@visionary-resources.com).



**Susan Wehry, MD**, is an Associate Professor and Director of AgingME at the University of New England College of Osteopathic Medicine. A physician, educator, and advocate with almost 40 years of experience, Dr. Wehry is passionate about promoting optimal, meaningful aging for all. In 2009, she developed an interdisciplinary person-directed training curriculum known as

Oasis 2.0, which is now used in over 1200 nursing homes, helping residents living with dementia enjoy a higher quality of life. In addition, she is part of a national effort to mitigate the impact of the Covid-19 pandemic on staff and residents of long-term care. Dr. Wehry proudly serves on the Dementia Action Alliance Board of Directors.

[daanow.org/board-of-directors/](http://daanow.org/board-of-directors/)



**Lynette Wilson, MSN, RN**, has both a clinical and administrative background in public health, hospice care, and developmental disabilities. She serves as a volunteer faith community nurse at Wake Forest Presbyterian Church. Lynette cared for her husband, Roy, during his 10-year journey through dementia which was complicated by a traumatic brain injury.

Lynette has been an active member of the Wake Forest Alzheimer's Support Group since mid-2014 and serves them in a clinical advisory capacity. She has co-taught the Wake Forest Dementia Caregiver Class since its inception in January, 2018, to continue her life-long commitment to bettering the lives of others through self-empowerment and support.





**Julia Wood, MOT, OTR/L**, is the Director of Professional and Community Education for the Lewy Body Dementia Association and is an occupational therapist who specializes in the treatment of individuals with Parkinson’s Disease and related dementias. Julia has served as faculty for the Parkinson’s Foundation’s Team Training for Parkinson’s program since 2016, and is certification and training faculty for the LSVT BIG® program. She serves on the Parkinson’s Foundation Rehabilitation Task Force and co-authored the first American Occupational Therapy Association Practice Guideline for Parkinson’s Disease in 2022.

## SUGGESTED RESOURCE

DAA’s Words Matter document

<https://daanow.org/words-matter/>



# SECTION 1: Living Well with Dementia

## 1.1 Identifying Cognitive Impairment/Dementia

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*This manual is inclusive for people who are experiencing some cognitive changes, have been diagnosed with mild cognitive impairment, or who have been diagnosed with a form of dementia. Instead of writing cognitive impairment/dementia throughout the manual, we use the term “dementia” for brevity to mean any type of cognitive change.*

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If you are reading this manual, chances are you have received a diagnosis of mild cognitive impairment, dementia, or else you suspect something is going on with your cognition. You may be feeling sorrow, loss, and fear. If you have received a diagnosis, you may also feel a sense of relief to at least know what is going on. Even if you were expecting it, getting the diagnosis is tough. This manual is a guide and resource to help you learn how to be proactive with your dementia symptoms and have a good quality of life.

Early on you might not even realize you have a cognitive problem. The symptoms are often more obvious to a family member or friend in day-to-day living. Not recognizing symptoms yourself can affect your ability to get evaluated.

It is important to see a physician who has expertise in this area and not, for example, your urologist, cardiologist, or gynecologist. While many internal medicine and family practice physicians can accurately diagnose types of dementia, not all have the specific training or experience. Some forms of dementia such as frontotemporal, Lewy body, and posterior cortical atrophy can be difficult to diagnose unless the physician has specialized expertise.

For instance, some people who have been diagnosed with Parkinson's disease actually may have Lewy body dementia. It is recommended that you see a geriatrician (physician with expertise in older adult healthcare) or a neurologist with expertise in dementia.

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*Not recognizing symptoms yourself  
can affect your ability to get evaluated.*

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"There's a belief that receiving an early diagnosis may add burden before it's necessary," says Angela Lunde, Associate in Neurology at the Mayo Clinic. "What I have heard from families is that by the time they are seeking a medical evaluation things have changed quite a bit, and they are looking for answers. Although receiving a diagnosis of Alzheimer's disease or a related dementia is not what anyone wants to hear, for many families knowing what is behind the changes and challenges they have endured offers some relief and becomes a source of empowerment.

Specifically, a diagnosis can:

- ◆ Validate what the person with dementia and their family are experiencing.
- ◆ Explain the symptoms and attribute them to a disease and not a personal failing.
- ◆ Increase the likelihood of developing positive coping strategies.
- ◆ Initiate action for drug and lifestyle approaches to manage symptoms.
- ◆ Offer access to support and resources.
- ◆ Provide time to learn about and prepare for potential care needs and encourage conversations around future wishes.
- ◆ Provide a possibility to participate in research.

## Steps to evaluation and diagnosis

There may be some bumps in the road to getting evaluated and diagnosed. The following are some suggested steps when getting evaluated and diagnosed:

- ◆ **Keep a list handy to write down changes you may be experiencing.** By doing so, you will not have to rely on memory when speaking to a physician. Also, invite others close to you to write down changes they may observe.

- ◆ **Bring someone you trust to see the physician with you.** It can be hard to take in all the information yourself. Ask your companion to take notes so that you both can review and discuss the information later.
- ◆ **Ask questions if you feel uncertain about your dementia evaluation.** You may feel uncertain about what is involved in a dementia evaluation. If so, call the physician's office and ask them to describe the evaluation process, where everything will take place, and how much time is involved.
- ◆ **It's okay to seek a second medical opinion.** If you and your companion don't feel confident or comfortable with the evaluation and/or diagnosis, seek a second opinion.
- ◆ **Ask your physician if they have the training and experience you need.** If your physician can't manage this condition, ask him/her to recommend a specialist.



## ***What I Wish the Doctor Told Us***

***Laurie Scherrer, Manual Guide***

*Reprinted with permission from Laurie's blog, [dementiadaze.com](http://dementiadaze.com)*

When I was diagnosed with dementia, the doctors told my husband and me:

1. My working days were over.
2. I needed to "Get my affairs in order and see an attorney."
3. The time would come when I wouldn't recognize my loved ones.
4. For any additional information, we should go to the Alzheimer's Association website.
5. I may experience "sun-downing" in the late afternoons.
6. Come back in six months to see how rapidly you have progressed.

What the doctors **should** have told us:

1. There are many things that can aggravate or enhance the confusion and agitation that comes with dementia. With observation and patience, you may be able to recognize what triggers these symptoms. For example, noise, stress, over-stimulation, or lack of sleep. These triggers are not the same for everyone.

2. Once you recognize the triggers you may be able to find ways to lessen their impact. For example, use earplugs when in a store or restaurant to reduce the noise, keep gatherings small to avoid over-stimulation, and when needed take an afternoon nap.
3. The more independence you give up and allow other people to take care of, the more dependent you will become on others. Change your thought process from “I can’t do this anymore” to “How can I accomplish this task” (what changes or modifications can we make to assist me).
4. On days when you are using a lot of cognitive reserve, your symptoms may be strong (usually in the afternoon). This is your brain saying it is tired and needs a break. Try listening to some music or taking a nap.
5. It is OK to take some time to grieve for your losses and accept that life will change. Most people need to experience this after diagnosis and again as their abilities change. In addition to grief, you may experience shock, anger, denial, and sadness. These are normal reactions that can help you come to terms with your disease and hopefully help you to move on.
6. Get involved with others with dementia as much as possible. There are a number of groups that offer video chats with other people living with dementia so you can socialize, ask questions, and encourage each other. [dementiamentors.org](http://dementiamentors.org) offers a mentor program so you can have weekly chats with someone living with dementia.
7. Stay active and socialize with old friends and new. Once you curl up into yourself, it is hard to get out. Enjoy life, friends, family, and activities for as long as you can.
8. Build your passion to fight back! Sometimes it is the passion within us that drives us to continue fighting. Get involved in advocacy work to educate about dementia. Contact Dementia Action Alliance at [daanow.org](http://daanow.org) to get started.
9. You will have good moments when you feel “normal” and think you should go back to work, and you will have bad moments when the world is a fog (dementia daze zone). You may feel confused and disoriented and find it difficult to think. There will be times when nothing seems to make sense and you can’t remember how to do things and then the fog will go away (at least for awhile). It’s OK to admit you are having a bad day.
10. Dementia is more than memory loss. You may experience problems with your balance, lights flickering in your eyes, hallucinations, develop fears, or smell things that aren’t really there. Don’t be frightened, and keep track of any changes or strange feelings to see how often they occur.

11. Dementia can progress fast, but in most cases it is a long slow progression. You may want to keep your affairs in order, but by implementing changes and strategies you will be able to overcome many obstacles and live a beneficial and happy life for some time.

Since your doctor may have said about the same thing as mine, I hope you find this helpful. Now go enjoy life — live, love, and figure out how to make adjustments to overcome your obstacles. **My motto is: I don't want just to survive — I want to live and thrive!**

## Misdiagnosis Happens — Be Persistent

Getting the right diagnosis can sometimes be difficult, as our Manual Guides, the Carson-Arand family, share. At Ray Arand's primary care doctor's office, a nurse gave him a Mini Mental State Exam. The results led the nurse to write Alzheimer's across the top of Ray's advance directive form, with no explanation. Upon seeing this, Ray's daughter, Jennifer Carson, insisted the doctor come talk to them. He did, telling Ray he suspected he had Alzheimer's. Ray was very upset with the news, and Jennifer asked for a referral to a neurologist or neuropsychologist for a comprehensive cognitive evaluation, so that an accurate diagnosis could be made.

An evaluation at a memory clinic confirmed the diagnosis. But that wasn't the end of the story. Ray's initial diagnosis was Alzheimer's, and later changed to vascular dementia. As time went on, his daughter, herself a dementia specialist, thought that his symptoms seemed a lot like Lewy body dementia, so they requested a second cognitive evaluation. He is now diagnosed with both vascular and Lewy body dementia. A mixed diagnosis like this is common. The moral of the story: Be persistent and don't hesitate to get second opinions.

## 1.2 Why Some People Resist Being Diagnosed

In the past, dementia was considered a normal part of aging. Older people with "senility" have been part of literature for centuries, including Shakespeare's withering descriptions of old age and its "return to childishness." Still today, many people believe that dementia is not a disease or a medical problem, but a common condition that besets elders. For example, Berta Carbajal, from the Center for Innovation in Healthy and Resilient Aging at Arizona State University, explains in the *Dementia Untangled* podcast that in many Hispanic communities, dementia is considered "normal when you're old. It's accepted."



Others avoid getting diagnosed because they fear the cultural stigma that dementia carries, and they want to put it off as long as possible. Or they are worried about the implications for their job or insurance.

People also hesitate because they have gotten the message that “nothing can be done.” It is true that there is no cure for dementia. The brain is extremely complex, and there are many types of dementia (see [Section 8](#), page 379) caused by many factors. Genetics, the environment, lifestyle, and socioeconomic status all play a role. Even without a cure, there is much that you as an individual, and we as a society, can do to support the well-being of people living with dementia.

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*The bottom line:  
It's important to get an early diagnosis.*

For more on [why this matters](#),  
see *Making the Case for an Early Diagnosis*, Section 8, page 390.

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Diagnosing dementia has come a long way, although it remains an imperfect science. According to the Keenan Research Center for Biomedical Science, approximately 20 percent of people may be misdiagnosed with Alzheimer’s disease rather than a different type of dementia. Even with access to the best medical care money can buy, actor Robin Williams did not receive the correct diagnosis of Lewy body dementia during his lifetime. After Robin’s death, his wife requested a brain autopsy that identified Lewy body dementia.

## 1.3 Personhood and Human Rights

Often people living with dementia are described by public media and in films as “empty shells” or somehow lacking in personhood. This couldn’t be further from the truth. Sadly, it is a reflection of how misunderstood and stigmatized dementia is in our society, even by most of the medical and healthcare professionals. With dementia there are changing abilities but your personhood remains lifelong.

This is a global issue. The World Health Organization published a position paper, "Ensuring a Human Rights-Based Approach for People Living with Dementia," to address the fact that people living with dementia experience discrimination, stigmatization, and other violations of their human rights. [www.ohchr.org](http://www.ohchr.org)

*I believe that one of the biggest and most ignored human rights for people living with dementia is the right to have hope, to be able to live positively, meaningfully, and as fully as possible.*

**Allen Power, MD, Contributor**



## Personhood



*Anne Ellett, MSN, NP, Contributor*

Personhood speaks to the uniqueness of each human being and their individual rights and privileges. Tom Kitwood, a pioneer in the field of person-centered dementia care, said that personhood "implies recognition, respect and trust."

Perceptions of personhood can be diminished by the perspective and actions of those around us. The perspective of others can erode our sense of person such as that experienced by people living with disabilities, or older adults who are deemed unproductive and less-than.

People living with dementia also struggle for recognition of their personhood, as they are often portrayed as "not all there." The stigma that our society attaches to the diagnosis of dementia is connected to the cultural value of equating independence and productivity with full personhood. It is important to recognize that personhood is not a transitory feature that can be switched off but rather is the very essence of each person throughout their whole life.

Dementia care in western culture is also influenced by the biomedical model that focuses on a person's losses and inabilities. The biomedical model has a bias that sees the person living with dementia only as a "patient" who is dependent and incapable. Medical professionals may tell a newly diagnosed person to "get your affairs in order" and offer

no recommendations on how to maintain skills and independence or how to continue a meaningful life with purpose. “[Persons living with dementia] enter a social environment which results in the erosion of personhood and consequent invisibility for the person with dementia,” while making the consequences of dementia “very visible,” as an article in the International Journal of Older People Nursing noted.

*Dementia doesn't strip a person of their essential humanity. There's so much to who we are as human beings than our cognitive function. And if people can embrace all those other aspects of what makes us human, they can more readily live well with dementia.*

**Jennifer Carson, PhD, Contributor**



People living with dementia often find their individual rights and needs unrecognized or minimized. For family members, friends, and healthcare professionals to better support people with dementia, it's essential to honor the history and qualities of each individual with attention to their unique talents, preferences, and retained abilities in order to acknowledge their personhood.

No matter where each person is along the dementia spectrum, they deserve to be recognized as an individual, not as their disease.

*I am not half full. I am not half empty. I am a whole person and will continue to be a whole person until I draw my last breath.*

**Richard Taylor, 2011**





## ***Dementia Does Not Define Me***

***Laurie Scherrer, Manual Guide***

Reprinted with permission from Laurie's blog, [dementiadaze.com](http://dementiadaze.com)

Dementia does not define who I am. It is merely a small part of the many facets of my life, affecting decisions and changes in how I live. I am Laurie Scherrer, and I am a wife, a writer, a scuba diver, an educator, and an advocate. I'm a traveler and a speaker. Oh, and I am also living with dementia.

People that live with dementia should not be reduced to simply a diagnostic label pronounced by a doctor. Nor should they be stigmatized by a society that sees the diagnosis rather than individual abilities and identities.

Living with dementia does not automatically equal total memory loss, inability to make our own decisions, nor undeserving of living an independent life enriched with purpose, beauty, and fulfillment.

We are not defined solely by a label of dementia. As with most people, we are the cultivation of our upbringing, culture, spiritual fulfillment, lived experiences, accomplishments, failures, and our many challenges.

The medical profession and those in our communities often perceive us as incapable of contributing to any aspect of daily living. We are viewed as dying of dementia rather than LIVING WITH dementia. We are viewed as having limitations, which makes us feel worthless and incompetent.

Together, we will lift our voices to shout out that we are not a label and dementia does not define who we are. Together we can focus on our abilities, not our inabilities, and on how we can be of help to others and thus help ourselves.

## 1.4 There Are Many Things You Can Do

Most of the narrative around dementia in our culture and in the medical community is about loss. And while it is true that there is loss and sorrow around dementia, the “tragedy narrative” is not a helpful perspective for moving forward. In fact, dwelling on the potential loss and fears about the future can become a self-fulfilling prophecy. The more you are isolated and stuck, the less opportunity you will have to continue to enjoy life and to extend the years of relative good health. Once you have taken in the fact of your diagnosis and allowed yourself a chance to grieve (see [A Time to Grieve](#), Section 1.9A, page 67), try to pivot towards a sense of possibility and hope.

*People with dementia are still people who contribute a great deal in their life and in our lives. Dementia doesn't make them less of a person. It is an aspect of their behavior. It doesn't diminish anything that we contribute.*

**Dave Baldrige, Manual Guide**



“This condition feeds on despair,” says Anne Basting, founder of TimeSlips and an English professor at University of Wisconsin-Milwaukee. Chances are, your doctor will tell you to eat well, exercise, and stay socially connected. That advice is good for everyone. In addition, though, Basting suggests taking a “purposeful approach” that might begin by creating a chart of what brings you joy. It can be simple things like pausing to watch the sunset or chatting with a kid in the neighborhood. It can be listening to favorite music, singing or dancing, walking with a friend or talking on the phone, going to the movies or having pizza on Fridays, re-reading beloved novels or poetry, swinging a golf club, or playing cards. Or you can dream big and plan something you’ve always wanted to do, whether it’s going up in a hot air balloon or seeing a Broadway play. For John-Richard Pagan, it was treating his mom to Disney World, where they’d both always wanted to go.

Add to your list over time as you pay more attention to what makes you feel contentment or laughter. “Over the next six months, dive in, keep connected, keep growing and challenging yourself,” says Basting.

*I have dreams that I used to put off for when I retire, when I get older. Now I look at how soon can I get them in. We went to Disney World, my mother and I, and we had a great time. My mom walked all four parks in four days. She was 77 ... We just had a blast.*

**John-Richard Pagan, Manual Guide**



Another list might be your strengths and talents. Although you may not be able to do complex tasks that you once were adept at, there are other strengths that you have or that you can discover. Making people laugh, being a good listener, playing pickleball, knitting, volunteering, caring for grandchildren, helping in your faith community — all of us have things we are good at that we may take for granted. Write them down or capture them in drawings or photographs. Joining a DAA discussion group can be an invaluable way to move forward. [daanow.org/virtual-discussions/](https://daanow.org/virtual-discussions/)

## 1.5 Self Care

As you begin to accept the reality of living with dementia, be gentle on yourself. Try to be in tune with what your body and your emotions are telling you. You will find that at various times of day you have more energy. Pay attention and allow yourself to take it easy when you feel like it.

Expect the unexpected. Dementia is not linear. It can be a zigzag of feeling good and optimistic one day, only to feel lethargic and blue another. This is normal. Do not be hard on yourself.

At the beginning, especially soon after being diagnosed, people often report they are depressed and full of fear. If you are feeling this way, it will pass, as long as you work on it and have support.

Laurie Scherrer fell into a deep funk after being diagnosed with frontotemporal dementia. “I had no idea what FTD was — flowers on the brain?” she recalls. The doctor had no literature to enlighten her. “The doctor basically said go home and die. I started cleaning out closets and gave away some of my things that I wish I hadn’t. You focus on dying. Therefore, your life is very depressing and sad. So I got to the point where I told myself, ‘You’ve never lived like this.’ I kicked myself in the tush and said I need to live.”

For Laurie, that meant getting involved in DAA. “It’s helpful to connect with and socialize with other people living with dementia, so you can talk about challenges and feelings. You have to have a reason to get out of bed and to make you smile.” Many people, even those who never thought they would join a support group, find that talking to others experiencing similar things is very helpful. You can learn tips and strategies for how to deal with challenges that inevitably arise.

You might prefer going to the gym, taking a walk in the woods, talking to a friend, hanging out with your grandchildren, working in the garden, going fishing, or listening to music. Look for those things that calm you, make you happy, and engage you.

Remember that depression and dementia are not the same thing. Depression can and should be treated. If you find you are continuing to be isolated and apathetic, talk to your doctor or a therapist. Get help.

The following sections of this manual will give you many ways to promote your well-being as you live with dementia. Will your life be the same as it was? No. There will be changes and challenges for sure. But there will also be many good times ahead of you.



## ***Three Rules for Anyone Newly Diagnosed with Dementia***

***Terrie Montgomery, Manual Guide***

- 1** Always focus on the CANs (what you CAN do).
- 2** We ALL are in this together.
- 3** No matter what don't give up; keep on going and press forward toward the next sunrise.



## 1.6 Myths and Misconceptions

There is an astonishing lack of knowledge and understanding about dementia, even among medical providers. Journalists, too, often repeat stereotypes and myths that are not grounded in fact. Educating the public about dementia helps reduce the fear and stigma. Below are a few of the most common misconceptions about dementia followed by the facts.

**MISCONCEPTION:** Dementia and Alzheimer's are the same thing.

**FACT:** There are many diseases which cause dementia. Alzheimer's is the most common cause, affecting roughly 60 to 70 percent of dementia cases. Other causes are Lewy body dementia, frontotemporal dementia, vascular dementia, and mixed dementia, among others.

**MISCONCEPTION:** If you live long enough, you'll get dementia.

**FACT:** While the prevalence of dementia increases with age, not everyone is impacted. According to the National Library of Medicine, the prevalence of dementia for people age 70 is 14 percent and increases to 37 percent for people age 90 and older.

**MISCONCEPTION:** If your family members had dementia, you will too.

**FACT:** Dementia is a complex disease caused by many factors, including genetics. Most cases of dementia are not solely due to your genes. A family history of dementia may increase your risk, but in most cases will not cause you to get dementia.

**MISCONCEPTION:** If you are able to read this manual, you must not be living with dementia.

**FACT:** People living with dementia can live for many years functioning well and enjoying reading the daily news. Reading may become more challenging, though, especially long or complex books.

**MISCONCEPTION:** If you can speak clearly, you are not living with dementia.

**FACT:** Many people living with early symptoms of dementia can and do speak clearly. Some people may be more articulate early in the day, others later in the day.

**MISCONCEPTION:** If a person has trouble finding words, they also have trouble following a conversation.

**FACT:** Word retrieval and expressing language are controlled by a different part of the brain than understanding language.

**MISCONCEPTION:** People who have dementia cannot learn new things.

**FACT:** The brain has vast neural reserves and with stimulating triggers can form new neural pathways, resulting in learning.

**MISCONCEPTION:** You can tell by looking if someone has dementia.

**FACT:** Dementia is an invisible disability. You cannot tell by looking at someone if they have dementia.

**MISCONCEPTION:** There are no treatments for dementia, so there's no use getting diagnosed.

**FACT:** It is true there is no cure for dementia. There are some medications that help some people manage their symptoms. There is also growing evidence that a healthy lifestyle, staying engaged, and learning new things may extend the time of good health.

**MISCONCEPTION:** If you are living with dementia, you cannot live alone.

**FACT:** Many people living with dementia live alone safely. Studies estimate that one-third of people with dementia live alone, and this number may rise as baby boomers age (*Care Weekly*, 2016).

**MISCONCEPTION:** If you are living with dementia, you should not drive.

**FACT:** Many people living with dementia continue to drive a car safely early on. Many people, though, can no longer drive safely because their reaction times and decision-making ability are impaired. It is recommended that people diagnosed with dementia undergo an independent driving evaluation to determine their safety to drive.

**MISCONCEPTION:** Most people with dementia live in nursing homes.

**FACT:** Only 15 percent of Americans with dementia live in nursing homes (*Population Reference Bureau*). Nearly half of the total nursing home population, however, has dementia.

**MISCONCEPTION:** People who are living with dementia can't do things.

**FACT:** People living with dementia can and should continue to do things they enjoy and need to do as much as possible. The individual may need supports or assistance over time depending on the task, but many people are able to continue to grow, to learn new skills, to explore the arts, and to enjoy relationships with friends and family, even if maybe slower or with an adaptation. An occupational therapist can help you adapt to changing needs and maintain independence.

**MISCONCEPTION:** People who have dementia will wander and get lost.

**FACT:** Many people do have trouble with navigation. It depends what part of their brain has been affected. But there are tools to help, from keeping a simple note in your pocket to using a smartphone. Later in the disease, some people do leave their home and may become lost.

**MISCONCEPTION:** People living with dementia don't enjoy things.

**FACT:** People with dementia continue to laugh, dance, go places, and enjoy favorite pastimes. They may have challenges doing things the same way and may need to modify the previous activities or identify new interests. Identifying personalized interests and providing opportunities for engagement in personally tailored activities, with supports if needed, is important for well-being.

**MISCONCEPTION:** People living with dementia no longer recognize people.

**FACT:** They may not be able to pull up the name or articulate the right relationship, but they still know a familiar face or voice and that they share a special relationship. Watch the individual's face and you will see signs of recognition, such as a smile.

**MISCONCEPTION:** All dementias are the same.

**FACT:** There are many different causes of dementia and many symptoms. Getting a diagnosis is important in order to best manage your particular disease.

**MISCONCEPTION:** Doctors know best about how to live with dementia.

**FACT:** Unfortunately, many doctors are not well-informed on how to maintain a good quality of life after being diagnosed with dementia. Many people living with dementia report that support groups or advocacy organizations like DAA are more helpful in sharing strategies for how to live with cognitive loss.

**MISCONCEPTION:** All people with dementia have behavior problems.

**FACT:** There can be many challenging issues and concerns that people with dementia and their care partners confront. But by learning how to manage your environment, de-stressing, and taking care of your emotional and physical health, you can reduce the frequency or intensity of many problems. Remember, each person is unique.

## 1.7 Stigma

The myths and misconceptions surrounding dementia have led to a long-standing, deep-seated stigma. Stigma permeates our culture, affecting the medical community, the media, government programs and policies, employers, family and friends, and even well-meaning advocacy groups. Stigma can be internalized and affect the health and well-being of people living with dementia. Eliminating stigma about dementia is critically important for the well-being of people impacted by it.

A 2021 AARP survey noted that, “Fears over loss of independence, emotional and financial suffering, and perception of how individuals with dementia or cognitive impairment are treated, feed many of the stigmas around dementia.”

“The stigma is very real and it still exists,” says Manual Guide Terrie Montgomery. “In my case, I had to be my own advocate when I talked to the doctors and even when I talk to the family. Please let me talk for me. If anybody can explain it better, it’s me. Sometimes our family is trying to help us, and society thinks we can’t think, we’re demented, we’re damaged goods, or they think we should have this stare about us or that we can’t say anything that makes sense. You can be having a friendly conversation and you say you have dementia and the person will stop talking to you.”

## Stigma in the medical community

The AARP survey found that “While one in five adults (19 percent) said they would feel ashamed or embarrassed if they had dementia, a staggering seven in 10 providers (69 percent) said their patients would feel ashamed or embarrassed.” This misperception on the part of some doctors can lead them to avoid telling patients their diagnosis.

Laurie Scherrer contrasts her own experience with that of her mother when she was diagnosed with cancer. “They told my mom, ‘Do as much as you can.’ They told me I wouldn’t be able to do anything. As I mentor people, 95 percent of them are told to go home and die, or ‘stop living.’ The amount of fear and negativity that some doctors give you and the whole stigma really brings down people living with dementia. It doesn’t give them encouragement to live. That’s sad.”

*This sets us up to live a life without hope or any sense of a future and destroys our sense of future well-being; it can mean the person with dementia behaves like a ‘victim’ or a ‘sufferer’ and many times their care partners as a martyr.*

**Kate Swaffer**



Angela Lunde, from Mayo Clinic agrees, “Healthcare professionals have the job of providing clear and honest information about the diagnosis they are giving their patient. Often this includes sharing current and anticipated areas of loss and decline. However, it is critical to see the bigger picture — dementia is a medical condition and not an identity. A person who is diagnosed with Alzheimer’s disease or a related dementia is still the same person they were before their diagnosis. Dementia changes some things, but not everything, and not all at once. What someone with dementia *can still do* is often overlooked or minimized. By focusing on preserved strengths and abilities we tap into potential and hope, which are essential to well-being.”

The message from physicians should be one that instills hope, not despair, says Allen Power, MD, who has worked extensively with people living with dementia. Unfortunately, that generally is not the case yet. Most physicians believe the only treatments for dementia are drugs. There currently are no pharmacological cures for dementia, so from the medical world's stigmatized perspective, nothing can be done.

Kate Swaffer, a co-founder of the Dementia Alliance International who is living with dementia, famously coined a term — Prescribed Dis-engagement™ — to describe this stigmatized belief. Instead of being provided with information about how to live with and manage the symptoms of dementia when being diagnosed, people are left to their own devices to figure out this complex, chronic condition.

## Stigma among friends and family

Stigma appears among people who have the best intentions, says Beth Soltzberg, director of Alzheimer's/Related Disorders Family Support Program, Jewish Family & Children's Service in Waltham, Massachusetts. "One thing I've run across is an assumption that support services should always be for the care partner," she says. Although care partners do need supports, too often the assumption is that the person living with dementia would not benefit from supports, which is not the case. "It's a subtle reflection of stigma," she says.

"Stigma is at the root of all of our problems," says Sherry Dupuis of University of Waterloo. "It's so entrenched in our society that family members can't help but to be drawn in. It's very hard for them to let it go. Part of it is caring for someone who has dementia that is causing changes that can be very emotionally and physically challenging. I've also met many care partners who are really good at being able to evolve themselves to be in the moment to wherever the person is evolving to."

Dupuis blames the two dominant narratives in society about dementia. "For decades and decades, dementia was only presented as a tragic event. I've got newspaper clippings and magazine stories and books and videos that portray it only as very tragic. It's hard for people to look at it another way. The other discourse is biomedical, which is only seeing it as a disease. As soon as someone is diagnosed, they become the disease. Everything that they do, whether intentional or not, is connected to a symptom of the disease."

She continues, "My work has been to find ways to present an alternative. That for sure is challenging, but also rewarding. People talk to me about their dementia being a gift and transforming them, about giving them strength and resilience they never thought they would have, taking them into possibilities they never thought would happen."

## How Advocates Reduce Stigma

People like the Guides in this manual play a critical role in undermining the entrenched stigma. Many people living with dementia have become outspoken advocates. Their first-person perspectives about living with dementia are powerful and are helping to enlighten others.

Manual Guide Jim Mann talks about a woman who had been diagnosed with dementia who shut herself off, not even telling her daughter, because of the stigma. She later saw an item about Jim in the Alzheimer Society of British Columbia newsletter. “She read that and said, ‘if he can do it, so can I.’ She started coming to the support group I was attending, she did tell her daughter, and she began going out. It’s that need for some of us who are more comfortable than others to be more public, to reassure people that there is a life after diagnosis.”

*With dementia, you have to get creative. If you don’t, you are going to stay home — because of the stigma, because of that sense of ‘what if I get lost,’ ‘what if ...’ And so you either create ways to do things outside the house, or you don’t. And when you don’t, you can easily become isolated.*

**Jim Mann, Manual Guide**



A 2015 CDC Brief called *Addressing Stigma Associated with Alzheimer’s Disease and Other Dementias: Role of the Public Health and Aging Services Networks* makes a number of recommendations, among them:

- ◆ Promote opportunities for people living with dementia to stay as engaged and productive as possible, focusing on their abilities rather on what they can no longer do.
- ◆ Enhance the public’s knowledge about dementia and include people living with dementia as speakers, to talk about their experiences and the stigma they have faced.
- ◆ Include people living with dementia and their care partners in the planning and development of programs and policies that affect them.



## Stigma Among Black Americans

Many believe that there is a particular stigma about dementia among Black Americans. Even though Black Americans experience dementia at twice the rates of white Americans, in many communities there is a reluctance to be diagnosed or to tell others. Manual Guide Rushern Baker notes that he shielded his wife, keeping her at home, in part because of the stigma in the Black community. As it turned out, once the family was open about his wife's diagnosis, they were embraced by the community.

Manual Guide Robert Reid agrees there is stigma, although he said his wife, Kim, has been spared that. "With Kim, because of her standing in our church and in the community, there hasn't been stigma, there's been more empathy."

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*With Kim, because of her standing in our church and in the community, there hasn't been stigma, there's been more empathy.*

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"But I will say overall there is a stigma in several areas. A lot of it does come from historical health-related issues. One of the prevalent things that has happened in Black families in the past is that someone who today would be diagnosed with Alzheimer's was considered a little crazy or that they were just old. I've seen that, especially being involved in the church and relating with different families, that stigma does truly exist in the Black community."

Part of the problem is lack of education and access to good healthcare. "I didn't know as much about dementia until we experienced it ourselves," he says. "There is a lack of education and lack of knowledge about the disease. Due to the prevalence of it, there needs to be more outreach and more education. Due to finances and different things, Black families have never really had a good track record of going to get a physical every year or even going to the doctor unless they absolutely had to." Black communities historically have had fewer healthcare facilities, he adds, and providers deal with day-to-day complaints and are less likely to suggest additional testing.

## ***The LGBTQ+ Community's History of Discrimination and Progress***

*Reprinted with permission from the Global Council on Alzheimer's Disease and the Dementia Action Alliance's, "Calling All Voices: Stories from the LGBTQ+ Community on Learning to Live Well with Dementia"*

The LGBTQ+ community has experienced a long history of bias, discrimination, and marginalization. Their identity has been — and still is, in many parts of the world — considered criminal behavior. They have experienced discrimination from employment, housing, and healthcare. Rates of violence to the LGBTQ+ community are heart-breakingly high.<sup>2</sup>

In the United States, the three-day Stonewall Riots in New York City in 1969 began what many consider to be a turning point in history of advocacy for LGBTQ+ rights.<sup>3</sup> In 2009, the Matthew Shepard Act was signed by the U.S. Congress to expand the 1969 Federal Hate Crime Law to include crimes motivated by the victim's gender identity and sexual orientation. And less than a decade ago, in 2015, the Supreme Court declared same-sex marriage legal in all 50 states.<sup>3</sup> Progress has not been unique to the U.S. Globally other countries are moving to legalize same-sex marriage and offer protections to the LGBTQ+ community.<sup>4</sup> These milestones, of course, only paint part of the picture. Culturally, LGBTQ+ rights, advocacy, and acceptance have merged into the mainstream.

While there has been progress, challenges persist — particularly for those in the LGBTQ+ community living with dementia. We must confront these realities and give voice to a group that at present is unheard. By 2030, the number of LGBTQ+ older adults living with dementia is expected to surpass one million.<sup>5</sup> And the number of older adults who openly identify as LGBTQ+ is expected to at least double.<sup>6</sup>

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<sup>2</sup> Casey, Logan S., et al. *Discrimination in the United States: Experiences of lesbian, gay, bisexual, transgender, and queer Americans*. Health services research 54 (2019): 1454-1466.

<sup>3</sup> Milestones in the American Gay Rights Movement. PBS.

<sup>4</sup> Cameron, Darla. Johnson, Richard. *How gay rights have spread around the world over the last 224 years*. The Washington Post. 2015. [www.washingtonpost.com/graphics/world/gay-rights-history/](http://www.washingtonpost.com/graphics/world/gay-rights-history/)

<sup>5</sup> McGovern J. The forgotten: dementia and the aging LGBT community. J Gerontol Soc Work. 2014.

<sup>6</sup> Caceres BA, Travers J, Primiano JE, Luscombe RE, Dorsen C. Provider and LGBT individuals' perspectives on LGBT issues in long-term care: a systematic review. Gerontologist. 2020.

Sharing will help others in the LGBTQ+ community live well with dementia and help the broader community to become more understanding and better equipped to support and advocate for LGBTQ+ individuals with dementia.<sup>7</sup>

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<sup>7</sup> GCAD, *Calling All Voices: Stories from the LGBTQ+ Community on Learning to Live Well with Dementia*, 2022.



## A Rallying Cry Against Stigma

*Pia Kontos, PhD, Contributor*

I've thought about and written quite a bit on stigma, focusing largely on the sources of stereotypes, prejudice, and discrimination associated with dementia. At the root of stigma is the dominant assumption that dementia leads to a total erasure of the self, and that people living with dementia are incapable of purposeful communication and the pursuit of relationships and activities. We see this in how they are represented in mass media, policy documents, academic literature. Dementia is characterized as a monstrosity by the lay media — there are countless metaphors and representations that liken dementia to a living death, a never-ending funeral, and construct people living with dementia as zombies.

The consequences of this “tragedy narrative” are multiple — not just for people living with dementia, but for their families. There is considerable evidence that receiving a dementia diagnosis leads to being defined solely through the disease and the stigma that it engenders. Opportunities for engaging in social life are significantly limited — whether it's work, volunteering, or engaging in arts. When stigma is internalized it leads to feelings of shame and inadequacy, depression, anxiety, and even suicide.

Stigma can become a barrier to help-seeking. Even in instances when help is sought, stigmatizing attitudes of healthcare professionals can be a barrier to timely diagnosis and can delay access to treatment. Stigma not only affects the person living with dementia but similarly affects the family; it is linked to embarrassment, shame, fear, increased career stress, and isolation. It poses a significant barrier to the social inclusion of people living with dementia and their family care partners, and it negatively affects their health and well-being.

The “tragedy narrative” fuels prejudice and discrimination. The assumption that people living with dementia are not people anymore, that they've effectively lost their self, enables and legitimizes restrictions on their freedom and their treatment as disposable.

There is no affront to human dignity with such practices if you believe that the person is not a person. Yet this is not so. There is meaning, creativity, humor, joy, sadness, and so much more human potential, and it is imperative that we support this. People living with dementia should have equal access to health, well-being, privileges, and opportunities. Regardless of their cognitive impairment, race, ethnicity, sexual preference, economic status, they should have equal access. They don't.

There are individuals and organizations across the globe that are doing really important advocacy work. There are dementia activists who have spoken at the United Nations, the World Health Organization, with the Senate of Canada and are fighting hard for dementia to be better supported. We need to work collaboratively to challenge stigma and then mobilize the practices and the political processes to assure the rights of people living with dementia are upheld.

We need a more just, inclusive, and caring society. We need to provide life-enriching opportunities for people living with dementia to support their engagement in social life to the fullest extent possible. We must prioritize the quality of human interaction. That requires strong leadership and a commitment to relational caring. It's recognizing at an individual level, an organizational level, and more broadly at a societal level that we can and must do more. Let this be our collective goal.

## 1.8 Dementia As a Disability

Is dementia a disability? A growing number of people say that it is. With proper support, many people living with dementia would have a better quality of life and be able to engage more fully in the wider world. Changing our perspective from one of a dreaded disease to a manageable disability can affect everything from employment to transportation and accessibility to cultural events. It can also push back against deep-seated social stigma.

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*Dementia is the leading cause of disability in older adults, but few countries provide disability assessment and support.*

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"Dementia is the leading cause of disability in older adults, but few countries provide disability assessment and support," says Pia Kontos. "The importance of recognizing it

as such is about ensuring the same kind of support and assessment as people living with other disabilities.”

Jennifer Carson says we need to move beyond the biomedical view. “We have to start thinking in terms of rights. We have to stop thinking of dementia as a disease only,” she says. “Not to negate that there is underlying pathology, but there has to be an additional frame.”

That said, many dementia advocates feel strongly that they do not want to be defined as “disabled.” “By legal definition and social recognition it is very much a disability as it decreases abilities I have traditionally been expected to fulfill,” says Manual Guide John-Richard Pagan. “But how I personally perceive it must be beyond that label, beyond that limitation. I must see that it is only a part of who I am, and I can do more to move through it than simply accept and wallow in it as a disabling thing.”



## ***Dementia as a Disability Reframes My Thoughts***

***Kirsten Jacobs***

*Senior Director, Shared Learning Initiatives, LeadingAge*

*Reprinted with permission from 2017 article*

If I think of dementia as an illness, for example, I might focus my attention on the medical aspects of the condition, and how its symptoms can be “fixed” with medication. I might see people with dementia as “patients” on the road to inevitable decline and diminishment.

Thinking of dementia as a disability, on the other hand, reframes my thought processes completely.

It makes me think about human rights and empowerment, about the Americans with Disabilities Act, and the international human rights treaty known as the Convention on the Rights of Persons with Disabilities.

It helps me see that people living with dementia have hopes and dreams, skills and talents, and the desire to keep learning and growing.

It stirs me to imagine modifications to our language, environment, and attitudes that could open doors for people with dementia, just as ramps and curb cuts opened doors for people with physical disabilities so many years ago.

## 1.9 A Time to Grieve: A Normal and Natural Process



*Rev. Dr. Cynthia Huling Hummel, Manual Guide*

I remember the day that I went to my first class on “Understanding Alzheimer’s.” I had read about the free 8-week class in the newspaper and figured, if this is what I have, then I better learn more about what’s ahead. I called the 800-number, signed up, and double-checked the directions to the Big Flats Community Center where the classes were being held. As I pulled into the parking lot, I felt a wave of sadness come over me. I turned off the car and just sat there as my sobs came in waves. I went through every tissue in my purse and every napkin in my car, wiping away my tears. Why me? Here I was at the peak of my career, and it felt like I had the rug pulled out from under my feet. I was mad at life and mad at God. And it took me a while, but my sobs gradually subsided enough for me to pull myself together, to get out of my car, and head into class.

The classes helped me to begin to come to terms with my dementia diagnosis and to begin a new chapter in my life — one that I had not planned on, one that I did NOT want. I grieved my old life — the life I had before dementia snuck in and changed everything. I was also grieving a future that was not going according to *my* plans.

The reality is that life happens and our dreams for our futures are sometimes dashed. In times like these, our reactions may include rage, depression, exhaustion, and grief. It’s important to remember that grief is a normal reaction to loss. And throughout our lives, we will experience times of loss and grief; for example, the death of a loved one, the loss of a significant relationship, an unexpected ending, or even receiving a difficult diagnosis like dementia.

In times like these, grief moves in — like an uninvited guest, disrupting our lives. Grief turns things upside down. Maybe we can’t eat or maybe we binge on comfort food. Maybe we can’t sleep and walk the floors all night or just the opposite: that we can’t keep our eyes open and sleep all day. Grief affects each of us differently and differently on different days.

Please be gentle with yourself and patient with your grief — because grief is helping you to adjust to a new reality, in this case **LIVING WITH DEMENTIA**. Grief may be helping you to move from “why me?” to “what next?” If we let it, grief can help us begin to move to a place of acceptance, where we can begin to rediscover joy in our lives and in our journey. Grief may help us to move from despair to hope.

My mother used to tell us kids, “no one ever promised you a rose garden.” What Mom wanted us to know, from very early on, is that **EVERYONE** faces disappointments, heartaches, and losses in life, and she reminded us to focus on our blessings. Some people will keep a blessing journal and take note of the good things and good times in their life. Some will keep a blessing jar where they jot a blessing on a piece of paper and watch the blessing jar fill.



- ◆ **Don't focus on what you can no longer do, but how you can still make a difference.** One of the best ways that I have found helpful in times of grief is to use our experience (our loss) to help someone else who is going through a time of loss.
- ◆ **When we help others, we help ourselves.** Volunteer at a food pantry. Call or visit someone who is homebound. Become a dementia buddy to someone else who has been recently diagnosed.
- ◆ **Keep moving.** Get up. Get showered. Get dressed. Set yourself small daily goals. Exercise! A walk around your backyard or neighborhood can do wonders for the weary soul. Think about joining a discussion group or memory café. It's a great way to hear how others have navigated this new chapter called *Living with Dementia*. DAA has many groups for people living with dementia and for care partners, too. Interested in art? We have an arts group! Interested in sports? There's a group for you. Check out the DAA calendar on the website. [daanow.org/virtual-engagements/](https://daanow.org/virtual-engagements/) Be part of a group! Build connections! Make friends!
- ◆ **Grief often comes in waves.** Sometimes the waves are gentle and sometimes they are more like tsunamis knocking us to our knees. You may feel like screaming — if so, scream into a pillow, not at loved ones. Some people find it helpful to write their angry thoughts down on a piece of paper and flush that paper in the toilet. I have a friend who took up boxing so he could punch a bag, rather than take his anger out on his family.
- ◆ **Reframe your experiences of changing abilities.** Here's an example: I have a friend living with dementia who, after much soul searching, decided to give up driving. Instead of being angry about NOT being able to drive, he reframed his experience, by deciding he wanted to be chauffeured. He asked his wife and friends to be his chauffeur. By changing his mindset, he was able to let go of his anger and grief.
- ◆ **Try something new.** This is the time in your life to try a new hobby, take a class, or try a new activity. After my diagnosis, I decided I wanted to learn how to kayak, and discovered I love it. Hey, you never know until you try. I have a friend with dementia who joined a hiking club. I have many friends who discovered their inner artist and that they love painting. Starting a new hobby or sport is not only good for the spirit, it is good for our brains.

Many people find comfort in their spiritual practices — by attending worship services, by incorporating a time for meditation and prayer into their daily lives, and by reading their sacred scriptures. Some have found great solace in sharing their diagnosis with their faith community, asking for prayer and care. Some have started programs in their houses of worship and helped their congregations to become “dementia friendly.”



- ◆ **Check out what's happening in your community.** Many activities and events are free or available for a modest charge. Your local library might be offering classes or programs. These are wonderful opportunities to learn more and make helpful connections.
- ◆ **Learn to ask for help.** This is a hard one for many of us, especially those of us who in the past were the ones providing the help. If you need a ride, ask a friend, ask a neighbor. Check in with your local office on aging to find out what kinds of community help are available. For example, you may be eligible for Meals on Wheels or for transportation to/from a doctor's appointment. Check in with your faith community, let them know your need, and see what help might be available.

— Blessings, Cynthia

## If you find that your grief is debilitating ...

... or you have thoughts of hurting yourself, please make an appointment to talk to your primary care physician and/or a grief counselor to explore other options that can help you move from sorrow to acceptance.

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*DAA is here to help you as you navigate this new chapter in your life — a chapter that has the possibility of adventure, of service, of joy!*

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## 1.10 Acceptance and Moving Forward



*Barney Nelson, Contributor*

Barney Nelson was diagnosed with Lewy body dementia in 2018. He writes:

Acceptance is where the living can really start — when you can accept the situation and realize you still have a lot of control over your life, it doesn't have to be a tragedy narrative. There's a lot of power that can come from acceptance. People compliment me on my positivity, but I think it's really acceptance. It's a very powerful thing.

You may decide you're going to pivot — maybe there's something you can't do anymore, so you pivot to and do different things. You're gaining a new life because of the choices you're making and you're facing that.

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*Viktor Frankl in his memoir,  
Man's Search for Meaning, wrote:  
Everything can be taken from a man but one  
thing: the last of the human freedoms —  
to choose one's attitude in any given set of  
circumstances, to choose one's own way.*

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Viktor Frankl talks about the last of the human freedoms, the last thing that anybody can hold on to, is the power to choose and take one's path. It's ultimately your attitude that you take towards things, that is the thing that people cannot take away from you.

You can still live a meaningful life, discovering what you can do. There's the joy of meaning, as opposed to just being happy. Being happy makes you feel good at the time but it lasts only for a little bit. A meaningful life is connecting with something deeper and connecting to your core. Meaningful things have the bigger impact.

We don't let dementia define us. It's the same thing with grief and loss — they are going to happen. One thing I've discovered, though, is loss can be such a powerful thing. I've become more empathetic than I used to be. I had covered up my feelings of grief and loss. As I've allowed myself to really feel those things, I've felt this level of empathy that I haven't had

before. I was a business executive working for tough companies — it's been an adjustment for me to find that empathy. And I didn't find it until I looked at the loss and grief I've had. You can get to the point you celebrate the grief because you realize what it can do for your soul.

## 1.11 Envisioning Your Future



*Rev. Dr. Cynthia Huling Hummel, Manual Guide*

When my kids were little, I was asked to be a fortune teller at the East End Elementary School fair — not because I had any special powers of prognostication, but because all parents were expected to help out. On the day of the fair, I put together a makeshift costume, donned a long black wig, and headed to the school carrying a small, plastic crystal ball.

Children and adults were already lining up outside my tent and, for just 25 cents, they could ask me about their futures and hear my amazing predictions. “You will meet a tall, dark stranger!”; “Your teacher will give you homework”, and the always popular, “Someone really likes you.” Amazing, I know!

As children, many of us not only predicted but started planning for our futures. We pictured ourselves as teachers, doctors, or plumbers and took classes to reflect those interests and help us reach our life's goals. Envisioning our future was not and is not a one-time event. Life happens. Life changes. And because of those changes, our hopes and dreams often change as well. Many of us have not only changed careers multiple times, we have moved in and out of different relationships. That's life! Many of us now find ourselves living a very different life than the one we had once dreamed about. (Trust me, I never imagined being a pastor with dementia.) ALL of us have been through good times and hard times (sometimes at the same time.) We've had to learn to adjust and adapt along the way and begin to accept our new life. Acceptance is the key that will help us move from “Why me?” to “What next?” Acceptance helps us move from bitterness to happiness.

Some of you who are reading this essay might still be reeling from the news of your dementia diagnosis and perhaps YOU are wondering what the future now holds. You may be fearful that the dreams that you had for yourself and those whom you care about were dashed to pieces on the day of your diagnosis. As a former amateur fortune teller, I have something important to share with you. Your future may not be unfolding the way you had planned but it's still unfolding. Your future may be different than what you dreamed, but different can still be good. It's like getting on a plane to visit Italy and ending up in France because of a mechanical problem with the plane. Getting angry and upset will not help

or change the situation. It is what it is. You're in France now. You can sit there and stew, or you accept this unexpected change. Instead of focusing on your disappointment, you could, IF YOU CHOOSE, begin to look for the silver lining. There will be detours in life, so try to find joy in your journey. Please don't let a dementia diagnosis put an end to your dreams.

There are so many possibilities waiting out there that are still open to you. Dare to dream BIG! Make a list of the things that you would still like to accomplish. Make a list of the places that you would like to visit. Jot down a list of the people you would like to see. Today, I would like to invite you to start envisioning a new and a bright future because we have the power to shape our futures and that visioning starts with introspection. As we dream our dreams, as we make plans, as we set goals, our future will begin to take shape. Sometimes people with a diagnosis will restrict themselves in the present (and in the future) by mentally setting up barriers and saying to themselves: "Well I can't do THAT anymore." Why do we do this to ourselves? True, we may not be able to live out the vision exactly as we planned, but that doesn't mean we can't reach for the stars. We may have to adapt. That's okay. We may need to change our direction a bit. But I can tell you that we can still find purpose and joy in life — in spite of a diagnosis of dementia. Start by shifting your perspective.

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*You can sit there and stew, or you can accept this unexpected change. Instead of focusing on your disappointment, you could, IF YOU CHOOSE, begin to look for the silver lining."*

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Instead of focusing on what you can't do, shift your focus to what you can still do. Here's an example: I can no longer serve as a Fire Chaplain and race to the scene of the fire. It is far too dangerous for me now. But I can still be part of the fire department and offer support (and goodies) to my friends who are serving. Think about adapting an activity that you enjoy. I have a friend who loves to bowl, but his symptoms made bowling difficult for him and Larry dubbed himself the "King of the Gutter Balls." Larry was embarrassed and discouraged and was ready to drop out of the league. The manager of the bowling alley learned of this and provided bumper cushions — no more Mr. Gutter Ball! Larry continues to love bowling with the boys. Our friend from DAA, Laurie Scherrer, had a dream to skydive and didn't let a dementia diagnosis slow her down. Dream big, my friends. Dream big!

Thinking about your future, you may be open to trying a new activity or sport. Join a golf league, try softball, pickleball, or soccer. Sports are a wonderful way to make connections, build friendships, and keep active. Keeping active is good for body, mind, and spirit. Take an art class. Learn to paint, crochet, or garden and share what you know with others.

As you envision your future, think about how you might use your work experiences and life experiences to help others. Could you tutor a child in math or reading? Volunteer at a food pantry? Shovel snow for a neighbor? One of my friends living with dementia volunteers at the library helping people with the computer. It's a win-win! Part of our life review is being thankful for those who provided guidance and leadership to us (and others). In this new season of our lives, how might we pay it forward?

As you envision your future, you may want to check with your financial advisor about how to secure your financial future. You may want to seek the advice of an eldercare attorney who can guide you in your planning with special attention to the laws in your state. It's important for all of us to take care of "getting our house in order" so to speak — to make sure that we have identified a family member or friend as power of attorney, someone who can and will speak for us when the time comes that we are unable to speak for ourselves. It's important for us to make our wishes known. (You will find helpful information on this topic in [Getting Your Financial and Legal Affairs in Order](#), Section 4.8, page 251.)

No one knows for sure what the future will bring, but we can dream our futures and shape our futures. A dementia diagnosis is not the end of our life or our dreams. We are still the same person we were before we got the news. Dementia may signal the beginning of a new chapter in our lives — one that is full of possibilities. Don't let your diagnosis define you. There will be changes and challenges ahead, but life is always full of changes and challenges. Keep going and growing. Keep learning and exploring. Cultivate an attitude of gratitude. Be a blessing. Follow your dreams, and we here at DAA will be here cheering you on.

— Blessings, Cynthia

## 1.12 The Importance of Having Purpose and Goals

Having a sense of purpose is basic to our sense of well-being and confidence. Someone's purpose can be as grand as fighting world hunger or as personal as making those around you smile. Your purpose might be living the best life that you can, given a diagnosis of dementia.

Researchers have been studying how a sense of purpose affects our well-being. A 2022 online article in the journal *Social Work Today*, "Cultivating a Sense of Purpose in People with Dementia," notes, "Individuals with dementia still understand that helping out, being

busy, lending a helping hand, giving to other people, being listened to, and feeling that they belong are important indicators of quality of life.”

But people living with dementia often feel — or are made to feel — that their life no longer has purpose. This can contribute to depression and anxiety. “Studies have shown that individuals diagnosed with depression and anxiety score significantly lower in purpose in life measures than those without,” the article stated. And conversely, “Studies also show a correlation between greater purpose in life and lower rates of depression and sadness.”

*You need to have a reason to get out of bed  
and things to make you smile.  
The Dementia Action Alliance has become  
a huge part of my purpose.*

**Laurie Scherrer, Manual Guide**



A 2017 review of 31 studies on purpose and aging, published in the *International Journal on Aging and Human Development*, found that although a sense of purpose does tend to decline as people grow older, “Nevertheless, the potential to experience purpose persists across the life span, by providing opportunities for older adults to continue contributing roles, participate in meaningful activities, and sustain their social value and sense of relevance.”

*My purpose now in life is to be an advocate  
for dementia and people living with dementia.*

**Mark Timmons, Manual Guide**



To fulfill your sense of purpose, it's a good idea to set personal goals and to write them down or record them, to remind yourself. Anne Basting suggests, "Ask yourself: 'What are my goals?' It might be about being open to creative and artistic languages ... capturing the world as I want to see it. Having more intergenerational relationships. Becoming an ambassador to these [dementia] coalitions. I want to teach my doctor how to accompany me on this journey. What are your goals for this?"

Your purpose and goals will likely change along with your condition and circumstances. There are inspiring stories of people living in nursing homes who refuse to become castoffs. They may pursue painting or singing. They may organize a quilt-making project or collect funds for employees' Christmas gifts. One woman who had always been an active volunteer before moving to the nursing home continued to do so over the phone, managing other volunteers at her church's food bank. Or they may simply show kindness in small ways to other residents.

Our Manual Guides readily share their purpose. Kim Reid says her purpose continues to be to ensure their children, now in their 20s, "keep going in the right direction."

With dementia, says Manual Guide Rev. Dr. Cynthia Huling Hummel, "It's all how we frame it. We can look at it as half empty or half full. Part of it is going through the grief process. It was a huge loss. But if you reframe it and look at all I've found: I've met new people. I have a new purpose that God's given me. It's been a huge blessing in a strange sort of way."

*I'm a longtime canine search and rescue dog handler. We tend to develop close relationships with our animals, with sophisticated levels of understanding. The care of my two doggies — we're radically bonded — is my purpose. They are my reason for staying alive.*

**Dave Baldrige, Manual Guide**





## 1.13 **Autonomy: Empowerment and Enablement**



*Rev. Dr. Cynthia Huling Hummel, Manual Guide*

I recently received a call from a care partner, whom I will call Lois. She called because she was concerned about her husband's lethargy. She told me that Bob used to be active, but since his diagnosis of dementia, he just sat on the couch all day watching TV. I asked Lois to tell me more about Bob, about what he did before he retired and about his hobbies.

Lois said that Bob was a repairman and loved to tinker in the garage, but after his diagnosis, the family felt that was dangerous and put an end to his tinkering time. I asked if Bob did any work around the house and yard, and again, Lois said, "Not anymore. He used to do the gardening, but we felt he might get hurt so we locked up the mower and the tool shed." I learned that Bob used to balance the checkbook and pay the bills, and the kids told him that someone else in the family was handling those things. Sadly, Bob had been stripped of all his responsibilities. I asked Lois if Bob was still driving — and she said, "No. We told him he couldn't drive and that we would take him if he needed to go somewhere."

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*Lois was coming from a place of love,  
and making all the decisions in order  
to keep Bob safe so that he wouldn't  
have to "worry" about anything.*

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I was frank with Lois that it sounded like Bob was a prisoner in his own home. I repeated the things that she had shared with me that: she chose Bob's clothes and decided what he would eat and drink and when he would do those things. She never asked Bob what HE wanted to do. She made all the decisions for him. When they went to the doctor's, Lois would answer on Bob's behalf and before he could even express himself. Lois thought she was doing the right thing, but my hunch was that she had made matters worse by her controlling behavior and that Bob was angry and depressed and was shutting down.

I suggested an experiment: that Lois would ask Bob questions about what HE wanted and wait for his answers — and that she would loosen the reins and let Bob make decisions about his day-to-day choices. Lois loved her husband and wasn't trying to be mean to him, but she admitted being more than a bit overprotective. Lois was coming from a place of love, and making all the decisions in order to keep Bob safe so that he wouldn't have to "worry" about anything. Bob, I'm guessing, was feeling bored and useless. He had nothing to do but sit

and watch TV. He had lost his autonomy, and autonomy is the ability to make decisions for ourselves. Who wouldn't be lethargic or depressed?

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*Weighing the dignity of risk over and against the duty of care means honoring the right of a person to make choices even if those choices may cause harm, such as getting cut with a tool.*

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Lois was more than willing to try my experiment and called me back two weeks later with some wonderful news. She began to ask Bob about his preferences and honored those choices. She urged Bob to weigh in on the matters that mattered to him. Bob was happier and more engaged. He got off the couch and headed back out to the garage to tinker. Lois shared that she learned a lot about herself and her relationship by honoring Bob's autonomy and his right to make decisions. She acknowledged that she was sometimes nervous about Bob being in the garage tinkering and possibly hurting himself, but also understood the joy that tinkering gave him. Lois was trying hard to weigh and to balance the risks versus benefits.

Counselors will sometimes use the expression: **weighing the dignity of risk over and against the duty of care**. What does that mean? Giving people the freedom and honoring their right to make choices even if those choices may harm them in some way: that the chance of being hurt is the price, if you will, for being able to engage in a desired activity. For example, Bob might cut himself on a tool — but that was a risk he was willing to take. People living with dementia have the right to make choices and sometimes care partners may not agree with the choices being made. Sometimes it's helpful to have a third person weigh in — a doctor, a social worker, or a counselor to help to find a resolution or common ground.

Where this difference of opinion becomes problematic and/or more nuanced is when a person's choices may put another person in danger. An example would be if someone living with a dementia diagnosis had multiple fender benders, and was a clear and present danger on the road. If this situation should arise, it is imperative that a care partner, family member, or friend intervene before a tragedy happens. Please don't ignore a situation like this or put it off. It would be terrible, for example, if Bob were to take the car on the road and hit someone or something. That's why weighing the dignity of risk over and against the duty of care is so important.

Those of us living with dementia should have the right to autonomy, that is the right to make choices about our lives, but at the same time, we may not always be the best judge of our abilities. We need trusted family and friends to help us to weigh the dignity of risk versus the duty of care so that as our dementia progresses and things get harder for us, our trusted friends and family will intervene. I have a “circle of care” — that is, a few dear friends who have agreed to “hold up the mirror” to help me to recognize that my abilities have changed. They will let me know when I may be lacking in capacity to make wise decisions and to flag some activities, such as driving, if it is no longer safe for me or for those on the road.

I trust that I will be able to accept their guidance with grace. I trust that together with my team, I’ll be able to live my life as fully as I can for as long as I can. — Blessings, Cynthia

## 1.14 Growth: Continuing to Learn New Things and Having a Sense of Accomplishment



*Rev. Dr. Cynthia Huling Hummel, Manual Guide*

My beautiful daughter Emily is a good seven inches taller than I am — even taller than that if she’s wearing high heels. Em jokingly calls me “My Mini-Mommy.” Needless to say, Emily takes after her father. She and I were together one day, and a friend looked at us and asked me, “So when did you stop growing?” My reply? “I haven’t!” We all laughed.

Oh, I knew what my friend meant. She was talking about my physical height, and I did tell her that I stopped growing taller in about 5th grade — but the reality is that I am still growing. Growth is more than just physical — it’s about learning new things about ourselves and our world. And that growth can be attained actively (like taking a class) or passively, through interacting with others on a day-to-day basis. What about you? Are you still growing?

I often describe myself as a lifelong learner. After I was diagnosed with amnesic mild cognitive impairment due to Alzheimer’s disease, I moved to Elmira, New York, and I was thrilled to discover that Elmira College was just five blocks from my house. I thought, “Oh boy! Maybe I could be a student there, and I could even walk to classes!” I filled out an admissions application and sent a copy of my transcripts. I called and made an appointment to see the Graduate Dean of Students to inquire about the possibility of my auditing classes. On the day before my interview, I went to the campus bookstore and bought an Elmira College t-shirt and matching purple and gold socks. I wanted to make a good impression and show my school spirit. During the interview, I shared my diagnosis and my hopes of being able to attend EC. As the meeting came to an end, the dean stood up, hugged me and welcomed me as the newest student.

Being a student meant more than just taking classes. Being a student meant that I could attend cultural programs, sporting events, and lectures and even eat in the cafeteria. Woo-hoo! It was so much fun to be around young people and learn from them. To date, I have taken 40 classes — from Art History to Ice Skating to The History of Pandemics. I try and complete as many of the assignments as I can, just to challenge myself, but I don't have to worry about tests or grades. I'm not there for a degree. I am there to grow.

There are so many ways for us to grow. We can take classes — and we can also teach classes! I'm not talking about teaching on a college campus (though you could), but teaching a grandchild how to change the oil in a car or teaching a friend how to crochet. There are many things that we know how to do. We can grow and help others to grow too, when we share what we know. Don't let that knowledge you've stored up go to waste.

When we challenge our brains, we grow, I like to do puzzles and love the satisfaction I feel when I put in the last of a 300-piece jigsaw puzzle that I've been working on. I also like crossword puzzles and word finds. What about you? Are you a person who likes to do Sudoku? These are all wonderful ways to exercise our brains and to grow.

Exercise is so important for brain health. Walking is a great exercise. Meet up with a friend and walk in your local park — or take up golfing and walk the course instead of taking a cart. I like to swim and make it a point to get to the school pool several times a week. Many exercise programs are available at no cost or online. Check with your community center or your local office on aging to see what's available in your area. Pickleball is the big rage where I am! Who knows, maybe I will try that next.

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*There are many things that we know how to do. We can grow and help others to grow too, when we share what we know. Don't let that knowledge you've stored up go to waste.*

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I'm not able to read books anymore, but that doesn't stop me from learning new things. I love listening to podcasts. I especially enjoy listening to *Dateline* murder mysteries. I spend time every day reading my newspapers (online) and following the news. I try to keep up with what's happening in our world. I want to know and I want to grow.

The arts help us to grow. I love all kinds of music (well, except rap). I enjoy singing along to Broadway tunes, singing in a choir, playing folk songs on my guitar, and singing rock and roll and country tunes with our band. I am always amazed when I remember the words to

a song that I learned in high school. Sing in the shower! Enjoy a night of karaoke. Sing along with the radio. Music is good medicine for the brain and the soul.

In the past few years, I've discovered photography and love to take photos with my phone, especially pictures of nature. Not long ago, I saw an ad for painting classes at our community center and discovered that painting helps me relax and my creative juices to flow. Recently, I took up painting using coffee as paint and have taught that to others via Zoom. Who knew?

Some believe that their education ends when they graduate from high school or college. I would disagree. There are always things to learn, new hobbies to explore, new insights to learn. Being a lifelong learner is a gift you can give yourself. So get going and get growing!

## 1.15 Tell People or Not

When you have received a diagnosis of dementia, you will need to think about how and if to share this with your friends, family, and co-workers. Some people are naturally open and comfortable sharing information freely, while others are more guarded and would not share medical information with others, no matter what the diagnosis. The stigma associated with dementia adds an extra layer of complexity when considering whether or not to tell people. Reactions from those who know you will vary and can often be unpredictable. Consider the strength of your relationships before sharing the news.

If you are still working, be especially careful about revealing your diagnosis. In her book, *The Spectrum of Hope — An Optimistic and New Approach to Alzheimer's Disease and Other Dementias*, Gayatri Devi, MD, notes that employers and co-workers can begin to view you through "Alzheimer's-colored glasses," meaning they will overnight assume you can't function, even if they had no previous problem with your job performance. "It is important to understand that a dementia diagnosis does not automatically disqualify a person from working. Depending on what type of dementia a person has and what skills are affected, he or she may continue working for many years."

Richard Taylor, one of the first vocal advocates living with dementia in the United States and author of *Alzheimer's From the Inside Out*, concealed his dementia diagnosis from his employer and taught college-level psychology for three years thanks to considerable help from his teaching assistant. Others, including some of the Guides in this manual, had careers involving complex financial details and their symptoms soon affected their job performance. (For more on [work and dementia](#), see *Cognitive Changes and Your Job*, Section 4.1, page 229.)

"If you're younger than 65 and very dependent on that job, it can be dangerous to reveal [a diagnosis of dementia]," says Tia Powell, director of the Montefiore Einstein Center for

Bioethics and author of *Dementia Reimagined*. “The more people who are able to do it, the more safe it will be for everybody to do it. We owe a huge debt to the advocates who say ‘this is the face of dementia.’”

Telling people, Dr. Powell adds, “takes bravery. You have to appreciate that you may be disappointed in some people. You may also find that someone says, ‘hey me too.’”

Pia Kontos encourages people living with dementia to be open about their diagnosis. “How can you thrive in relationship if you’re hiding?” she says. “Of course disclosing this with the current culture that really is not supportive, we can see why there’s fear, but we need to challenge that.”

*I had friends who disappeared, and my professional friends disappeared. That’s okay. It was painful at times, and it’s painful when you’re newly diagnosed and people distance themselves. Sometimes they’re afraid to face it, or what it means. They have this horrific view in their minds of what it could represent. I encourage people to talk with family and have an open discussion. Some of those fears are misfounded. You find new friends, if you’re willing to. I really feel sad for the person who locks themselves in their home and stops living. You prevent yourself from experiencing all kinds of things.*

**John-Richard Pagan, Manual Guide**





Explaining to your friends what you hope for may be helpful, suggests Anne Basting. “We have to say to our friends, ‘this is going to be hard on all of us. I don’t care if we don’t talk. Let’s go for a walk.’ We have to be able to learn. That said, it’s not just loss. There are all kinds of strengths that can be built upon.” Even if the disease progresses and words are hard to find, there are ways your friends can share with you, through art, singing, movement, and music, she adds.

“We toyed with it, then we decided to tell our friends,” says Laurie Scherrer. “You definitely lose some friends — like you’re contagious and they don’t know how to deal with you. But that happened to my mom with her cancer. People don’t know what to say. We lost some of our friends, but are still glad we did tell our friends.”

She recalls being at a party with their scuba friends (Laurie and her husband continue to love scuba diving). “I asked a friend, ‘how’s your dad?’ Well, he had died a year ago, and I was at the funeral. When you don’t tell people, they’ll think you’re not paying attention to them or not listening. They are going to think that what they said didn’t matter to you.”

The best advice is to follow your heart AND confide in someone close to you before sharing any information further. This gives you a chance to say how you’re feeling as you become more comfortable with the diagnosis. After a few conversations with those closest to you, you can decide what you want to say to others.

*There’s a need for some of us to be more public about the diagnosis to reassure people that there is a life after a diagnosis.*

**Jim Mann, Manual Guide**



## SUGGESTED RESOURCES

### Articles

Dewing J. (2008). Personhood and dementia: revisiting Tom Kitwood's ideas, *International Journal of Older People Nursing*.

Kingston, D. Batsch, N. and Mittler, P. (2017). Brief for Alzheimer Associations: Access to the United Nations Convention on the rights of persons with disabilities by people living with dementia, Dementia Alliance International and Alzheimer's Disease International.

Vernooij-Dassen, M., Moniz-Cook, E., Verhey, F., et.al (2019). Bridging the divide between biomedical and psychosocial approaches in dementia research: The 2019 INTERDEM Manifesto, *Aging & Mental Health*.

Swaffer, K. (2015). Dementia and Prescribed Disengagement, *Dementia*.

### Books

American Geriatrics Society-Health in Aging Foundation. (2016). *Alzheimer's and dementia*. John Wiley & Sons, Inc.

Power, G.A. (2014). *Dementia beyond disease*, Health Professions Press.

Devi, G. (2017). *The spectrum of hope: An optimistic and new approach to Alzheimer's Disease and other dementias*. Workman Publishing. [Note: also available in large print edition]

Bute, J., Morse, L. (2018). *Dementia from the inside: A doctor's personal journey of hope*. SPCK Publishing.

Swaffer, K., (2016). *What the hell happened to my brain?* Jessica Kingsley Publishers.

Snyder, L. (2011) *Living your best with early-stage Alzheimer's: An essential guide*. Sunrise River Press.

Taylor, R. (2007). *Alzheimer's from the inside out*. Health Professions Press.

Powell, T. (2019). *Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End*. Avery Publishing.

Fenker, R. (2016). *Don't Rain on My Parade — Living a Full Life with Alzheimer's and Dementia*. Cimarron International LLC.

## Websites

Alzheimer Society of British Columbia dedicated to helping people with Alzheimer's disease and related dementias, to supporting caregivers, to promoting public awareness, and to funding research.

[alzheimer.ca/bc/en](http://alzheimer.ca/bc/en)

Dementia Alliance International is an independent self-advocacy organization of people with dementia.

[www.dementiaallianceinternational.org/](http://www.dementiaallianceinternational.org/)

Dementia Friendly Airports is an international collaboration of professionals, academics, and volunteers in aging and dementia services and support systems.

[www.dementiafriendlyairports.com/](http://www.dementiafriendlyairports.com/)

Dementia Map is a free guide to the resources needed by those diagnosed with a form of dementia, family members, and professionals providing care or services

[www.dementiamap.com/](http://www.dementiamap.com/)

The Lewy Body Dementia Association is a nonprofit organization dedicated to raising awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and care partners and promoting scientific advances.

[www.lbda.org/](http://www.lbda.org/)

TimeSlips is a non-profit alliance of artists and caregivers bringing meaning and joy to late life through creative engagement.

[www.timeslips.org/](http://www.timeslips.org/)

## *SECTION 2: Well-Being — Your North Star*

### **2.1 Supporting Your Well-Being**

For thousands of years the North Star has been a guidepost for navigators and travelers enabling them to cross wide expanses, often into unknown territories. The North Star serves as a steady beacon and has taken on a symbolic meaning of hope, inspiration, and guidance. The North Star is a good symbol for living with dementia — an unknown territory that each individual experiences in a unique way.

The concept of “pillars of health” has emerged over the past decade or so to identify key practices that are necessary to support overall health and well-being. There are many variations of the pillars but the general pillars are: healthy food, movement, sleep, and connection. Additional foundation pillars have been identified for living well with dementia. We call these “pillars of well-being,” and they are essential whether you are living with dementia or are a care partner:

- ◆ **Stay connected**
- ◆ **Find fun and interesting things to do and stay engaged**
- ◆ **Limit stress and stressful experiences**
- ◆ **Eat and drink healthily**
- ◆ **Get restorative sleep**
- ◆ **Be physically active**
- ◆ **Keep your spirits up**

Each of these essential pillars are detailed in the following pages.



## **The Guys**

### **Angela Lunde, M.A., Contributor**

*Sharing a story that captures the essence of nurturing a sense of well-being*

I know a group of friends who call themselves “the guys.” Each month they meet at the same restaurant and have lunch together. They all have dementia.

One afternoon as we were talking, I asked them, “How would you rate your quality of life right now, on a scale of 1 to 10 — one being extremely poor, and 10 being exceptional?” None of them would give me a single number, instead they responded with a range, like 3 to 7, or 4 to 9. So, I asked, what makes a day a 3 and what makes a day an 8?

The responses I got from all of them were similar. “A low day, such as a 3, is when I feel like I’m a burden to my wife or family. An 8 day is when I feel I am contributing to something or someone in a meaningful way.” They did not say, an 8 day is when I can remember everyone’s name or remember what I had for breakfast or to take the garbage out.

For these guys, what diminished the quality of their lives most was not about forgetting things. Rather, it was about the absence, or presence, of purpose and sense of self-worth.

While we cannot restore good memory in a person living with dementia, we can play a large role in improving the quality of their life by supporting their need to feel connected, valued, and to contribute to their family and the community in meaningful ways.

## 2.2A Pillars of Well Being: *Stay Connected*

As Angela Lunde’s story of “The Guys” illustrates, having relationships is fundamental to our well-being. Your network need not be vast, but it needs to be meaningful. It can include family members, friends — both old and new — people in your congregation, or neighbors.

Many studies find a correlation between social connection and our health and well-being. To be health-promoting, our relationships should provide us with a sense of belonging and make us feel competent and valued. Having a strong network of people who care about us is entwined with a sense of purpose, as we look out for others, and they look out for us. Good relationships appear to act as a buffer, protecting our bodies from ills such as inflammation and high blood pressure.

In contrast, loneliness and isolation lead not only to depression and feelings of sadness. Loneliness can also harm our physical health. Studies have found that loneliness can contribute to high blood pressure, heart disease, obesity, a weakened immune system, cognitive decline, and even death, according to the National Institute on Aging.

As we grow older it can become harder to maintain our social ties. Aging can bring with it physical problems that make it difficult to get out and about or to connect with others. Loss of mobility and poor vision or hearing can be obstacles. So too can lack of reliable, affordable public transportation, if driving is no longer an option. Long-time neighborhoods can change, with new people moving in who may have little interest in connecting with older residents.

Living with dementia can add another layer of difficulty. Some people living with dementia report that they have lost friends who felt uncomfortable once they learned of their diagnosis.

In addition, some people living with dementia say that it can be hard to go to public places they once enjoyed, like a crowded restaurant or shopping mall. Noise, commotion, many voices talking at once, can be stressful and difficult to manage.

### **Develop and Maintain a Caring Support Network**

Being intentional about maintaining or building social connection is important. Even if you are a person hard-wired to “do things myself,” now is the time to gracefully accept that you need support to maintain your independence for as long as possible. If you find it hard to ask for help, the good news is that asking for support gets easier each time. Surround yourself as much as possible with people who are positive and supportive. Be with people who make you feel good about yourself and see the upside and humor in life.

You'll find that most people want to help and be supportive, but some may not know how. You may not know how they can support you either, in which case say so and ask them to work with you to figure it out.

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*Opening yourself up to others can be  
a bonding experience for you both.  
Let your friends know how much you  
appreciate and value their support.  
If someone becomes overly protective,  
taking over doing something for you,  
gently tell them you would rather do it  
yourself but with a little support from them.*

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"We have to say to our friends, 'This is going to be hard on all of us. I don't care if we don't talk. Let's go for a walk.' We have to be able to learn," says Anne Basting.

Opening yourself up to others can be a bonding experience for you both. Let your friends know how much you appreciate and value their support. If someone becomes overly protective, taking over doing something for you, gently tell them you would rather do it yourself but with a little support from them.

Thankfully there are a growing number of opportunities to be connected to others. Support groups initiated by the Dementia Action Alliance, local Alzheimer's Association chapters, and others give people living with dementia a chance to share their feelings and strategies for living well. Memory cafés, dementia-friendly neighborhoods and towns, arts courses, and senior center programs are among the options that are spreading. (For [more ideas](#), see *Community Supports*, Section 2.4, page 118.)



*The people I have met living with dementia are amazing. We were at a big Alzheimer’s forum in D.C. In the evening about 12 of us — six living with dementia and our care partners — were in the bar, laughing and joking and telling stories. People around us were amazed. They were buying us drinks, and saying, “Can we sit with you guys?” “How can you talk about [dementia] and laugh?” And we say, well, because we don’t want to cry! It opens your eyes, the joy you can get in being around people who understand what you are going through.*

**Chuck McClatchey, Manual Guide**



## **2.2B Pillars of Well Being: Find Fun and Interesting Things To Do and Stay Engaged**

There are endless ways to find fun and interesting things to do. Being socially engaged is one avenue. You don’t have to join a party circuit!

Being social can involve activities large and small, such as having coffee together, going to the movies or out for a meal, taking your dog for walks and seeing people along the way, shopping, and going on a trip. Some of these you may find stressful. Others will sound fun. Each person is different.

You might try taking up a new hobby such as making pottery. For others, a new hobby may be a frustrating experience instead of something enjoyable. Others like to return to former hobbies that they didn’t have time for while they were working.

Humans are hardwired for social engagement but the amount and type of engagement is individualized. Some people enjoy a lot of socializing while others just a little, one-on-one. What is important is not to become isolated. Social connections with people we are close to can be mood boosting, fulfilling, and enjoyable. These are valuable to the balance of your overall well-being. It is important to invest the time to stay socially engaged and connected. Being socially active online with chat groups and helping others can be enjoyable and helpful if you live in a rural area or have limited access to transportation.

Throughout life your brain needs to be engaged in regular cognitive activity. While growth of neurons and synaptic connections weaken with age and dementia, it does not stop altogether. Your brain needs stimulation to continue triggering generation of neurons and synaptic connections to form new neural pathways. Research shows there are important things to do that can make your brain less vulnerable to the effects of disease and aging. There are lots of fun and interesting ways to stimulate and give your brain a workout.



**TIP**

**WALK AROUND YOUR NEIGHBORHOOD**

regularly to keep you in touch with neighbors and activities going on around you.

**TIP**

**GO OUT AND EXPLORE NEW THINGS.**

Try a restaurant you've never been to before. Go for a walk with friends. One person, who lives near a city zoo, walks once a week with friends through the zoo. It's great exercise, and they always see interesting things.

**TIP**

**LOOK FOR A MEMORY CAFÉ**

near you. State listing: [www.memorycafedirectory.com/state-directories](http://www.memorycafedirectory.com/state-directories)

**TIP**

**ENROLL IN A CREATIVE ARTS**

**COURSE** for writing or poetry. You may find you have an inner artist.

**TIP**

**TAKE UP A HOBBY**

such as photography. If you can't manage some parts, it's a fun opportunity to do something with a spouse, friend, neighbor, former colleague, or grandchild.

**TIP**

**CONSIDER BEING A DEMENTIA MENTOR**

and helping others. See [www.dementiaallianceinternational.org](http://www.dementiaallianceinternational.org) and [www.dementiamentors.org](http://www.dementiamentors.org)

## 2.2C Pillars of Well Being: *Limit Stress and Stressful Experiences*

Stressful situations cause your central nervous system to respond by releasing stress hormones, such as adrenaline and cortisol, which prepare your body for action. Your heart beats faster, your muscles tighten, your blood pressure increases, your reaction time speeds up, and your senses become sharper and more focused.

Experiencing occasional stress is okay. Regularly experiencing stress, however, isn't okay for your body as it can disrupt your immune system, increase the risk of heart attack and stroke, and negatively impact your emotional, social, and spiritual well-being.

Living with dementia symptoms can produce stress, so it's very important for you to establish ways to deal with stress in a healthy way. Sometimes stress cannot be avoided, such as holiday events that can feel overwhelming. When there are stressful situations that cannot be avoided, find ways to limit your exposure to the stress. For example, during an event that includes a group of people, make sure there is a quiet place to get away if you start to feel overstimulated. Bring earbuds or headphones. You can listen to music or something else soothing. Both earbuds and headphones have noise cancellation options (depending on the model you buy) if you just need quiet.

Overstimulation can also affect other senses such as sight. Some individuals feel overwhelmed by too much color or pattern, or too many items such as in a store or on a restaurant menu.

When stress can't be avoided, have healthy ways to release the stress, such as take a walk, watch or listen to something funny, or ask your spouse or a friend for a back and shoulder massage. One person chops up a mass of vegetables to deal with stress and another likes to pull weeds from the garden. There are many ways to release stress; the key is finding what works for you.

## Ways to Ease Stress

The Cleveland Clinic Foundation offers “10 Ways to Ease Stress.” [health.clevelandclinic.org/how-to-relieve-stress/](https://health.clevelandclinic.org/how-to-relieve-stress/)

In addition to our other Pillars of Well-Being (such as eating well, getting a good night’s sleep, exercising), the Cleveland Clinic Foundation suggests:

- ◆ **Practice relaxation techniques** such as deep breathing, progressive muscle relaxation, and meditation.
- ◆ **Assert yourself.** It’s okay to say no if you don’t have the time and energy to do something. You don’t have to meet the expectations of others.
- ◆ **Set realistic goals and expectations.** No one is successful at what they set out to do 100 percent of the time. Remind yourself of what you can and cannot control.
- ◆ **Sell yourself to yourself.** When you’re feeling overwhelmed, remind yourself of what you do well. Have a healthy sense of self-esteem.

Remember, life for all of us includes stressful times. Although we can’t eliminate the negative stress, we can do our best to reduce and manage it.



### TIP

#### **AVOID PEOPLE WHO ARE UNPLEASANT**

and negatively oriented. If you cannot avoid them altogether, you can limit the amount of time you spend with them. Set a time limit; knowing ahead of time, for instance, that you will only spend 20 minutes together can help you feel empowered and lessen stress.

### TIP

#### **DECIDE IF YOU NEED TO KEEP DOING IT**

if you find something has become frustrating and stressful to do, such as paying bills and managing your finances. Perhaps your spouse or a trusted family member or friend would be willing to take this on for you. In return, you could reciprocate and do something special for them that doesn’t cause you stress.

### TIP

#### **TALK ABOUT HOW YOU ARE FEELING**

with people to whom you are close. Verbalizing what causes you distress can be a benefit.

## 2.2D Pillars of Well-Being: *Eat and Drink Healthily*

Eating is more than sustenance. The foods we eat can help keep our brains healthy. For example, things like fish, spinach, blueberries, and nuts are especially good for brain health. Scientists are studying the relationship between nutrition and our brains. There is still much to learn, but generally diets that are good for the heart are also good for the brain. These include the American Heart Association diet, the Mediterranean diet, and the MIND diet, among others.

Drinking plenty of water also promotes health, especially when taking multiple medications. Dehydration is common in older people, in part because the thirst sensation may decline. There are also changes in the water-sodium balance that are common as we age that can contribute to dehydration. Here are some key points to keep in mind:

### Mind Your Sugar

Sugar is a two-edged sword. Our brains use a lot of energy, and they need glucose to function. But excessive sugar is too much of a good thing. Excess sugar affects the hippocampus, a key part of the brain for memory. “Research shows that rats eating high-sugar diets were less able to remember whether they had previously seen objects in specific locations before. The sugar-induced changes in the hippocampus were both a reduction of newborn neurons, which are vital for encoding memories, and an increase in chemicals linked to inflammation,” according to “A Neuroscientist Explains What Sugar Really Does to Our Brains,” a 2019 article by Amy Reichelt in *Science Alert*.

One study by researchers at Washington University in St. Louis looked at the effect of sugar on mice that had been genetically modified to have Alzheimer’s-like plaques in their brains. When the researchers infused the mice with sugar water, the plaques produced faster. “A doubling of blood glucose led to 20 percent higher levels of beta-amyloid compared with mice that had normal blood glucose levels,” according to “Could High Blood Sugar Be a Cause of Alzheimer’s Disease?”, a 2015 article in *Medical News Today*. When the team repeated the experiment in older mice that already had amyloid plaques in their brains, beta-amyloid levels rose by 40 percent.

Excess sugar also contributes to Type 2 diabetes, which in turn increases your risk of developing dementia. “We don’t really know the safe amount of sugar for the brain,” says nutritionist Nancy Emerson Lombardo. She advises limiting sugar to six teaspoons a day. This translates into 24 grams of sugar, which is how food labels list it (four grams equal one teaspoon of sugar). One 12-ounce can of Coke, for example, contains 39 grams of sugar.

“The modest amounts of sugar in whole foods such as fruit and root vegetables are not a problem,” she adds.

## Bye-bye Burgers?

Nutritionists generally say to significantly reduce red meat for brain health. The rationale is that meat is not good for the heart, and therefore is probably not good for the brain. Studies are inconclusive. A 2020 review of the scientific literature on meat consumption and cognitive function, published in the journal *Nutrients*, found inconsistent results and urged more research be done.

Some dementia specialists encourage a vegan diet, based completely on plants. “The best studies show that if you eat well, plant-centered, your risk [of Alzheimer’s] goes down as much as 53 percent,” according to Dean Sherzai, a neurologist at Loma Linda University, speaking of brain health in the video “Alzheimer’s — What You Can Do.”

Vegan diets can be quite healthy (not to mention good for the planet by reducing methane from livestock production). Lombardo cautions though that vegans need to be sure they are getting adequate amounts of Omega-3s, which are plentiful in fish and fish oil supplements. Vegans also need to be sure they are getting B-complex vitamins, she adds, found in meat, fish, eggs, and dairy.

Until more is understood about the effects of diet on our brain, it’s a good idea to limit the amount of beef and pork we eat. Some suggest one serving a week, with a serving about the size of a deck of cards. Instead of red meat, get healthy fats from fish, nuts, avocados, and olive oil, among other sources.

## What about Alcohol?

Not surprisingly, experts agree that too much alcohol is not good for brain health. According to the National Institute on Alcohol Abuse and Alcoholism, “Alcohol interferes with the brain’s communication pathways, and can affect the way the brain looks and works. Alcohol makes it harder for the brain areas controlling balance, memory, speech, and judgment to do their jobs, resulting in a higher likelihood of injuries and other negative outcomes. Long-term, heavy drinking causes alterations in the neurons, such as reductions in their size.”

Some neurologists urge their patients to refrain from alcohol altogether. Others range in their advice, from an occasional glass of wine to one or two servings a day.

According to the Alzheimer’s Society in the United Kingdom, “Excessive alcohol consumption over a lengthy time period can lead to brain damage and may increase your risk of developing dementia. However, drinking alcohol in moderation has not been conclusively linked to an increased dementia risk, nor has it been shown to offer significant protection against developing dementia.

“As such, people who do not currently drink alcohol should not be encouraged to start as a way to reduce dementia risk. Conversely, those who drink alcohol within the recommended guidelines are not advised to stop on the grounds of reducing the risk of dementia, although cutting back on alcohol consumption may bring other health benefits.”

Remember to ask your doctor if alcohol should not be consumed with any of the medications you are on.

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*Remember to ask your doctor if  
alcohol should not be consumed with  
any of the medications you are on.*

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## **Spice it up**

Lombardo urges people to generously use herbs and spices. Some small clinical trials looking at spices and the effects on dementia suggest some short-term benefits. Among the most promising spices: saffron, turmeric, lemon balm, cinnamon, and aloe vera. For example, a randomized double-blind clinical trial (considered the gold standard of testing) in Iran of 54 people over 22 weeks compared the effects of saffron versus donepezil (Aricept) for people with mild to moderate Alzheimer’s disease. The results were similar, based on two cognitive assessment scales, according to a 2010 article in *Psychopharmacology*.

More research is needed. Unfortunately, Lombardo notes, funding is limited for non-pharmaceutical approaches to treating dementia.



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THE UNIVERSITY OF WISCONSIN ALZHEIMER'S DISEASE RESEARCH CENTER



## THE MIND DIET FOR HEALTHY BRAIN AGING

- The Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet is a hybrid of the Mediterranean and DASH (Dietary Approaches to Stop Hypertension) diets.
- MIND diet was developed as a result of a four-and-a-half-year study through the National Institute of Aging led by Dr. Martha Clare Morris, a Rush University nutritional epidemiologist.
- This study found that people who ate more of the MIND diet foods had less risk for Alzheimer's disease. People who followed the diet moderately reduced their risk for Alzheimer's disease by 35%, and those who followed it closely reduced their risk by 53%.
- MIND diet recommends 10 items to incorporate into your diet and 5 to limit.

### 10 THINGS TO INCORPORATE INTO YOUR DIET

- **Green leafy vegetables**  
(at least 6 servings a week)
- **Other vegetables**  
(at least 1 a day)
- **Nuts**  
(5 servings a week)
- **Berries**  
(2 or more servings a week)
- **Beans**  
(at least 3 servings a week)
- **Whole grains**  
(3 or more servings a day)
- **Fish**  
(at least 1 serving a week)
- **Poultry**  
(2 servings a week)
- **Olive oil**  
(use as in cooking and dressings)
- **Wine, especially red**  
(1 glass a day)

### 5 THINGS TO LIMIT IN YOUR DIET

- **Red meat**  
(less than 4 servings a week)
- **Butter and margarine**  
(less than 1 teaspoon daily)
- **Cheese**  
(less than 1 serving a week)
- **Pastries and sweets**  
(less than 5 servings a week)
- **Fried or fast food**  
(less than 1 serving a week)



Source: "MIND Diet Associated with Reduced Incidence of Alzheimer's Disease"  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4532650/>

## 2.2E Pillars of Well Being: *Get Restorative Sleep*

A growing body of research finds that a good night's sleep is important for our brain health. But an enormous number of people are plagued with insomnia. An estimated one-third to one-half of adults in the United States have sleep problems, and the condition increases with age. A 2021 article in *NIH Research Matters* reports that people in their 50s and 60s who slept six hours or less per night were more at risk of developing dementia later in life.

For people living with dementia, sleep disturbances are especially common. Some causes of sleep problems are not directly related to the dementia disease process and may be treated or self-managed. These include conditions, such as:

- ◆ Depression
- ◆ Anxiety
- ◆ Stress
- ◆ Chronic pain
- ◆ Prostate or bladder problems (needing to use the bathroom in the middle of the night)
- ◆ Menopause (hot flashes)
- ◆ Restless leg syndrome
- ◆ Sleep apnea

Sleep apnea, a condition where you momentarily stop breathing many times throughout the night, deprives the brain of oxygen. Being overweight can contribute to sleep apnea. Sleep apnea can contribute to high blood pressure, memory loss, and depression, according to Gayatri Devi, MD, in *The Spectrum of Hope*.

### **Poor sleep-related habits**

- ◆ Too much screen time before bed (video games, social media, TV in bed)
- ◆ Eating too much before bedtime
- ◆ Drinking caffeine or alcohol in the evening
- ◆ Irregular bedtimes
- ◆ Too sedentary in the day
- ◆ Exercising vigorously less than four hours before bedtime

## Medication side effects

According to the Mayo Clinic, “Many prescription drugs can interfere with sleep, such as certain antidepressants and medications for asthma or blood pressure. Many over-the-counter medications — such as some pain medications, allergy and cold medications, and weight-loss products — contain caffeine and other stimulants that can disrupt sleep.”

Reading the fine print of medication inserts can be daunting. But it’s worth checking to see if something you are taking has a side effect of insomnia. Your local pharmacist can be a helpful resource to educate you on the potential side effects of medications, including insomnia.

## Dementia-related sleep problems

Three-quarters of those who have Lewy body dementia, for example, have a REM (rapid eye movement) sleep disorder. They may act out their dreams, and call out or violently thrash around, and may harm themselves or their bed mate.

“Thanks to good ol’ Lewy, my dad is prone to night terrors and sleep disruptions,” says Jennifer Carson. “Good sleep is so important. If my dad doesn’t get good sleep, his cognitive function takes a serious nosedive.”

People with Alzheimer’s disease also have changing sleep patterns, often becoming more tired in the day and restless at night. This can be challenging for them and for those they live with.

## Ways to Sleep Better

There are several strategies for promoting sleep, depending on which of the above causes is at the root of the problem.

Depression, anxiety, and chronic pain should always be treated, for a host of reasons, including sleep. There are pharmacological, psychological, and behavior modification strategies to treat these.

Restless leg syndrome may be alleviated by good sleep hygiene (see below) and by soaking in a warm bath and doing gentle massages. Use of heat or cold packs or alternating these may help. Or try a vibrating pad or specially designed foot wraps.

Sleep apnea is most commonly treated with a Continuous Positive Air Pressure (CPAP) machine that sits by your bed. A plastic hose connects the machine to a mask that you wear throughout the night to push pressurized air into your airway as you sleep. There is also a dental device that can be worn to keep your airway open while you sleep. Weight loss and sleeping on your side may also help.

Maintaining good sleep hygiene can help a range of issues. Sleep experts offer these suggestions:

- ◆ **Your bedroom:** Keep the temperature at 66 to 70 degrees. Reduce light as much as possible, although you may need a small nightlight to safely get to the bathroom. Keep the room as quiet as you can, given where you live. A white-noise machine may help block out external noise. Invest in a good mattress and pillow. Keep your clock faced away from the bed, and do not check the time during the night.
- ◆ **Your bedtime routine:** Go to bed at the same time each evening and develop a regular bedtime routine. Aim for 7 to 8 hours of sleep at night. Avoid screen activities, such as watching TV, looking at your smartphone, reading on a smart device, and, instead, listen to relaxing music, take a warm bath, or do gentle yoga.

Get up at the same time each morning, even if you have to set the alarm, to get your body used to a regular sleep schedule.

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*Be sure to let your doctor know  
if you are having trouble sleeping.  
Ask if any of your medications may be  
contributing to your sleep disturbances.*

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- ◆ **Food and drink:** Avoid large meals close to bedtime. Reduce alcohol, caffeine, and tobacco close to bedtime. Caffeine is found not only in coffee and black tea, but also chocolate and some soft drinks. Reduce all liquids in the evening.
- ◆ **Reduce stress:** Avoid heated conversation or work before bedtime. If you are feeling stress, write down what's triggering it in a journal, so these thoughts don't keep you up.
- ◆ **Daytime:** Don't nap more than 30 minutes a day. Exercise regularly and try to get outdoors. Get exposed to bright light in the mornings.

Even the best sleep habits won't solve all problems. Sometimes your doctor will determine you need medication.

"After many sleepless issues, we finally did request a prescription for trazodone," says Jennifer Carson of her father who has Lewy body dementia. "Trazodone is the better sleep aid option for older adults, according to the American Society on Aging BEERS Criteria." (For more information, see [Medications and Medications to Avoid](#), Section 5.4, page 280.)

The Alzheimer's Association advises —

Any time you are prescribed a new medication, make sure to ask your healthcare team:

- ◆ What are the benefits of this medication?
- ◆ What are the risks of this medication?
- ◆ What other treatment options are available?

## Ongoing Research on Sleep and Dementia

Recent research finds a relationship between sleep (too much or too little) and the buildup of beta-amyloid plaques in the brain. In rodent studies, scientists found that during sleep, the glymphatic system clears away “junk” in the brain. This cleansing appears to reduce beta-amyloid, helping to keep brains healthy. In a study of a subset of the Baltimore Longitudinal Study of Aging, 70 participants were asked about their sleep patterns. The researchers then did brain imaging. They found that those participants with greater amyloid build-up also slept fewer hours and had less restful sleep. It is not clear, though, if poor sleep causes the amyloid to increase, or if the amyloid is contributing to poor sleep.

According to an Alzheimer's Association “In Brief” article for health professionals, “Further studies in other cohorts are needed before we can say poor sleep promotes AD [Alzheimer's disease] pathology. If similar results are found, sleep length and quality could be early, modifiable risk factors, and interventions to improve sleep or maintain healthy sleep may help prevent or slow AD.”

## 2.2F Pillars of Well Being: *Be Physically Active*

A mountain of evidence shows the importance of exercise and movement. “Exercise is the silver bullet,” says nurse practitioner Anne Ellett, CEO of Memory Care Support. “Don’t give up being active. Whether or not you’re living with cognitive impairment or dementia, the best predictor of quality of life while we age is are you able to walk from here to there and stand up, remaining mobile, and having strength.”

Being sedentary is one of the worst things we can do for our bodies, our minds, and our moods. “People who sit down all day and then stand up feel dizzy,” explains Ellett. “We need that homeostasis in our inner ear to help us maintain our balance. We lose that ability if we’re sedentary. It’s a cascade of bad things that can happen.”

*At nighttime I’ve had a delusion, a bad episode where I thought people were trying to break into the house. Again, part of me also knew that something about this was wrong and wasn’t really happening. I have my cell phone close at hand. I have night terrors, I have active dreams, REM sleep disorder. A lot of swinging and kicking, I’ve thrown myself out of bed, so I have rails on both sides.*

**John-Richard Pagan, Manual Guide**



One recent study on exercise and our cognitive health compared mice who were sedentary and those who had a running wheel. “Older mice that were active showed increased generation of new brain cells called neurons and higher levels of nerve cell growth factors than sedentary mice,” according to the National Institute on Aging (NIA) in a 2020 article. “Exercise-induced protein may reverse age-related cognitive decline.” The older active mice also made fewer errors in learning and memory tasks.

Before launching a new exercise program, talk to an expert. Ask your doctor to refer you to a physical therapist to design a program for you. Go to a gym and talk to a trained staff member. If you can afford it, hire a trainer to tailor a fitness program just for you and to encourage your progress.

*Exercise is so critical and I'm not as good at doing it. I have an exercise bike. When I exercise rigorously, it certainly improves my mental abilities, capacities, and outlook.*

**Dave Baldrige, Manual Guide**



## Why Exercise?

Exercising and staying active have all sorts of benefits. Among them:

- ◆ Improving balance and reducing falls
- ◆ Managing or preventing some diseases like arthritis, heart disease, osteoporosis, diabetes, and many types of cancer
- ◆ Controlling blood pressure (high blood pressure increases your risk of vascular dementia)
- ◆ Controlling weight gain
- ◆ Sleeping better
- ◆ Improving your state of mind

You can exercise at no to little cost, depending on your choice of activity. The amount of time exercise takes can fit into anyone's schedule. Experts recommend we get at least 150 minutes vigorous exercise a week — just over 20 minutes a day.



## Types of Exercise

NIA suggests we strive to do four types of exercise.

**ENDURANCE (AEROBIC):** Aimed at getting your heart and breathing rates up. Examples:

- ◆ Dancing
- ◆ Climbing stairs
- ◆ Raking leaves
- ◆ Swimming
- ◆ Riding a bike
- ◆ Playing tennis or pickleball
- ◆ Walking briskly

**STRENGTH:** To build your muscles to remain independent and to protect against breaking bones. You can maintain strength by:

- ◆ Carrying your groceries
- ◆ Squeezing a tennis ball
- ◆ Lifting weights
- ◆ Doing wall push-ups

**BALANCE:** Falls are one of the most common problems of aging. A broken hip can send you to the hospital or even land you in a nursing home. To prevent falls or cushion their impact, try:

- ◆ Learning tai chi
- ◆ Standing on one foot
- ◆ Standing from a seated position without using your arms to push up

**FLEXIBILITY:** Keeping limber will allow you to continue to perform simple daily acts, like tying your shoes. Stay flexible by:

- ◆ Doing muscle-stretching exercises
- ◆ Practicing yoga

What kind of exercise is best? Whatever kind you will actually do on a regular basis. You don't have to run marathons to stay fit. Find something you enjoy and stick to it.

## Staying Motivated

Sometimes we begin an exercise program with a burst of enthusiasm, only to find we fade over time. Just ask any gym how many new members they get after the New Year — and how many are still coming a few months later.

“

*I have participated in physical therapy and speech therapy to help me to continue with living life. I started a gym membership which I do 2–3 times a week at a pace that is comfortable for me and does not overdo it. This has improved my mobility, assisted me in improving weight loss, and has generally given me new energy to enjoy each and every day.*

**John-Richard Pagan, Manual Guide**



To stay motivated, **get an exercise buddy**. It could be a family member, a neighbor, a new friend, or someone you meet in an exercise class. Exercising with a friend has the added benefit of staying connected to others — a key part of living well.

Some people find motivation from one of the many smartphone tools or wearable devices, such as those that count how many steps we take each day or computer programs where we report on our daily exercise.

- ◆ **Take a class.** Senior centers, the YMCA, public libraries, neighborhood organizations, parks departments, and gyms are among the many places with classes for all levels and all ages. Some Medicare plans and employer-covered health insurance pay the cost of SilverSneakers, an exercise program for people 65 and older. If you can't get to a class in person, there are now many exercise and dance classes offered over Zoom or through online videos.

◆ **Sign up for an organized sport.** All kinds of sports have teams, many of them for older people. Some are competitive, some are just for fun. Bowling, basketball, baseball, softball, pickleball, tennis, ping pong, golf, swimming — anything that is appealing to you and keeps you moving is beneficial. Try something new or return to a sport of your youth.

Try not to be discouraged if exercise feels like a chore. Start small and build up.

Anne Ellett stresses that getting fresh air is also good for our well-being. If you can safely do so, get outdoors every day. “There’s value in getting out,” she says. “There are benefits to sunshine and fresh air.” She tells the story of a Green House, a type of small-house nursing home in northern New York State, that was determined to get residents outdoors on a cold winter day. “They bundled them up, took them out, and brought them hot chocolate.” Even though the outing was brief, “people were talking about it for days.” It was fun and it felt good.

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*I’m very adventurous and always have been. My husband and I scuba dive. Since my diagnosis I’ve been parasailing in South Africa, hiking, kayaking. Life isn’t all peaches and roses. With FTD [frontotemporal dementia] I have agitation. I go for a run. My husband will go out with me.*

**Laurie Scherrer, Manual Guide**



*I've begun to walk. That gives me a chance to forget everything. I'm into my walk, I pay attention to the sky, to birds, to nature. It's my quiet time. I told my doctor I wanted to get up to eight miles. I did make eight miles one time! I'd be content with three or four.*

**Terrie Montgomery, Manual Guide**



## **2.2G Pillars of Well-Being: *Keep Your Spirits Up***

In 1964, Norman Cousins, editor of the *Saturday Review*, was diagnosed with a painful and crippling collagen disease that his doctors thought was incurable. Determined not to give into the fear and pain, he did what he could to remain positive. He famously self-prescribed heavy doses of laughter. Beginning with a hospital stay, he convinced the nurses to bring him clips of the TV show *Candid Camera* and old Marx Brothers movies. He maintained that 10 minutes of hearty laughter led to at least two hours of pain-free sleep. He went on to pioneer "laughter therapy." He also beat his illness, although not even Cousins claimed that laughter is a cure-all.

Since then, researchers have looked at why laughter is such good medicine. Among the potential benefits:

## LAUGHTER ...

- ◆ Relaxes your whole body. It relieves physical tension and stress.
- ◆ Boosts your immune system by decreasing stress hormones and increasing immune cells and infection-fighting antibodies.
- ◆ Triggers the release of endorphins, the body's natural feel-good chemicals. Endorphins promote an overall sense of well-being and can temporarily relieve pain.
- ◆ Protects the heart by improving the function of blood vessels and increasing blood flow that can protect you against a heart attack and other cardiovascular problems.
- ◆ Strengthens relationships. Sharing experiences that make you laugh with others is a bonding activity. Laughter can unite people during a stressful time and diffuse conflicts.
- ◆ Can help you release distressing emotions. You can't feel anxious, sad, angry, or frustrated when you're laughing.
- ◆ Is also free and abundantly available!



**TIP** **SMILE**, it's the beginning of laughter. Spend time with people who put humor and laughter into their daily lives. It's contagious.

**TIP** **WATCH A FUNNY MOVIE**, TV show, or family videos.

**TIP** **LAUGH AT YOURSELF.** You'll take yourself less seriously when you can laugh at your mistakes and antics.

**TIP** **RECOUNT FUNNY THINGS** that happened to you with others. Not only will it make you laugh again, but likely will spur others to share their funny experiences.

**TIP** **WATCH LIVE ANIMAL VIDEO CAMS.** It's hard not to chuckle at puppies or kittens crawling over each other.



## ***Sometimes You Just Have to Laugh!***

### ***Laurie Scherrer, Manual Guide***

Reprinted with permission from Laurie's blog, [dementiadaze.com](http://dementiadaze.com)

I knew I shouldn't. I knew it was a bad idea — but I tried it anyway. There are times when things go so wrong you just have to laugh. That was my evening last night.

The day started out fairly well. With the help of my alarms and lists, I had a very productive day. Three loads of wash — complete; clean the refrigerator — complete; find a ride to take me to two appointments — complete. I felt so accomplished. And then ...

Towards the late afternoon, I began to feel out-of-sorts. As my world became clouded and disoriented, and my speech was slow, I decided I was going to make dinner anyway. That's where I went wrong! Lesson number one: how to ruin a perfect day — when you know your dementia symptoms are taking over — stay out of the kitchen!

First let me say, I HATE cooking anyway. I call it "the dirty four letter 'C' word." I don't have the knack for it, and by the time I'm done, my kitchen looks like a war zone. Honestly, I'd rather change the oil on the car than "cook." In 34 years of marriage, I have not been able to escape the horrors of the kitchen. OK, I digress — back to the bad day.

While retrieving two eggs, I knocked a bottle of Italian Salad Dressing on the tile floor. This caused me to jump, tossing the two eggs in the refrigerator. One actually survived — the other, not so much! There was egg on all the condiments (ketchup, mustard, relish, salad dressing, horseradish, etc.). There was egg all over the racks, which of course seeped down to the next rack. There was egg on the door and egg on the floor (that could make a song). There was egg on me.

How I wish I could tell you my tale ended there, but no. As I began the process of cleaning out the refrigerator for the second time, the ketchup lid was not on tight, so I added some ketchup to the other end of the kitchen — the floor, the sink and the cabinets.

Poo — "What's that burning smell? Oh no! — Dinner!" Well done does not describe it! Looking around at the kitchen, which was covered with egg, ketchup, and salad



dressing. I called my sister and cried. Unfortunately, I did not heed her wisdom; “Stop crying, get out of the kitchen, and let Roy clean it up.” I didn’t want him to come home and see this mess!

Feeling totally overwhelmed and frustrated, I headed to clean the kitchen. Dementia symptoms often cause balance issues. When there is ketchup, salad dressing, and egg on the floor — it’s just inevitable. BOOM! I slipped, knocked over the dog’s water, and fell smack into the mess.

At which point my husband Roy walks in the door, sees me on the floor — wet, wearing ketchup, dressing and egg. And simply says: “Oh, you’ve been cooking again! I think I’ll put the groceries in the dining room for now.”

What he did then really made the difference! He pulled out a towel, sat next to me on the floor, gave me a hug, and said; “Oh, by the way, I decided to pick up a Stromboli so you don’t have to cook tonight!” We just burst out laughing. We laughed and we laughed until, yes, I started to cry! I cried with laughter and happy tears over how blessed I am to have him as my husband.

Cleanup took a while, but we got it done. Today, I see last night in slow motion, I see the egg flying through the refrigerator, the ketchup splatting all across the room, and my wonderful husband holding me and making me laugh. I love you, honey!



## 2.3 Spirituality



*Steven J. Sonnenberg, M.D., Contributor*

What is spirituality? Spirituality is what provides meaning to our lives. Spirituality differs widely from person to person. For some, spirituality involves a longstanding relationship to the personal God of their childhood with an abiding faith supported by hymn, liturgy, and ritual. Often this religious spirituality is grounded in the social life of a church, mosque, or synagogue. Sometimes our faith evolves over the course of a lifetime into a more general sense of a higher power. And some find spirituality outside of religion — often in nature.

For some, spirituality is found in love and devotion to family. For others, it is their service to a wider community. Music, poetry, theater, or the visual arts can be the source of a spiritual life. The beauty, peace, and solace of nature are transcendent for some.

How does a life living with dementia affect spirituality? It differs from person to person and even over the course of the condition. Like any serious illness or anticipated loss, living with dementia can be a challenge to our religious beliefs in a caring, loving God, leading sometimes to a rejection of faith that has sustained us. At other times it can enhance our faith as we rise to the challenge. Faith changes over our lifetime and it's important to recognize that it may continue to change over the course of living with dementia.

*Your loved one's mind is changing but their heart and soul are still there. A lot of spiritual stuff is going on that we don't even see ... but there's such beauty.*

**Cyndy Luzinski, MS, RN, Contributor**



What can be at risk living with dementia is a loss of access to our spirituality. When meaning and transcendence are found in our relationship with nature, limitations to our mobility or our ability to navigate independently may put a walk in the woods or a stroll along the beach out of reach. Lack of understanding from others or our own social withdrawal out of fear or

embarrassment can limit our ability to get to concerts, galleries, or places of worship that fill our spiritual needs. Worship services may become too long to sustain our attention, leading us to withdraw further. When it becomes too complicated to serve our community in the ways we are accustomed to, finding new ways of serving and accepting our limitations can be challenging.

*I'm blessed that God has given me a purpose. I believe that the purpose is what has kept me going... God let me get dementia, but He also has given me so many friends, so many people I can help.*

**Laurie Scherrer, Manual Guide**



How do we maintain our spirituality, our connection to what is most meaningful in our lives, in the face of this progressive illness? First, start early. Begin by exploring what has brought meaning to your life, discussing this with your care partners, your family, your friends, and your faith leaders. Writing these thoughts down can become an invaluable guide to others when communication becomes difficult further down the road. This process may need to start with an honest acknowledgment of the fact that you will be living with dementia, a discussion of what the future may hold, and an openly expressed hope that others will support you and help you maintain those activities that provide meaning.

Flexibility and adaptability, personally and in our system of support, is essential. Increasingly, worship leaders are recognizing that shorter, less complicated worship services focusing on familiar text, liturgy, and song are needed to meet the needs of aging congregations. Brief, accessible religious services are widely available on YouTube when mobility becomes a problem. When communication makes active participation difficult, familiar prayer, psalms, and hymns read or sung by care partners can provide that essential connection to the divine. Keep in mind that spiritual needs may change. Familiar songs and prayers learned early in life can provide solace and comfort near the end of life, even when that faith practice was long neglected or abandoned.

Flexibility is crucial wherever your spiritual center lies. Helping your neighbors with their taxes or chairing the local garden club may become too complicated for you, but you may still be able to serve at the local community supper or help with the neighborhood cleanup.

Sometimes isolated elders blossom when they enter a care home and simply have the opportunity to help others with their meals. Music and the arts shared at home can be just as satisfying if the social context of viewing with family or friends is added. A chair by an open window with plants and a bird feeder brings nature to you.

Meeting your spiritual needs throughout living with dementia can be a challenge. Meeting that challenge begins with exploring where you've found meaning, remembering that you are loved by others who want to help, and working together with flexibility and creativity.



## ***Alter — A Pioneering Program for African American and Faith Communities in Georgia***

***Fayron Epps, PhD, RN***

Fayron Epps, PhD, RN, a nurse scholar at Emory University, is pioneering programs to promote the quality of life for families impacted by dementia through her research, education, and service efforts. One such service effort, the Alter program, addresses the lack of resources and awareness for dementia in African American and faith communities in the state of Georgia. Dr. Epps founded the Alter program in 2019.

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*Even as dementia symptoms advance,  
spirituality can shine through  
and religious traditions can comfort.*

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Alter's mission is to encourage culture change, shift perceptions of dementia, and inspire and equip faith-based organizations anchored in African American communities to better support families and create Alter Champions.

Alter Champions are people who:

- ◆ Accept and value people regardless of their cognitive abilities;
- ◆ Ensure that individuals living with dementia and their care partners are supported through their journey;

- ◆ Make sure that individuals living with dementia and their care partners are spiritually and pastorally supported and nurtured; and
- ◆ Are supportive to what individuals living with dementia have to offer so that they may participate in their faith community.

## The Benefits of Spirituality

John-Richard Pagan, a Manual Guide who is living with Lewy body dementia, is a contemplative Christian, who was formerly trained in Buddhism. “Being closer to my Creator has definitely helped me to see a bigger picture and to be okay with where I’m at right now,” he says. “I’m also in 12-step recovery. I’ve really gotten to know a Higher Power and that it’s important to not live in the future and that I cannot control everything.”

He values his mindfulness practice. “I do centering prayer, which is a lot like meditation,” he says. Living in the here and now is fundamental to his well-being. “When you’re living in the past and thinking about what you used to be you’re living with regret. It’s not only depressing, it brings up anxiety. When you live in the moment, you’re not worried about when the next doctor’s appointment is or when you may have a bad day. You’re enjoying the present.”

A number of studies have looked at the potential benefits of spiritual and religious practices for people living with dementia.

- ◆ One literature review in *International Psychogeriatrics* found: “Participants who used their spirituality or religion more, through their faith, their practices, and in maintaining social interactions, their cognitive impairments tended to decrease or stabilize. Other studies found the use of spirituality or faith in daily life enabled people to develop coping strategies, maintain their relationships, maintain hope, and find meaning in their lives, thereby improving their quality of life.”
- ◆ A 2019 “meta-synthesis” in the journal *Dementia* found “the ongoing importance of spirituality to people living with dementia and its importance as a means of finding hope, meaning, and linkage with past, present and future.”

Even as dementia symptoms advance, spirituality can shine through and religious traditions can comfort. John McFadden reflects on his experience of being a chaplain serving people with advanced dementia who live in nursing homes.

“I spent 30 years serving as pastor to very privileged people, and then I left to do memory care chaplaincy and to experience this beautiful, quirky, profoundly moving world. Among the things I would note is that many of my residents became spiritual

mentors to me. My friends with advanced dementia only have the present moment and they taught me how to live there. Dementia could not take away deeply memorized hymns and sacred scriptures and prayers, which they found centering and calming. I had residents who were largely aphasic [unable to communicate through speech] but could say the 23rd Psalm with me as long as we did the King James version. A man came to mass in a wheelchair, [seemingly] with no awareness of what's going on. When he was approached with the Host [the sacramental bread that is part of the communion ritual], he responded with complete receptivity. It's a deeply practiced thing that for the older age cohort comes out of their faith traditions.

"I also learned that people with dementia who can't cognitively absorb your words are still picking up on things. Often you cannot fool someone with dementia by covering up if you're in a bad mood or faking friendliness. One woman with very advanced dementia reached out and rubbed my arm because she perceived me as someone who was hurting and in need. Some of my colleagues have said to me 'I know what they get out of it, but what do you get out of it?' What I got out of it was being cared for. Spiritual journeys can deepen within advanced dementia."

*Faith has given us hope that we can live through this, that we can make it, that it's going to be alright.*

**Kim Reid, Manual Guide and living with dementia**



*Kim might forget a lot of things, but whenever we're talking scripture, those things automatically come back up. When a Christian song comes on, she remembers all the words to the music because it lives inside her. She still knows how to pray and say our daily prayers even though she may forget other things.*

**Robert Reid, Manual Guide and Kim's care partner**





## ***My Faith Keeps Me Going***

### ***Rev. Dr. Cynthia Huling Hummel, Manual Guide***

*A minister reflects on how spirituality helps her live with dementia*

Many years ago, I joined an Adult Education class at the high school to learn how to play the recorder. Not the tape recorder — the musical instrument. Once we learned the fingering to play different notes, we started with simple songs like the “ABC Song” and “Row, Row, Row Your Boat.” Our teacher decided that we would have a concert for our family and friends on the last night of class to show off our amazing musical skills AND — drum roll, please — that we would play the finale by memory.

I immediately panicked and decided to cheat and came up with this plan: to write the notes of the final selection on my hand in INK. The night of the concert came, and I was relaxed and good to go — that is until I noticed that the notes on my hand were gone. Yep. You guessed it. During the intermission, I went to freshen up and just like that, the notes were washed down the bathroom drain. I wondered how I would make it through the finale! So much for my “handwritten notes.”

Those of us with memory problems often will write ourselves notes to help us get through the day and week — and some will even write a note or two right on their hands. Did you know that there is a passage in the Bible about this? It’s Isaiah 49:16a. The passage says that God has already written OUR names on the palm of his hands. Amazing. As a person living with early-stage Alzheimer’s disease, this passage gives me great comfort. It assures me that even though I may forget my name and the names of my loved ones, God will never forget me. God loves us more than you can imagine.

As a pastor, I often have conversations about faith, especially as folks struggle to find meaning in what is happening in their lives. Those who have been diagnosed with dementia often wonder: Why ME? Some look at a dementia diagnosis as a punishment for a perceived wrong committed earlier in their lives. The reality is that life happens. There is illness. There are accidents and, yes, death. Life is full of pain and of physical, mental, and spiritual challenges. Instead of focusing our energies on “Why me?”, I invite you to ponder, “What’s next?” Who will you meet on this dementia journey? Who will walk with you? Help you? And who will you offer your hand to in support and friendship? Remember, when we help other people, we help ourselves. You just might be the answer to someone else’s prayer. Really!



I have been a Presbyterian pastor for more than 25 years, and I am especially blessed because I grew up in an interfaith family. What about you? Did you grow up going to temple on Friday or attend Sunday school or prayer services at the local mosque? I am so grateful to my parents for the gift of faith. It sustains me on my dementia journey. It's interesting, we come from many different faith traditions (or no faith traditions at all) and have different spiritual practices, prayers, and rituals — but dementia and love connects us all. I am at home attending a Catholic Mass, a Friday Shabbat service, or a Baptist revival.

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*When we pour out our hearts to God  
(or to the universe),  
we often find peace.*

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I love singing the great hymns of the church and hearing the sound of the mighty organ. I've sung in church choirs and praise bands. I spent the summer of my sabbatical as a cook in a Benedictine Monastery and Friday evenings singing Hebrew prayers. If you aren't in a faith community now, I would invite you to check out the faith communities in your area — perhaps the one you attended as a child or a new faith community of like-minded folks who are worshiping and working together and growing in faith, hope, and love. Being part of a faith community can be a HUGE support for those of us living with dementia as well as our care partners.

In times of adversity, many find great strength in reading the holy books of their faith tradition. As a pastor, I often invite people to share something out of their spiritual tradition. Sometimes a person will tell me a favorite story, a parable, or a prayer that gives them strength, hope, comfort, and more. What about you? Do you have a sacred text that you turn to that gives you peace? Perhaps it's a song of faith that helps you to get centered? Even if you are not a believer, you may be inspired by meaningful poetry or literature or by songs that move you. I often invite people living with dementia to reconnect with the spiritual practices of their childhood — to dust off the sacred texts to see what speaks to them.

Our faith often evolves over the course of our lives, and perhaps we want to explore another religion or a humanist tradition. I have friends who have attended the same services every week of their lives and others who are visiting different communities looking for answers to their spiritual questions. Attend a prayer service. Join a Bible study. Meet with a spiritual leader (pastor, rabbi, priest, Imam) to talk about the challenges and the blessings of your dementia journey. Join a meditation group or try a spiritual retreat in nature.



There are many faith communities that offer programs for those living with dementia and care partners — programs like memory choirs, arts classes, support groups. A few years ago, my friend Diane and I started a singing group that we called “Faithful Friends” for those living with dementia, care partners, and community members. We then visited nursing homes to sing with those living in memory care units. Singing together was a blessing for all. Speaking of blessings, think about starting a blessing or gratitude journal where you can write down some of the “day-to-day blessings” that you might experience, such as talking to an old friend, hearing a song on the radio that puts a smile on your face, or holding a puppy. I know many folks in various congregations where I have served over the years who talk about their “God Sightings” — that is, the occasions during the day, when they witnessed God’s presence and God’s peace.

Prayer can be a wonderful way of helping folks find healing and peace and trust me, I did a LOT of praying the night of the recorder concert. I wanted to walk out the door, but I prayed and stayed and played what I could remember and faked my way through what I couldn’t and before I knew it the finale was over and the audience was giving us a standing ovation. Who would have guessed? Not me. But by centering myself in prayer, I was able to calm myself to get through a difficult situation. Prayers don’t have to be long or elaborate. *Please Help Me* or *Thank You Lord* are simple and calming. Some people find that breathing deeply and focusing on their breath helps bring calm.

When we pour out our hearts to God (or to the universe), we often find peace.

Some of us pray in the morning, some pray at night. Some pray throughout the day. Some pray in the car, others in the shower. Some get down on their knees. Others stand with outstretched arms. Some will pray with eyes open wide, others with eyes shut. Some repeat a mantra and meditate each day. There are many different ways to pray. But instead of just praying for ourselves and our situations, why not take the time to lift others up as well? Cultivate an attitude of gratitude. Help others. Make a difference, and you might just find joy and meaning in your dementia journey.

Blessings and peace.

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### **SUGGESTED RESOURCES**

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## 2.4 Community Supports

Local organizations and diverse networks throughout the country are working to support people living with dementia. Here are a few of the many excellent initiatives.

### 2.4A Raising Awareness in Indian Country



Contributor Carla Eben, Director of Numaga Senior Services for the Pyramid Lake Paiute Tribe in northern Nevada, knew little about dementia when she was hired. She had years of experience working for the tribe and was eager to learn more about her new area of responsibility. When she received a flyer from the state of Nevada, offering training on dementia and hoarding, she asked her boss if she could go. She ended up driving three hours north to Winnemucca for the four-hour training.

As the training wrapped up, she realized that she knew people who might be living with dementia. “It was an eye opener,” she says. She also noticed, looking around the room, that “there were no brown people, no Natives there. I asked the lady when we were packing up if they send their flyers out to Indian country — to the Nevada tribes. The lady said, yeah, but they never come.”

Driving home, Carla thought about how many people she knew who fit the description and patterns of what she’d heard in the training. She wanted to learn more and to share it with others. And the woman’s comment that “They never come” stayed with her.

The next day Carla dropped into the clinic, which is in the same building as her office. “I asked one of the nurses, ‘Do you have any programs for elders? Do you guys do any trainings through IHS [Indian Health Service]? Do you have a doctor who deals just with elders?’ She said no. I asked, ‘could you bring us a training?’ She said, ‘probably not.’ It was no, no, and no.”

Carla didn’t give up. She next tried the University of Nevada Cooperative Extension Service, which eventually led her to Jennifer Carson, Director of the Dementia Engagement, Education and Research Program at the university. Jennifer was happy to lead a training, and she and Carla soon met to make plans for an information session, open to anyone.

Around the same time, Dementia-Friendly Nevada announced they were awarding three grants. Carla applied and received a grant to accomplish three things: “Educate my elders and caregivers. Educate our tribal departments and agencies outside of our department — social service, EMS — and community members. Educate my neighboring tribes.”

Dementia Friendly America, Carla found, had resources on how to work with hospitals, banks, and restaurants. But that didn't apply to her work. "We had to be creative," she says. "We don't have banks, we don't have restaurants — that's why I geared it towards tribal departments. We do have the visitor's center, housing, and clinics."

The first year they established the Pesa Soaname Advisory Committee and a board. (Pesa Soaname translates as "good think" — there is no word for dementia in the Paiute language.) Jennifer Carson and her colleague Casey Acklin held four training sessions in the first year. "That helped us meet our first and second goal," says Carla. "For our third goal we decided to hold our tribal summit." They reached out to all the tribes and elder programs as well as Dementia-Friendly Nevada partners.

Participants were asked to register online ahead of time. As the day grew closer, few people had signed up. "Jennifer and Casey were freaking out. I told them, people will come and register that day. I said just relax," says Carla.

The summit was a big success, with 114 participants. Out of the 27 tribes in Nevada, 14 were represented. "One hundred percent of the surveys said they'd like to do it again," she says. The speakers covered topics like the Healthy Brain Initiative, the need for comprehensive geriatric assessments, and diabetes and dementia in Indian Country. At least half the participants were Native elders or caregivers.

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*Unfortunately, there are no reliable data on how many tribal elders are living with dementia. Diagnosis of dementia is virtually unknown on the reservation.*

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Unfortunately, there are no reliable data on how many tribal elders are living with dementia. Diagnosis of dementia is virtually unknown on the reservation. The IHS focuses on "life and limb," says Carla. "There's like a priority list of what they deal with. Dementia is at the bottom. Now that COVID has hit, dementia is probably further down. Even within families it's not an open subject."

She worries about the number of elders who are isolated. "We have elders that live alone," she says. "Our meal delivery might be their only contact. Their house may be one-eighth of a mile from another house. Their best friend is their cat or dog. It's sad to think that. If we hold our elders in such high esteem as we say we do, we should be doing more."

Carla's experience in Indian country is not unusual. According to Manual Guide Dave Baldrige, founding director of the International Association of Indigenous Aging (IA2), "Dementia has not been addressed formally or historically. There's a lot of denial, and a great lack of education. It's been a challenge just to get it on the radar screen in the communities we're trying to serve.

"There are some long established principles that we have used to do work with Indian country. The elders are an extremely important voice and as they are most affected by dementia, we go to them to get their input. Nothing about 'em without 'em." To reach elders, they go through Title VI Senior Service meal programs like Carla's. "Those directors and staff are on the front lines with anything dealing with elders."

IA2 received a five-year National Healthy Brain Initiative award from the U.S. Centers for Disease Control and Prevention's Alzheimer's Disease and Healthy Aging program. This Healthy Brain Initiative promotes brain health and addresses cognitive impairment and dementia. According to IA2, the award establishes them as a national hub for dementia information resources for tribes, tribal leadership, healthcare and public health staff, Urban Indian Health Centers and organizations, and tribal elder services advocates across the country. To learn more, visit: [iasquared.org](http://iasquared.org)



## ***Staying Positive with an Unexpected Diagnosis***

### ***Dave Baldrige, Manual Guide***

*Executive Director of the International Association  
for Indigenous Aging (IA2)*

*Reprinted with permission from Dave's IA2 blog post*

Last year, I unceremoniously collided with the greatest irony of my ongoing 30-year career/mission as an Indian elder advocate. The day before my 74th birthday, the director of a local cognitive assessment center called me into her office to explain her unexpected diagnosis of PSP — progressive supranuclear palsy. This is a terminal neurological disease, loosely related to Parkinson's or Huntington's disease.

Overall, it's kind of like winning the lottery in reverse — it affects only five out of every 100,000 people. Causes are unknown but may include genetics, although there's no verified link. It has to do with damaged tau proteins in the brain.

A primary symptom is frequently the loss of executive function (Ruh Roh!) — an expression of dementia. At the time of the diagnosis, I felt a bit overwhelmed by the irony. IA2 is among the first Native organizations to engage in national work to recognize and cope with ADRD [dementia], and then earned the CDC BOLD grant [Building Our Largest Dementia Infrastructure] that now brings us together.

Symptoms also include imbalance (I was/am having plenty of that). This has been a long time in the making — a formerly-avid bicyclist, I remember on a guided mountain bike adventure in Nepal 18 years ago inexplicably losing my balance and falling off of a steep cliffside trail. There were other incidents.

“Even though it’s progressive,” she explained, “you’ve probably got 8–10 good years left.” So here I sit, a year into this new adventure, pondering what “8–10 good years” means.

Will I miss scheduled meetings? Lose my train of thought while presenting at a conference? Break my ankle while walking to the bathroom? Get lost while driving to an appointment? Become wheelchair dependent? Jeez!

The doubts are constant and troubling. They’ve led me to take closer control of my options — refinancing my house, exploring in-home care, should it become necessary, and updating my will and advance directives.

Interestingly, my personal circumstances haven’t seemingly affected my work with ADRD. I’m very appreciative for being able to continue to contribute to our ongoing efforts to help American Indians and Alaska Natives to address ADRD within their communities and families. The issue is top-of-the-ladder for many of my generation and will become even more central as time progresses. Our mission is important.

I’m keenly aware that many of you — my colleagues and friends — have and continue to experience far greater health issues and difficulties than I do. I admire your courage and dedication to our work together.

And I’m constantly reminded that many of the folks we serve — Indian elders — face far greater obstacles than most of us ever have.

I’m convinced that the best solution for me — perhaps for all of us — is actually pretty simple — to stay positive and to keep trying. So I’ll offer up my best to you, and to Indian elders, as we continue our important work together.

## 2.4B Dementia-Friendly Initiatives

### ***“Innovative Communities Expand and Redefine the Dementia Experience: The movement that’s changing the culture from stigma to inclusion”***

*Beth Baker*

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Ron Grant of Oklahoma City was 55, enjoying his career as a chaplain and happily married, when he began to experience memory problems. After undergoing a battery of tests, he received an unexpected diagnosis: early onset Alzheimer’s disease. “Nobody in my family had it,” he says. “I knew it was a bad disease, but I did not know anything about the progression.” When he pressed his doctor about what to expect, Grant was told he’d likely be dead or in a nursing home within two to seven years.

That was 14 years ago. Today, Grant continues to live fully. As co-chair of Dementia Friendly America, an initiative that began during the White House Conference on Aging in 2015, he is a leader in the movement to change societal views of what it means to live with dementia. “We do not lose our humanity and our right to dignity just because we have this disease,” he says.

The Dementia Friendly America network promotes communities, organizations and individuals who are committed to keeping people living with cognitive impairment/dementia and their care partners engaged and thriving in their communities.

Too often, though, the “tragedy narrative” prevails, says gerontologist Karen Love, CEO of the nonprofit Dementia Action Alliance. Instead, communities can seek “to empower and enable people and instill a sense of positivity. It’s important to support their abilities rather than focus on diminished abilities,” she says.

Anecdotally, Love has found that engagement and hope may help extend the time of cognitive health. Grant agrees. He continues to have purpose and meaning. He credits his faith and the changes he and his wife, Vicky, made early on with taking him as far as he’s gone. “We learned that our worst enemy is stress, fear and anxiety,” he says. “We purposefully tried to de-stress, to try to overcome fear and avoid all anxiety that we could.”

He also found help in a support group he organized. Support groups, often led by those who have the disease, are among many activities cropping up around the country to improve the quality of life for people with dementia.

Memory cafés that offer the chance to socialize and build new networks, volunteer opportunities for those living with dementia, concerts and special art gallery tours are spreading. There is even the nation's first dementia-friendly airport in Tulsa, Oklahoma.

Dementia Friendly America has registered 350 communities so far. That number does not include several other dementia-inclusive communities that are not under the organization's umbrella. "This is a movement that's gaining momentum," says Sandy Markwood, CEO of the National Association of Area Agencies on Aging.

That momentum continued during the pandemic. Over the last year, 25 more communities joined, pledging to include in leadership people who are living with dementia and to work across sectors, including local government, business, and faith- and community-based organizations, to implement dementia-friendly practices. Dementia Friendly America developed a toolkit to guide communities that wish to become dementia-friendly.

The organization is now working with partners to develop an evaluation tool to measure if and how such practices improve the lives of people living with dementia, their families and their communities. The tool will be piloted later this year.

"The key is being dementia-inclusive," says psychology professor Susan McFadden, author of the new book *Dementia Friendly Communities: Why We Need Them and How We Can Create Them*. She adds: "We need to listen to [people living with dementia] and we need to talk to the folks who are shy and hesitant to find out what they want in their communities." The following are a few examples:

### **Dementia-Friendly Indiana**

A standout in this effort, according to Love, is Dementia Friendly Bloomington (Indiana). Its first workshop was in 2017 to brainstorm what a dementia-friendly community would look like. Today, committees work on expanding legal and financial services, safe driving and making public spaces dementia-inclusive. This initiative offers employee training to businesses and, with the guidance of people with dementia, suggests ways to make places more navigable and safer.

"My philosophy is that people living with dementia need a friend to help them walk through life," says Jan Bays who helped found DF Bloomington. "They have many, many abilities, and they see the world differently because their brains process things differently. The key to living successfully is having a safe environment that supports them."



Among Dementia-Friendly Bloomington's many activities:

- ◆ The Sing for Joy! choir for older adults includes those living with dementia. "They do very sophisticated music," says Bays. "We have the music and the pacing done for people living with dementia. We do dementia-friendly training for all choir members, and then we put on programs four to six times a year."
- ◆ In collaboration with a theater group, people living with dementia have also acted in plays over Zoom. "It might be hard for them to remember lines, so they can have their scripts," explains Dayna Thompson, who heads up the Alzheimer's and Dementia Resource Service at Indiana University Health. "They are over the moon to be included in this," she says.
- ◆ Thompson's team also partnered with the Monroe County History Center and the Community Foundation to create Living with History. The History Center reserves times for people living with dementia. In a quieter environment, they can go on Memory Walks, hang out at a Memory Café or borrow Memory Boxes to take home.

Dementia-Friendly Bloomington has now spread to 12 counties and plans a statewide conference this year. "I truly believe that if we're focusing on people living with dementia in our community, it will make life better for all of us — giving information, safely finding transportation in town, improving wayfinding, checking on our neighbors, having places where people can socially engage across generations," says Thompson. "We might call it dementia friendly, but it's what we all would like."

## **Dementia Friendly Nevada**

Jennifer Carson, a dementia researcher at University of Nevada, Reno, wanted to expand programs for people living with dementia beyond the usual orbit of aging services professionals.

"We want to transform the broader community, so how do we find those pathways to change?" she says. "We set as a standard to have diverse representation" across many sectors and to include people living with dementia in leadership.

Today six communities, each representing a range of sectors, are active in Dementia Friendly Nevada. For example, Dementia Friendly Pahrump, on the edge of Death Valley, hosted a film series, complete with popcorn and post-film discussion. With no theater in town, they first used the local electric company for showing, *Cracked: New Light on Dementia*, a research-based drama that seeks to change the stigma around dementia and to promote inclusion.

Dementia Friendly Pyramid Lake Tribe-Pesa Soaname (interestingly, there is no word for dementia in the tribe's language) focused initially on education. They then organized a summit in 2019 which drew 114 people from 14 tribes.

“The whole summit was developed by our partners,” says Carson. “There was a color guard from the tribe, traditional songs and a heart-healthy lunch prepared by tribal members.”

One of the best programs, says Carson, is a support group, Dementia Conversations, now held biweekly over Zoom.

Chuck McClatchey, who is living with dementia, leads the Monday group. At a recent gathering, made up of people living with dementia and family members, one participant asked for advice on how to get her husband (who was not attending) to agree to counseling, to help him overcome denial and better accept the disease. Others shared their own positive experiences with counseling, which in turn led to a conversation about how they each dealt with learning their diagnosis and getting to a place of acceptance.

The conversation was sprinkled with humor (one participant with Lewy body dementia personifies the disease as “that rascal Lewy” who disrupts his thinking) and with deep appreciation for the trust and openness in the group. At a closing sharing, McClatchey said, “What I took away is that it’s okay to ask for help. Everyone handles stress and anxiety in different ways. All the stigma can go in the trash where it belongs.”

### **Dementia Together in Northern Colorado**

What began as a caregiver support group at Cyndy Luzinski’s church in 2014 evolved into the nonprofit Dementia Together, based in Windsor, Colorado. Luzinski, an advanced practice nurse, is the full-time executive director, supported by three part-time staff.

In 2020, nearly 1,800 people went to 80 Memory Cafés (in-person and virtual) in Northern Colorado. “The agenda is joy, reminisce, sing, and play games,” Luzinski says. “The main purpose is having fun and for the couples to realize they can still have fun together.” More than 500 attended “virtual variety shows” including concerts, gardening and cooking programs.

Luzinski saw the power of connection in 2015 when researchers at Colorado State University launched a collaborative to study how the arts could benefit people living with dementia. Through the B Sharp Arts Engagement program, people living with dementia and their partners attended concerts of the Fort Collins Symphony and participated in post-concert receptions and in research studies.

The first study found not only improved alertness, mood and engagement among participants, but increases in cognition over nine months of going to concerts. For their part, the caregivers found a sense of community and felt a sense of “normalcy.”

The group also tackled a common problem they heard from newly diagnosed patients. “The doctors would say, ‘You have dementia, see you in six months,’” says Luzinski. “That is such a trauma for them.” Dementia Together developed a resource folder and distributed

it to internists, family practitioners and neurologists to give to their patients. The folder includes basic information about the disease, caregiver tips and helpful local organizations.

“Our elevator pitch,” says Luzinski, “is the dementia journey can be overwhelming, but no one has to walk alone.”

## 2.4C Memory Cafés



*Beth Soltzberg MSW, MBA, Contributor*

Memory cafés started in Holland in 1997. It seemed like a great model that could be cost effective and could reach a lot of people. You do different things each time and you can be more responsive to the people who come. You’re co-creating with whoever shows up.

In 2014, the Jewish Family and Children’s Service launched the second memory café in Massachusetts. I had talked to people in other parts of the country, and they were so energized about memory cafés. I think the name “café” is really important — it’s fun, social, comforting, it has to do with food and coffee. At that time, there were very few offerings for people living with dementia and their care partners that weren’t just about problems, but that were places where you could go and have fun. It really addressed an unmet need. Fortunately there’s more of that type of programming but still not enough.

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*There were very few offerings for people living with dementia and their care partners that weren’t just about problems, but that were places where you could go and have fun.*

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There’s an incredible spirit of sharing among the cafés. Originally there were eight organizations meeting. We decided to pool our ideas and resources. That’s how the JF&CS Percolator Memory Café Network got started. I never in my wildest dreams expected it would grow the way it did.

Through the Percolator we offer free toolkits. We have a PSA [public service announcement] video in English, Spanish, and Portuguese. Most people don't have a picture in their mind of a memory café, the way they might when you say support group. We have a directory of guest artists and how-to webinars, and we hold quarterly convenings where people will present what they're doing at their café. We have participation throughout the U.S. and a few other countries. The first café in Brazil started that way. We've touched many hundreds of cafés.

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*Each café should be inclusive  
and try to identify barriers that might  
make it harder for some members of  
their community to participate.*

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The most common setting for memory cafés is senior centers. Libraries are another sector that has been very involved. Wisconsin, for example, has amazing library networks that run memory cafés. Some museums do it or historical societies, or community nonprofits. There used to be one at a bowling alley. Another one meets at an outdoor garden, then goes in a church in the winter.

What I've learned is that the best ones create a sense of home. They make people feel so welcome and so that means the best cafés are really interactive. The people who come share a part of themselves. There are cafés that have really cool activities, but the best ones are in some ways structured so there's time for people to hang out and have great conversation. For some people, conversation is hard, but there are other ways to share and connect. A lot has gotten harder being virtual, but a silver lining is you can share things in your own home. We take advantage of that. People do a little show and tell what makes them smile in their own home. That is almost the best part, people feel so connected. That said, people love music, dance, and movement. At our café, we had two sessions about the Boston Red Sox — we had all these people come who don't usually attend. A group called Memories International led this, and they showed great clips from history, and people argued about the best plays. More men came out for that one.

Each café should be inclusive and try to identify barriers that might make it harder for some members of their community to participate. Also it helps to have specialized cafés, say houses of worship. People connected with that faith may have something special, a prayer, or a setting that resonates. It's also good to have cafés in specific languages.

For the café that I run it's a challenge. We have a lot of immigrant communities. I've tried to connect with community members with greater and lesser success. We're not multilingual. We've had some Spanish-speaking families attend, and I can chat a little with people living with dementia, which I think has helped. Nationally, there have been some really good inroads.

It's been fascinating, the differences in how people of different cultures think about dementia — what it is, what causes it, do they turn to a faith leader, or keep it in the family, or talk to a medical person? What are their values around caring for an older relative — do they feel we all need to do it ourselves, is it okay to involve professionals? There is also historic discrimination and ruptures in trust that make people feel there isn't someone they could trust. It's important that they have a resource from their community.

There are a lot of strengths as well as barriers. A lot of communities might find it hard to connect with a professional, but they have a strong ethic of "we're in this together." The differences are complex. One partner of ours is made up of Russian speakers. The community was Jewish immigrants, from the former Soviet Union. Because of what they had gone through, there was a strong feeling that you keep any kind of disability to yourself. Where they lived [in the USSR], it was really dangerous to show disability or weakness. Some immigrant communities who came here from better circumstances may have a different feeling about sharing what's going on with professionals or other community members. It's very specific to what people's life experiences have been.

This transcends any kind of category. It's about listening, finding out what the specific group is dealing with and what they need.



## ***SA Amigos Memory Café***

### ***Sara Masoud, MPH, Contributor***

*Sara, with the University of Texas Health in San Antonio, Texas, spearheads the Café. Since the pandemic, the café team has met over Zoom. She shares these reflections.*

Our team founded the first memory café that we know of in San Antonio. We began meeting in person in 2018 and went through several iterations before we found our groove. In 2019, the memory café went through a process of deciding what to call ourselves. The attendees spent three months and voted to choose SA [San Antonio] Amigos.

We are cultivating ownership of the space by the attendees. We wanted them to name the memory café, to suggest ideas for activities, and we've built that into our model. This year [2022], we have implemented "12 New Things" as our theme. In January, we had our regular guests all talk about something they have always wanted to try. I'm excited. Out of the 12 things, I've only done two of them.

One is making parquet [wood] coasters. A lot of our older gentlemen living with dementia don't resonate with craft stuff, but they liked this idea.

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*We want the conversations to help us build  
real connections with each other that  
honor the personhood of our guests.*

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A lot of people said they always wanted to be in a band or play music. So we started the "SA Amigos Found Sound Band" at one of our gatherings with a music therapist. People made music with everyday objects they could find around their house. For example, some people tapped on empty jars, shook a can full of dried beans, or ran a pencil along their jacket zipper. We've never tried to write or perform a song together. We've recorded it so the guests could share with friends and family members.

We also have some outdoor activities planned for the summertime. For example, a lot of people wanted to try making mosaics so we planned a gathering in the park to make those together.

There are a lot of conversation-based activities themed around the month. We really take care to not make our activities cheesy or childish. We want the conversations to help us build real connections with each other that honor the personhood of our guests. In one of our most beautiful “Creative Conversations” activities, we asked things like, “If your childhood were a smell, what smell would it be?” It evoked tears in a good way — “the smell of my mom’s baking,” “my dad’s work boots.”

We have a pretty loyal base of 10 to 15 people who are regular attendees at our gatherings. Out of 12 months, they attend at least six to eight a year. Others join in and out. In any given café, attendance goes up and down, we will have maybe 15 to 20. Maybe 70 percent are caregivers who attend by themselves, the rest come alongside someone living with dementia. It’s pretty rare that we have someone living with dementia attend by themselves, but we do have some attend on their own.

Zoom isn’t the most friendly way for everyone to join. Before COVID-19 hit, we met in person and had a free transport service offered by our community partners. Being virtual brings its own challenges, but we try our best to make it work. We now host quarterly in-person gatherings to include those who don’t like to, or can’t, join online.

We had 70 households log on for a virtual game of Lotería [a Bingo-like game popular in Mexico]. It was a bilingual activity. We do sometimes have some people who join us who don’t speak fluent English. To help them be included, we have a volunteer co-host who translates. I found an artist on Etsy of unique tablas [boards] that you put the beans on. We got the registration and we mailed people their individual playing cards, making sure everyone had something different so we wouldn’t have double-winners. We had prizes mailed to the guests who won. In between calling out cards, we would read the traditional riddles that go with each card and would invite guests to stretch with us or take deep breaths to help them feel relaxed.

People went bananas for it — they just loved that activity. We try to do it every six months at our virtual Memory Cafés. We don’t do it too often because when we are busy playing, there’s not that inter-connection happening between the players and our goal is really to help people stay social and build connections. I want people to talk to each other.

There are also things that did not work for us. Starting in person, we were doing our memory café at a senior center. We thought this was a cool way to get into the older adult



community and provide an activity that is age-friendly. But people there were already connected in some ways. They didn't really need the memory café as much as those who weren't already attending senior centers. We moved into a community space with a local organization, Jefferson Outreach, who provides free transportation to homebound seniors and people living with disabilities. It was truly a great partnership and the transportation really helped people. One participant said, once a month, this is the only time I leave my house.

In terms of virtual cafés, we had to plan a lot harder. You can't put people in a Zoom room and expect conversations to just happen on their own. In real life, that happened organically, and same with being bilingual. I didn't realize how much planning had to go into a virtual café. We plan at least a month out. I have what I call our "secret ambassadors." I'll reach out to guests who are really committed to the Memory Cafés and ask their advice on planning, outreach, and more. We have members who share our goals to help families impacted by dementia stay socially connected to their communities. These guests are really the best partners. During the memory cafés they'll often try to help me engage quiet or reserved guests by saying, "Hey so-and-so, tell me about this." The ownership component [by attendees] is something I'm really proud of. This is their space to make connections, explore their creativity, get to know their partners, and cognitively engage in a judgment-free gathering.

## 2.5 Being a Dementia Advocate



*Jim Mann, Manual Guide*

It took me about a year to be more open about my diagnosis of dementia. I needed to feel comfortable with my new reality. I needed to know more about dementia and what it would mean for me in all facets of my life because I knew I would be asked questions. I needed information so I could adequately respond.

My early journal entries remind me how scary I found Alzheimer's in the early days. The disorientation. Understanding the sensory changes caused by dementia and my new feelings about crowds, all took a bit of time as did the constant adjustments to my activities of daily living. I understood the need to come to grips with this new life, adapt, and continue living sensibly.

A diagnosis shatters your self-confidence. Your self-esteem. Which I now realize is a factor in our withdrawal from activities. And for some, society. I'm glad I took the time to learn and understand as it gave me newfound confidence.

I realized too, I needed more than that: I needed a purpose. I needed a reason to get out of bed in the morning. What could I do? I was still driving but I wasn't able to continue consulting. Perhaps, I thought, I could volunteer using the same skills I had in business where I was an advocate, a communicator, and a marketer. Plus, I had the experience of seeing dementia through my mother's eyes.

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*I once read, 'If they don't give you a seat at the table, bring a folding chair.'*

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And there it was. I'd identified my purpose, I had confidence, and I knew some of the issues. The stigma surrounding dementia I'd seen when my wife and I were alongside my mother after my father's passing was eye-opening. I realized what a big issue stigma was. But what about opportunities to hear from the person living with a diagnosis? It was there I felt a vacuum, so I put my hand up. And then my world changed.

Being an advocate and speaking out whether one-on-one or in a meeting, we educate. We advocate to educate. We increase awareness because we live with dementia, which others need to hear. If we don't tell the story — our story — who will, and how will stigma be challenged and the stereotype of a person with dementia change?

- ◆ We can downplay the power of advocacy. But we shouldn't.
- ◆ We can diminish the strength of education. But we can't.
- ◆ We can ignore the significant power of the individual. To our peril.

Each and every one of us is a powerhouse. As a self-advocate, I have chosen to be active through committee and board work with dementia-related organizations. I have also focused my time and work in areas where I feel I may make a difference and in some of those areas the voice of a person with dementia has been absent.

I was diagnosed with Alzheimer's in 2007 at the age of 58. The experiences, the conversations I've had, and the reactions I've heard, have all added to the richness of my life. Some have been heart-warming and some have been jaw-droppingly surprising.

Like a well-educated person in medicine who assured me he knew, after seeing me on a panel, that I didn't have Alzheimer's. Look at the way you're dressed, he said. (I'm glad I had someone with me for that one!) I consider encounters like these to be teachable moments, my opportunity to nicely outline where our perspectives and experiences differ. Hopefully they will walk away and reflect on what they have heard.

- ◆ That's how we make a difference.
- ◆ That's how we can improve our environment.
- ◆ That's how we can move mountains.

And that's why it is important for us to be at the table. A policy table or a table alongside researchers as the preparatory work on their project's submission is being compiled. Where our perspective, our lived experience can and will contribute to better and more robust outcomes. I once read, "If they don't give you a seat at the table, bring a folding chair."<sup>1</sup>

I speak to university students periodically and after speaking to one class of master's students in health, I received a note from one of them saying in part:

*Your talk was very insightful and gave me a completely new perspective of understanding dementia patients, their challenges and the problems faced by patients and relatives at care facilities. It would definitely help us in gaining a deeper understanding and help us do good work in future.*

That is how we will effect change. That is how you can effect change. Are you ready?

## 2.6 Living Alone with Dementia



*Rev. Dr. Cynthia Huling Hummel, Manual Guide*

Soon after I was diagnosed, I started to look into some of the programs and services in my area for those living with dementia. I figured since I was diagnosed with younger onset Alzheimer's, I should learn as much as I could about what was ahead.

I did some research and started making phone calls. One receptionist at an area agency on aging told me bluntly that their programs and services "were for dyads."

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<sup>1</sup> The quote is from Shirley Chisolm, the first African-American woman elected to the U.S. House of Representatives.

I asked her what she meant, and she gave me some examples. "Typically we will get a call from a husband or a wife who is caring for a spouse who has Alzheimer's, or we sometimes will get a call from an adult child who is caring for a parent with dementia. We don't have services for people who are living with dementia by themselves. If you want to use our services, you have to come with a care partner." I was fuming, but I explained as calmly as I could that I didn't have a care partner, that I was my own care partner and that I was living alone. The receptionist seemed annoyed and told me I wouldn't be eligible to attend their programs unless I came with a care partner. I hung up. I was so angry and humiliated.

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*Too often, single people living with dementia are singled out and excluded from supports and services because we do not have a care partner.*

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I've talked to other friends who are living alone and living with dementia — and my experiences are not unique. This happens all the time. It's hard enough to find the right supports and services for those living with dementia. But if you're looking for an additional challenge, try doing this on your own. It sometimes feels like I am running an obstacle course.

I remember a time when I tried to register for an upcoming conference and was told that I needed to have a care partner accompany me. I was really miffed and I shared this with my friend, Diane, who immediately offered to meet me at the conference and to be my "care partner" for the day. While I appreciated Diane's kind offer, I declined it. I ruminated on the agency's negative response. It was crazy because I could drive 100 miles (each way) to get to the conference, but I would not be able to attend the conference unless someone like Diane was there to "keep an eye on me." AARGH! Another time, I heard about an upcoming picnic for those living with dementia (and care partners) with the same requirement of having a care partner there to supervise. That gave me an idea. I called my friend, Neil, who also lived by himself with dementia, and we decided that we would be each other's care partners. I drove to Neil's house and we went together. The organizers weren't too happy with our showing up without care partners. Too damn bad!!

It's upsetting enough to be diagnosed with dementia. It is even more upsetting to be treated as incompetent. It is humiliating to be excluded from educational and social events simply because you do not have a care partner. Thankfully, there are allies out there. Over the years, I met a number of sympathetic people who were willing to "bend the rules" and look the other way and let me attend programs by myself, but I worried at times that they might lose their job for allowing me to attend events alone. I am well aware that I am considered

by some to be an insurance liability — and that if something should happen to me while I am at an event by myself, there could be repercussions.

I am very aware that, at some point, I will NOT be able to travel or attend events on my own — but right now, I am able. Shouldn't that fact be acknowledged and celebrated?

Some of us are single by choice and some are single by circumstance, such as death, divorce, and relocation. According to the Alzheimer's Association, there are approximately 800,000 of us living alone with dementia. Too often, single people living with dementia are singled out and excluded from supports and services because we do not have a care partner.

As a pastor, I have often comforted people who have found themselves suddenly single, such as a grieving spouse, who is just trying to figure out next steps as she tries to imagine her life without her husband of 20 years. Sometimes "singles" will move in with a family member rather than live alone, and this arrangement works well for many. Some may take in a roommate. Some like myself are content to live alone. We are all different. There are benefits to the single life! I can get up when I want. I can eat what I want and when I want. I can travel when I want. I have heard too many stories from those living with a dementia diagnosis of family members who have taken over and forbidden them to do the things they once loved to do.

Yes, for now I am quite content to live alone. I say "for now" because the time will come when that will be more difficult. It is sometimes tricky to balance autonomy versus heteronomy — that is having someone who makes decisions for me.

Sometimes people react with pity when they hear that I live by myself. "Oh you poor dear! Isn't there anyone who might live with you?" I believe these people are trying to be helpful as they offer ideas for companions. "Couldn't your daughter move in?" or "What about having a home health aide?" "You've got an extra room, how about getting a roommate?" This unsolicited advice is not terribly helpful and seems to say, "Doesn't anyone care about you?"

It's time for organizations to rethink their policies around requiring care partners for individuals with early symptoms of dementia in order for that individual to be able to attend a program. Dementia is not a cookie cutter condition. Symptoms may progress more quickly for some people and require the assistance of a care partner. Others seem to experience a slower rate of symptom progression. Some may have trouble with wayfinding — others may not have this problem. We are all different and some require more support than others.

If you are a single person living with dementia, you may find that there are extra obstacles in your way as you seek to find the services and supports that will allow you to live your best life. Please don't give up. Keep pushing the envelope. If you are not already a member of Dementia Action Alliance, please connect with us. We have a number of online discussion groups as well as educational, social, and art events online — and we are here for you.

— Blessings, Cynthia

## 2.7 Finding Silver Linings in Your Unexpected Journey



*Rev. Dr. Cynthia Huling Hummel, Manual Guide*

I was chatting with a friend, and she told me that she was waiting for a contractor to provide her with an estimate for a hole in her roof. A heavy branch had come down during a storm and she had a mess. She said, “Thankfully, no one was hurt — and, thankfully, insurance will cover the repairs!” As she looked up at the sky through the hole in her house, she said wistfully, “Well looks like, I’ve finally got the skylight I’ve been wanting.”

Carol experienced a silver lining. What’s a silver lining? A silver lining is a sliver of hope or a positive prospect about a negative situation, such as having a hole in your roof.

I was facilitating a dementia support group for men, and one man was sad because he wasn’t able to take care of his yard the way he used to. His wife had to hire a kid from the neighborhood to mow the lawn and trim the shrubs. Another man in the group said, “Jerry, Jerry — that’s not a problem because now you have more time for golf. Heck, tell the kid to mow you a putting green.” Soon all the men in the group were jumping in the conversation: “Hey Jer! No more dealing with poison ivy, no more raking! No more having to put out the grass clippings.” The men in the group were pointing out the silver linings, and soon Jerry was joining in the fun. His face brightened and so did his mood.

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*Having a sense of humor helps! If we can laugh  
at a situation, it can help diffuse  
the anger or frustration we may be feeling.*

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Looking for a silver lining can change our outlook on life. Finding a silver lining can change our tears of frustration to tears of relief or even happiness. Some people are able to find a silver lining right away. They seem to do it automatically. For others, finding the silver lining is next to impossible. They just can’t see anything positive about THEIR negative situation.

Thankfully, we can get better at finding silver linings — by exercising our positivity muscles and asking ourselves this question, “Is there anything, at all, no matter how small, that gives me a sliver of hope in this difficult or bleak situation?” Or make “Finding Silver” a game and challenge yourself to find one small silver moment. One of my favorite silver

lining stories is when I attended a free art class for people living with dementia. The focus of the class that day was mask making and attendees were invited to make one mask. I enjoyed mask making so much, I went home and over the next few weeks, I created 35 more masks.

My masks illustrate what it feels like for me to live with early symptoms of Alzheimer's. I took photos of each of my masks, wrote about each one, and published a book called, "unMasking Alzheimer's: The Memories Behind the Masks." My masks have been on exhibit in various conferences around the U.S., and ten of my masks were exhibited at the National Gallery of Art in Stockholm, Sweden. Additionally, free copies of my book were given to all the attendees at an international conference in Stockholm. A silver lining, for sure!

One way to get better in detecting silver linings is to "rerun the tape" in our mind of an upsetting encounter, like getting in an accident. We can go ballistic, or we can try to calmly assess the situation. What happened? A man in another car ran the stop sign and ran straight into your car. It was a scary situation indeed. But if you stop and breathe, you might notice that no one was seriously hurt, that the police came right away, and there was no real damage to your car. Sometimes, when we revisit situations, we can better see things in a positive light.

What do these examples have to do with living with dementia? For many, it is easy to focus on the negatives of living with a diagnosis. It's easy to focus on the challenges and problems that we may encounter each and every day. But if we choose to shift our focus and look for the silver linings, or positives, in our daily lives, we may just find that we feel better about life and about our situation.

Having a sense of humor helps! If we can laugh at a situation, it can help diffuse the anger or frustration we may be feeling.

Another way that we can find a silver lining in a situation is to ask ourselves questions like these: Who helped me today? What did I learn today? What happened today that surprised me? Who or what made me laugh? Sometimes, I don't see the silver lining in the moment — but it appears later when I reflect or reminisce. Instead of focusing on things in our lives that went wrong or the decisions that we regret, why not focus on the silver linings? Life is full of these little blessings if we only take the time to look. Practice gratitude! Give thanks for those people in your life who care for you and about you and for those sweet silver lining moments the day brings. — Blessings, Cynthia

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### **SUGGESTED RESOURCE**

Dementia Friendly America Toolkit. [www.dfamerica.org/community-toolkit-introduction](http://www.dfamerica.org/community-toolkit-introduction)



## 2.8 By Us For Us Guides

The By Us For Us guides are a series of guides created by a group of talented and passionate people living with dementia and care partners. They were founded in 2004 by Brenda Hounam, who was diagnosed with dementia at 53 and recognized there was a clear gap in support for people living with dementia and care partners in Canada. What makes these guides unique is that they were created BY people living with dementia, FOR people living with dementia.

The guides were developed using the Authentic Partnership Approach, which values the contributions of people with lived experience and involves working collaboratively and equally with others. People living with dementia were actively included in all aspects of developing the guides, from identifying topics and gathering information, to making decisions on final content and cover artwork. Input was gathered from people of different ages and backgrounds, who were living with different types of dementia.

The project was later expanded and now includes three series:

- ◆ A series for people living with dementia
- ◆ A series for people living with dementia and care partners
- ◆ A series for care partners

There are currently 15 guides that provide people living with dementia and care partners with information, strategies, and tools to enhance their well-being and manage daily challenges. Free copies are available online and hard copies are available for purchase.

The guides are supported by the Murray Alzheimer Research and Education Program (MAREP) at the Schlegel-UW Research Institute for Aging (RIA). To learn more and download the guides, *Enhancing Communication* and *Managing Triggers*, which are reprinted in this manual with permission., visit: [the-ria.ca/resources/by-us-for-us-guides/](http://the-ria.ca/resources/by-us-for-us-guides/)



A BY US FOR US GUIDE

# Enhancing Communication

An inspirational guide  
for people living with dementia

SERIES 1

# Introduction

This guide discusses the most important tool we have, which is communication. Communication is BOTH verbal and non-verbal. Both means of communication are important, but non-verbal communication becomes an even more valuable tool when dealing with memory changes. Watching other people and their body language helps us understand a conversation better, as so much of our language can have different meanings depending on how it is stated. A hand signal can be used to stop a conversation while thoughts are gathered. A meaningful glance can be used to let others know that help is needed. Body language can tell others that we are uncomfortable or tell us whether someone is truly interested in what we have to say. A warm touch can tell us that you understand and care.

Some people are excellent communicators and find it easy to use this tool in difficult situations, while others find it very difficult to have sensitive conversations. If a strong effort is made to communicate in the beginning, it will benefit all. It is important that care partners remember that asking what would work best is the ideal approach, as everyone is unique in their likes and dislikes, their experiences, and their feelings.

# Introduction continued

Memory changes may affect our communication skills, but we can use communication to our advantage. This requires us to be very open and candid with others, and for others to be open and honest with us. This is a very difficult and emotional time, but the rewards of these early conversations will be carried with us throughout our journey. It is important to communicate and document everything now, while you are still able. Don't be afraid to ask for help, as working together in these times will be some of your fondest memories. Vocalize: write letters, poems, songs, or stories; or use videos and pictures to help with this. Don't be afraid to tell others how you are feeling and what your experience is like. Tell people now how much they mean to you and thank them ahead of time for all their future assistance. That way they can remember this on the days that dementia causes you to say or do something inappropriate. Also, we need to be willing to hear from our care partner about how they are feeling and what their experience is like. It is important that all parties listen carefully, respect each other's perspectives, and never judge.

There is great power in saying, **I LOVE YOU! THANK YOU!  
CARRY THESE WORDS WITH YOU EVERY DAY OF OUR  
JOURNEY TOGETHER!**

– Brenda Hounam, Paris, ON

This By Us For Us guide is dedicated in memory  
of a dear friend, **Sharon Smith**

# Things we have always wanted to say...

We are so close to our care partners, and we realize how much we rely on them at times, so we do not want to hurt them with our feelings. This is why it is often hard to say what we really want to say, which is....

- ✓ **I need to be open about my experiences and not protect you.** I have always wanted to tell my family members how hard this diagnosis is for me and the problems that go along with it. I have not told them much because I want to keep a positive attitude and I need them to help me. At first, I wanted to protect my family from knowing what may happen to me as the disease progresses because I didn't want them to be scared or feel bad, but I decided that it is more important to be honest with family right from the beginning.
- ✓ **I get frustrated, too.** I know I must frustrate you sometimes, but please know that it is never my intention. Keep in mind that I get frustrated too, and we have to work at not letting small things bother us.
- ✓ **Treat me like an adult.** Don't treat me like a child, do everything for me, speak for me, or smother me. Please ask me what I need and want.
- ✓ **I need your support.** Make me feel part of you and stick with me. Please don't correct me; encourage me instead.
- ✓ **Please don't make assumptions or speak for me.** Listen to me. Hear what I am saying and don't assume you know. Just ask me what would be helpful



# Communication challenges with family and friends

## I feel discredited and devalued

It hurts when I am second-guessed or when people ignore me and talk to my care partner before talking to me. I do not like being treated like a child or treated as though I am not there. I sometimes do not feel validated, or I feel that I am no longer considered 'an expert' capable of making valid decisions.

### Personal solutions

- ✓ Join a support group to talk with people who understand what you are going through.
- ✓ Share your challenges and coping tips with others.
- ✓ Talk with others about how you want to be involved in decision-making.

### What others can do

- ✓ Speak directly to me.
- ✓ Really listen to what I am saying and ask questions if you do not understand.
- ✓ Do not talk to me as though you are speaking to a child.



# Communication challenges with family and friends continued

## What others can do

- ✓ Offer gentle encouragement and “quiet help” when I need it.
- ✓ Please respect me as a person and preserve my dignity.
- ✓ Allow me to try things on my own.
- ✓ Acknowledge that I still have a lot to offer and can still contribute in some way. My life doesn't stop here.
- ✓ Treat me in the same way you would want to be treated in the same situation.
- ✓ Problem solve as a family.
- ✓ Write reminder notes for me and leave them where you know I will find them.
- ✓ Make a checklist for me or help me use timers as reminders.
- ✓ Don't be afraid to ask me for help.
- ✓ Give instructions one step at a time.

# Communication challenges with family and friends continued

## My friends lack understanding or doubt my diagnosis

Friends are often uncomfortable around me, now that I have dementia. It is almost as though they forget that I am still the same person. They tell me they understand, but really, they don't, because they can't. Sometimes, friends and family do not accept that I have Alzheimer's, and as a result, they do not discuss it with me. They even question the diagnosis and they say things like, "You look so well", or "I forget things also". It is hard to communicate about the disease when others do not acknowledge it.

### Personal solutions

- ✓ Be open about your diagnosis and share your feelings and experiences with others.
- ✓ Use laughter to communicate to others that you are at ease and it will make them more receptive to what you are sharing.
- ✓ When you accept your diagnosis, and are comfortable talking about it, then others will be comfortable and open as well.
- ✓ Take initiative to ensure that people understand you by asking them if they understand.

# Communication challenges with family and friends continued

## Personal solutions

- ✓ If friends and family don't phone or visit, call them.
- ✓ If available, use a computer or other device to keep connected.

## Notes

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**“We appreciate your effort to understand what it is like to have dementia, but you really cannot fully understand what the experience is like until you have walked in our shoes. We hope that, through this guide, you can gain a better understanding of our experience and gain tips on how we can all work together to enhance our lives together.”**

(Gail Robinet, BA., M.Div., Burford, ON)

# Communication challenges with family and friends continued

## What others can do

- ✓ Ask me what I am experiencing, how I am feeling, and validate what I am saying.
- ✓ Acknowledge that you do not totally understand but that you are trying.
- ✓ Please listen to me and believe what I am telling you about my experiences.
- ✓ Don't get angry when I repeat myself.
- ✓ Be open with me, even about those things you think will upset me.
- ✓ You can tell me that you are grieving as well, because we are going through this together.
- ✓ Please don't give up on me.

## Opening up and asking for assistance is difficult

It is difficult to open up to people, or ask someone to drive me places. It is also hard to request special outings, such as going to hockey games, because I do not want to interfere with others' lives.

# Communication challenges with family and friends continued

## Personal solutions

- ✓ Explain that you are having difficulties and ask them to be patient with you.
- ✓ Realize that sensitive or personal conversations can be more difficult depending on the topic. Choose to speak to someone with whom you feel comfortable.
- ✓ The sooner you start open dialogue with your loved ones, the easier it becomes.
- ✓ Make a list of your needs and share them with others.
- ✓ Don't be afraid to ask for help.

## What others can do

- ✓ Please don't back off after I have exposed my feelings to you, because I will see it as a form of rejection.
- ✓ Try to be comfortable talking to me about difficult topics, such as sexuality.
- ✓ Ask me how you can help.

# Communication challenges when in social situations

## Sometimes, I am at a loss for words or cannot find the right word

Communication is challenging when I cannot find the right words. My vocabulary gets lost and my mind goes blank. My sentences 'derail', I have difficulty projecting my voice, and sometimes I stutter.

### Personal solutions

- ✓ Keep a pen and paper handy and write down notes for reminders.
- ✓ When in a group setting, write down one word that can bring the point back when you get an opportunity to speak.
- ✓ Keep conversations simple and on the light side.
- ✓ Take a few moments, relax, and think about what you want to say, or what people want you to do; the words often come when you feel less pressured.
- ✓ If you cannot remember, simply say so.
- ✓ Be a good friend to yourself.
- ✓ Don't be afraid to tell others if you are having a bad day.
- ✓ Ask people to slow down.

# Communication challenges when in social situations continued

## What others can do

- ✓ Pay attention to non-verbal cues and body language, such as eyes and hands.
- ✓ Give me reminders and prompts.
- ✓ Tell me your name and remind me of my connection to you.
- ✓ Allow me time to think, find the right word, answer questions, or write down my thoughts.
- ✓ Remember that I have something to say too.
- ✓ Ask me how I would like to be helped.
- ✓ Remind me what we are speaking about.
- ✓ Ask me if I want help with a word, but do not rush in to finish my sentences.

## Difficulty maintaining focus and keeping on track, especially in large groups

When talking with friends, I often lose my train of thought. I cannot keep up or on track. People often talk too quickly and do not give me enough time to talk. I have something to say; I just need more time and less distraction.



# Communication challenges when in social situations continued

## Personal solutions

- ✓ If you can't think of anything to say, ask the other person a personal question. Then pay close attention to the answer and comment on something they said.
- ✓ Listen to your peers and learn what works for them.
- ✓ Do your important communicating when you are rested.
- ✓ Communicate in a quiet environment and minimize distractions.
- ✓ Ask people to speak one person at a time.
- ✓ Make notes before important conversations so you don't get sidetracked.
- ✓ Communicate during mealtimes, while walking, or when working on projects, as these conversations tend to flow more easily.
- ✓ Ask people to slow down and use shorter sentences.
- ✓ Ask people to repeat a question in a different context, or have them provide an example.
- ✓ Try to keep to one-on-one conversations or small groups.

# Communication challenges when in social situations continued

## What others can do

- ✓ Keep conversations light and simple and talk to me slowly and calmly.
- ✓ Provide me with one suggestion at a time and provide fewer options/choices.
- ✓ Don't avoid talking about something difficult, be direct, specific and open with me.
- ✓ Please don't interrupt me or I'll lose my thoughts.
- ✓ Do not move ahead in a conversation without me because I will not move on in my head. I often repeat myself because I am still thinking about that issue and I don't know that I already spoke about it.
- ✓ Allow me the time I need to process my thought and communicate it to you.

## Notes

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# Communication challenges when in social situations continued

## Others forget the range of communication strategies

Many people believe communication involves only the things that we say, when it is really so much more. Communication also incorporates the things that we do not say – the looks we give, the hand gestures we use, or the body language we use. It can include writing, gestures, signs or signals, behaviours, and displays of emotion. The manner in which we say something can clarify a message or provide room for misinterpretation. For example, someone may shout in order to be heard, which may lead to a perception of anger or impatience, even if the words do not reflect these emotions.

## Notes

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# Communication challenges when in social situations continued

## Personal solutions

- ✓ Use hand signals. Hold your hand up to stop a conversation or prevent someone from interrupting, or use the 'time out' signal if a question is too long or complicated, or if you lose your concentration.
- ✓ Writing is an easier way for some people to communicate.
- ✓ When you need to start a difficult talk, leave a note for someone saying that you would like to talk about something.
- ✓ The computer is a good tool for writing letters to tell others about your feelings, and you can also use it to help you proofread.
- ✓ Use other visual aids or non-verbal cues. Use your eyes and body language, draw pictures, write notes, or point to photos or pictures.
- ✓ Use a voice recorder for the times when you think of a thought and writing it down may be difficult (like in the middle of the night).
- ✓ Keep lists of things you would like to share with others.

# Communication challenges when in social situations continued

## What others can do

When in public and I would like my children to step in and help me with what I am trying to communicate, I give my children a look. We joke about it being a ‘Mother’s Look’ – you know, the look a mother gives when her children are misbehaving in public. Now that look means “PLEASE HELP!”

- ✓ Recognize that I rely on your body language.
- ✓ Some conversations are easier in person than over the phone or email.
- ✓ A warm touch can tell me that you care.

## Notes

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**“I like to use the computer to proofread letters and rewrite for feelings and expressions.”**

(Clayton Wilson, B.A., M.Ed., Brantford, ON)

# Challenges when communicating with health care professionals

## I have difficulty remembering, describing, or relaying my experiences

I have difficulty finding the right words or remembering my feelings in order to explain my situation to doctors or other health care professionals. Plus, doctors are always rushed and they do not allow us the time we need to express the issue.

### Personal solutions

- ✓ Write down any questions or symptoms you have and prioritize these comments before your appointment, as you might not have time to discuss all your concerns.
- ✓ Ask the doctor to write down any instructions for you, no matter how small, such as going to the lab or making a new appointment.
- ✓ Take a trusted family member or friend with you to a doctor's appointment and ask them to make notes, ask questions, and support you.
- ✓ Be totally open and honest with your doctor about everything that has changed and the things that are not normal for you. Make a list or keep a diary to help you remember.
- ✓ Ask a trusted family member to make a list of changes that they have noticed in you and have them discuss this list with you BEFORE they show it to your doctors.

# Challenges when communicating with health care professionals cont.

## Personal solutions

- ✓ Book an extended appointment if needed (like 30 minutes instead of 15).

## What professionals can do

- ✓ Have patience with me.
- ✓ Give me time to express myself and think. Slow down during my visits.
- ✓ Get to know me beyond the dementia. I am a person first.
- ✓ Encourage me to keep a diary of my experience and allow me to share it with you.
- ✓ Ask me what I have been experiencing.

## **They lack an understanding of the disease or they deny that something is wrong**

Doctors seem to have a misconception of my disease and how it affects me. They may think I am in the late stage already, or they might not think anything is wrong. A short appointment is often not enough time for them to see the extent of my disease, especially if I am articulate or I appear capable.



# Challenges when communicating with health care professionals cont.

## Personal solutions

- ✓ Realize that doctors are not gods; you are the expert about yourself!
- ✓ Be your own advocate and have confidence in yourself.
- ✓ You know your body more than anyone else so be firm about how you feel and keep persisting!
- ✓ Many issues arise from interactions with your family doctor, so get them to refer you to specialists who will be more likely to understand what you are going through.

## What professionals can do

- ✓ Listen! Listen! Listen! Don't assume you know what is best for me.
- ✓ Ask me what I am experiencing and how you can help!
- ✓ Learn as much as you can about dementia, and if you are not sure, please refer me to a specialist.
- ✓ Know what supports are available in the community and refer me to those resources, such as the Alzheimer Society.
- ✓ It's better to say you don't know than to say nothing.

# Challenges when communicating with health care professionals cont.

## They treat me like I am not there

They think I am less credible than others, so they talk to others instead of me. They assume they know what is best for me.

### Personal solutions

- ✓ If you are unhappy with how your doctor treats you, say how you feel or find a new doctor.
- ✓ Ask doctors to explain things to you in simple terms, so you can be involved in the discussion.

### What professionals can do

- ✓ Please ask me what I want or how you can help.
- ✓ Speak to me directly, not to the person I am with.
- ✓ Allow me to be involved in decision-making.

# We asked the doctor for you

## An appointment checklist...

“I have been asked by the By Us For Us participants, as a physician specializing in the care of individuals with cognitive loss, to supply the following checklist for your next doctor’s visit:”

- Did you bring all of your medications, in bottles, including over-the-counter medications like vitamins and herbal medications?
- Did you write down questions or concerns before the appointment?
- Recognize that not all issues can be dealt with at one appointment.
- Did your trusted family members or friends write down observations regarding changes (either good or bad) that they have observed in your behaviour since your last appointment? This will help the doctor to better gauge the progression of the disease (either positive or negative), and to follow any improvement after medication.
- Did you arrange for a trusted family member or friend to accompany you to the appointment to provide information and be a second set of ears?
- Did you keep a list of all doctor or therapy appointments, medical tests, and hospital admissions forms to bring with you to the appointment, to help keep track of important issues?

E. Anne Braun, M.D., M.Sc., F.R.C.P.(C), F.A.C.P.  
Associate Clinical Professor Medicine  
& Psychiatry McMaster University Geriatrician



# What research says

## Factors that influence communication

Certain health events (e.g., hearing loss, strokes) can affect communication, and the ability to process information slows with age. People may take medications that have side-effects that change communication. All these things may cause increased isolation, which leads to decreased opportunities for communication.

## Communication issues

The impairment of our short-term memory impacts our ability to hold and maintain a conversation. Changes in communication are reflected by losses of vocabulary, word-finding ability, understanding of abstract language, ability to understand messages on the telephone, ability to express ideas, and ability to keep up with the conversation.

People living with dementia are often aware of their communication difficulties and can feel embarrassed, frustrated, or scared. Positive encouragement, helpful cues, or gentle reminders to complete thoughts and sentences will become necessary with time.

People living with dementia may become less aware of their difficulty, but increasingly frustrated and stressed. Please only help us find our words when necessary, and do not correct or insist. You can use pictures or objects to help us remember.

# What research says continued

People living with dementia may be unable to communicate with exact words, and may use other ways of communicating. Even though the words or gestures may not make sense to some, they still communicate something. People living with dementia may enjoy non-verbal communication, so use gestures, facial expressions, tone of voice, and caring touch, to help make a connection.

## **Attitudinal factors influencing communication breakdown**

Attitudes and stereotypes of dementia can influence the way people communicate to us, causing them to inappropriately modify their speech, such as using baby talk, shouting, or using demeaning language. This leads us to become disempowered, ignored, and banished from many meaningful opportunities for relationships and personal exchange. This is why it is important for people living with dementia to seek opportunities to express themselves. We all need to focus on a wide range of non-verbal communication techniques, and celebrate strengths and abilities.

**“I want to learn more about Alzheimer’s. It helps to remove the fear and denial. I want to learn how to stay healthy longer. I’m not prepared to just fade away.”**

(Carl Wilson, Sarnia, ON)

# Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the By Us For Us (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.



## Resources

### **Alzheimer Society of Canada**

Toll-free telephone: 1-800-616-8816

Email: [info@alzheimer.ca](mailto:info@alzheimer.ca)

Website: [www.alzheimer.ca](http://www.alzheimer.ca)

### **Alzheimer's Society UK**

Website: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Refer to information on communicating with someone with sensory impairment.

### **BrainXChange**

Website: [www.brainxchange.ca](http://www.brainxchange.ca)

### **World Health Organization**

Website: [www.who.int](http://www.who.int)

We also suggest that you check for other local, national and international resources.

## Endorsements

As Chief Executive Officer of the Alzheimer Society of Canada, I want to congratulate the 'By Us For Us' team for their continued support to people, like themselves, who are living with early stage memory loss. The innovative ideas and suggestions contained within this Communications Guide are valuable tools for anyone living with the day to day challenges of dementia. Whether you are someone living with the disease, a family member, a friend or health care professional, the 'By Us For Us' guide provides unique insight into how communication, both verbal and non-verbal, can be a powerful tool. Thank you again to everyone involved with this project, as your guidance and inspiration is truly helping to make a difference in the lives of people touched by dementia.

### **Scott Dudgeon**

CEO, Alzheimer Society of Canada

[www.alzheimer.ca](http://www.alzheimer.ca)

This practical guide clearly shows how persons with early-stage memory loss can take steps to maintain satisfying communication and how their conversation partners can learn to listen to them and follow their lead in interactions. These concrete suggestions flow from the same wisdom evident in published memoirs by writers with dementia. The problem-solving format will be very useful for individuals and for group role-play sessions.

### **Dr. Ellen Ryan**

Professor, Gerontology and Psychiatry McMaster University

# Acknowledgements

## The development team

Brenda Hounam, Gail Robinet, Sharon Smith, Elaine Smith, Scott Millar, Clayton Wilson, Janet Dupuis, Carl Wilson, Mary Barret, Andy Vershoore, Gordon Sinclair and Maggie Fox

## The refresh team

Brenda Hounam, Mary Beth Wighton, Paul Lea and John Hammel

## Refresh team support

Sian Lockwood, Emma Bender, Hilary Dunn-Ridgeway and Michelle Stillman

## For their personal contributions, we would like to thank:

- The Alzheimer Society of Brant
- The Alzheimer Society of Niagara Region – Early-Stage Support Groups and individuals living with dementia who took the time to share their experiences to help inform the information in this guide.

There are many more who have offered support and input over the past few years, while this project was just a dream, who deserve credit, but wish to remain anonymous. You know who you are! Thank you.

## Thanks also to:

- Dr. Anne Braun
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- Funding: Homewood Foundation

# About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

## **People Living with Dementia: Series 1**

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

## **Partnership: Series 2**

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

## **Care Partner: Series 3**

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

**To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:**

**[www.the-ria.ca](http://www.the-ria.ca)**

## **We welcome your input...**

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

# Connect with us!

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Murray Alzheimer Research  
and Education Program



A BY US FOR US GUIDE

# Managing Triggers

An inspirational guide  
for people living with dementia

SERIES 1

# Introduction

Before our first 'memory workout' guide was completed, we in the By Us For Us group knew our second booklet would be on 'triggers' (stressors). Triggers are so often discussed in our support group sessions. They are the episodes where we have our buttons pushed and our emotions are triggered in a 'knee jerk' reaction. They are those things that cause us to become agitated and experience increased stress. Or, they are those situations that cause us to have MORE difficulty thinking and perceiving, when in the past we may not have been bothered or affected in the same way. Previous to our diagnosis of dementia, we were able to control our emotions in different types of settings. But now, we quite often react before we have a chance to think about it. As if that is not enough of a challenge, new triggers often emerge as dementia progresses.

Understanding our triggers and the causes of them can be very difficult, but is so important if we hope to be able to reduce the incidence of them or learn how to respond to them more effectively when they happen. First though, you have to acknowledge that triggers do happen and reach beyond the embarrassment in order to ask for help in identifying what your individual triggers are. Once you have become agitated, it is difficult to process your thoughts on what has caused you to become upset, but trusted family and friends can assist you with this. When a trigger occurs, write down everything that occurred, as sometimes you may not be readily able to identify what may have caused the reaction. Reflection, when your head is clearer, will bring some clarity.



# Introduction continued

Accepting that this is part of the process and identifying your individual triggers are important, as these steps allow you to improve your own personal control capabilities and help your care partners better understand your experience with memory changes and better support you throughout the process. This is the time to be open and honest with yourself and with your loved ones. Don't be embarrassed to communicate what your triggers are, as nothing that you experience is insignificant. Think about what some of your triggers might be, write them down, and share them with all those around you! The purpose of this By Us For Us guide is to help you get started with this.

Dealing with triggers is also a great time to draw on your sense of humour. Laughing at a situation first puts you in command and makes those around you feel more relaxed.

Understanding and accepting what happens empowers you to take control of your life. It will give you back those quality days that are so cherished and will take some of the stress out of your tomorrows.

Humour is a great tool! Remember, **CRY FIRST, LAUGH LAST!**

– Brenda Hounam,  
Retired Industrial Accountant, Paris, ON

**“I don't know what I'm saying sometimes,  
but I know what I WANT to say.”**

(Gordon Sinclair, Brantford, ON)

# Tips for managing triggers

I have found that the more open I am about those things that cause me to become stressed, and communicate this with my children, family, and close friends, the more that the stress in our lives is reduced.

## What can you do to help gain back control after you become stressed?

- ✓ Practice deep breathing. This is very important to do, especially if you are not physically active, because it allows oxygen to go to your brain.
- ✓ Enter a quiet place with softer lighting, or close your eyes.
- ✓ Meditate.
- ✓ Listen to soothing/calming or favourite music depending on your mood and personality.
- ✓ Participate in something that will distract you.
- ✓ Try to step back, and take a breath of fresh air and calm down. (Count to 10!)
- ✓ Share your feelings with others.

We also ask that others help us in minimizing triggers and stressors. This can be done by listening to us about what we need and by providing gentle assistance.

# Social situations

## Crowds and loud noise

Many public areas, such as restaurants or shopping malls, are filled with large crowds, lots of noise, including loud music, and there are multiple conversations happening at once, which is very overbearing for us. Family outings can also be tiring and frustrating because of the noise and crowds.

### Personal solutions:

- ✓ Remove yourself from crowds when triggered.
- ✓ Go to malls, restaurants, and other public places at less busy times.
- ✓ Ask the establishment to turn down the music volume.
- ✓ Ask those you meet to move to a quieter spot for a conversation.

### What others can do:

- ✓ It's nice to feel included, but allow me to leave when I start to get stressed. Ask me if I would like to go home. That lets me feel I have enjoyed it, too.
- ✓ Keep it as quiet and calm as possible and give me space.
- ✓ Remind me to use earplugs.
- ✓ Search out quiet spaces I might escape to if needed.

# Social situations continued

## Being rushed and not included in plans

Many of us do not like sudden plans or when we are not given enough time to get ready. We do not like to feel pressured or when people rush us and say “get on with it” when we are completing a task.

### Personal solutions:

- ✓ Prepare a calendar or daily schedule to keep track of events. Plan ahead.
- ✓ Give yourself plenty of time to get ready.

### What others can do:

- ✓ Allow me enough time to prepare.
- ✓ Involve me in decision making and keep me up to date if we are going out or doing something.
- ✓ Take my schedule into account when making plans.
- ✓ Make sure all events are added to my calendar and remind me of them on the day of the event.
- ✓ Be patient and allow me to complete a task at my own pace.

# Social situations continued

## Shopping and restaurants

It can be frustrating when you get to a store or restaurant and you cannot express what you want or what you are looking for. In a restaurant, it is difficult when there are too many items on a menu because you forget what you just read by the time you're through reading the menu. It is also difficult to remember when the server reads the specials or wine/beer list. Making change and figuring out tips is even more challenging now.

### Personal solutions:

- ✓ Write down what you want to buy at a store before you go, or take a picture of it with you, so you can show the staff members exactly what you need.
- ✓ Show the staff a card saying you have memory changes or tell the person serving you – they will likely be more patient.
- ✓ When going to a restaurant, write down a list of your favourite foods and drinks so you remember what you like, or so you can show the wait staff.
- ✓ Go to restaurants where you already know the menu.
- ✓ Ask the wait staff for a written copy of the specials.

# Social situations continued

## Personal solutions:

- ✓ Ask the wait staff what they have on special or on tap that suits your preferences, instead of having them list the specials or wine/beer list.
- ✓ Ask a trusted friend/family member for help with ordering, tipping, or making change.

## What others can do:

- ✓ Restaurants can offer quiet areas (such as booths) that will allow us to eat out in a quiet space or call ahead to arrange this.
- ✓ Allow us to keep a tab, so we can dine regularly but not have to pay immediately.



For more tips on enjoying meals at restaurants refer to the By Us For Us guide: **Food and Mealtime.**

## Notes

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# Social situations continued

## Being tested, quizzed, or pushed for answers

People test, quiz, or push us for answers. They may think that this is helpful in making us think, but it is not.

### What others can do:

- ✓ Remind me who you are; don't keep me guessing.
- ✓ Don't quiz me or test me unnecessarily.
- ✓ If you do ask a question, give me time to think and respond.
- ✓ When talking with me, give me as much information as possible in the conversation.
- ✓ I will let you know if I don't know something or can't remember something.

## Notes

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# Verbal communication

## Difficulty finding words

When having difficulty communicating, it is upsetting when people respond, “I forget all the time, too” or “We’re all getting older”. They will also jump in too quickly with what they think we are trying to say or they’ll change the subject instead of allowing us time to retrieve our thoughts. They may also show physically how uncomfortable **they** are with our inability to converse at the same level as them.

### Personal solutions:

- ✓ Tell others how you feel and how you would like them to assist you.
- ✓ Allow yourself the time to pull your thoughts together.

**“I GOT IT! I don’ t need to be hit over the head with it.”**

(Janet Dupuis, X-Ray Technologist, St. George, ON)

# Verbal communication continued

## What others can do:

- ✓ Remember, sometimes things said with the best of intentions have the opposite effect.
- ✓ Ask when or if you can offer me a word or suggestion, or fill in words in a gentle, non-threatening way.
- ✓ Don't **patronize** or **test** me, but encourage me.
- ✓ Be patient and relax in my presence; I can still read your body language.
- ✓ Hints can go over our heads, so please be clearer in what you are asking.
- ✓ Don't say, "I've already told you twice."

## Communicating with others and expressing myself

Sometimes, we are expected to make small talk, which makes us uncomfortable. People talk too quickly, too long, they are too loud, or they talk at the same time, making it difficult for us to verbally communicate. It is also hard to be involved in long conversations or be asked for lots of information.

# Verbal communication continued

## Personal solutions:

- ✓ Participate in one-on-one conversations or small groups.
- ✓ Learn to ask others to slow down their speech.
- ✓ Feel free to leave a conversation.
- ✓ Keep social events or conversations short.
- ✓ Reduce distractions and feel comfortable asking others to move with you to a less distracting space.

## What others can do:

- ✓ Don't interrupt when I am speaking, as I will lose my train of thought.
- ✓ Talk about my needs with others to reduce my stress.
- ✓ Don't make me feel guilty or anti-social. Gently suggest I sit in another room to regroup, and then I might be able to return to the gathering.
- ✓ Give me time to put my thoughts together and respond.



For more tips on communicating with others, refer to the By Us For Us guide: **Enhancing Communication**.

# Your environment

## Room temperature and weather conditions

A room's temperature is often a problem for us, be it too hot or too cold. No matter what the condition, when uncomfortable, we become stressed. Bad weather or dressing inappropriately for weather can be triggers.

### Personal solutions:

- ✓ If hot, step outside, have a cold shower, use ice in a cloth, or use a fan.
- ✓ Cooking over a stove might be a trigger. In this case, cook with others or have someone else cook when it involves the stove or burner.
- ✓ Anticipate changes in weather – bring a sweater/hat or wear layered clothing.

### What others can do:

- ✓ Take notice of how temperature affects me.
- ✓ Control the environment around me as best as possible.
- ✓ If I'm taking off my clothes or putting on extra layers, realize I am just really hot or cold and uncomfortable.

# Your environment continued

## What others can do:

- ✓ Discuss weather conditions with me and respectfully suggest appropriate clothing.

## Being in a car as a passenger

Even as a passenger, we feel the pressures of the road. We may have driven in the past, and so we still drive every part of the route in our mind. Bad weather or traffic can stress us out very quickly.

## Personal solutions:

- ✓ **Learn how to be a passenger** when others are good enough to drive us.
- ✓ Try to avoid being in a car during bad weather conditions.
- ✓ Think about how you're feeling that day, and recognize when you are having an off day, then decide whether you can go for a ride.
- ✓ Try relaxing techniques (e.g., closing your eyes).

# Your environment continued

## What others can do:

- ✓ Recognize that passengers still drive the distance.
- ✓ Drive with caution and don't get offended if I am anxious or fearful.
- ✓ Pull over and take a 10-minute break for me to regroup.
- ✓ Lower the music volume.

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# Change of memory and abilities

## Getting lost or losing things

It is frustrating and frightening to get lost or misplace articles. It is very upsetting when people respond in a way that does not validate our feelings.

### Personal solutions:

- ✓ Go on walks with trusted friends and family members.
- ✓ Get to know staff at stores so they can assist you.
- ✓ Constantly use the same stores to help familiarize yourself with surroundings.
- ✓ Organize your time and your belongings.
- ✓ Try to have a place for things and try to remember to put them there.
- ✓ Establish a routine
- ✓ Do only one thing at a time.
- ✓ Write down what you have been asked to do, or what you are planning to do.
- ✓ Use labels on cupboards and closets.
- ✓ Write out directions before you leave the house and reverse them to get home.

# Change of memory and abilities continued

## What others can do:

- ✓ Don't say, "I lose things all the time, too", or "Why didn't you put it where it belongs?"
- ✓ Don't say, "It's not important anyway", or "You don't need it right now."
- ✓ Realize that it is important to me or I wouldn't be looking for it.
- ✓ Offer to help look for items or help with reminders and establish a routine.
- ✓ Say, "We don't have a lot of time now, but I can help later."
- ✓ Help us label cupboards and closets.



For more tips on staying safe in the community refer to the By Us For Us guide: **Safety When Out and About.**

## Change of abilities

It is a trigger when we can't do something we used to do really well, like tie a tie or make change at the store, and now someone has to do it for us.



# Change of memory and abilities continued

## Personal solutions:

- ✓ Slow down and have realistic expectations of yourself.
- ✓ Focus on one thing at a time.
- ✓ Try to be as kind to yourself as you are to others.
- ✓ Have patience with yourself.
- ✓ Get enough sleep – it is very important.
- ✓ Leave the task for a bit and try again later.
- ✓ Be comfortable asking for assistance.
- ✓ Try not to let small problems upset you.

## What others can do:

- ✓ Allow me to try and endorse the effort.
- ✓ If I become frustrated, gently ask to help.
- ✓ Allow me to cry – it is therapy to me!
- ✓ Don't protect me or be my gatekeeper.
- ✓ Be patient with me.

# Negative emotions

## Being degraded and judged

It is hurtful when someone judges us or provides us with comments that degrade our self-worth.

### What others can do:

- ✓ Show me affection. Hold my hand or give me a hug – it helps.
- ✓ Just accept me the way I am.
- ✓ Do not yell or shout at me.
- ✓ Don't assume we are incapable of making decisions.
- ✓ We are still sexual people who enjoy intimacy. We can still have discussions on this topic.

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# Negative emotions continued

## Not being listened to or included

We feel a negative emotion when people don't listen or ask us what we want or need. We also get frustrated when we have not been fully included in what others are doing or going to do.

### What others can do:

- ✓ Do not assume you know what I need or want.
- ✓ Keep me involved and aware of plans. I do not need to have the first or last comment on a situation, just involve me.

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# Negative emotions continued

## Stress, frustration, pain or fatigue

Stress, frustration, pain and fatigue can all be triggers.

### Personal solutions:

- ✓ Avoid situations and things that trigger a negative response.
- ✓ Try to remove yourself from stressful situations.
- ✓ Try to decrease the number of triggers by controlling your environment as best you can.
- ✓ Get plenty of rest to avoid fatigue.
- ✓ Pet therapy – There's a calming effect when caring for a pet because they give you comfort and love. Talking to your pet might help with easing your frustrations.
- ✓ Relaxation techniques – Music, exercise, reading, deep breathing and meditation can all help reduce anxiety.
- ✓ **Share** your feelings with others. It helps to talk to a willing listener.

# Negative emotions continued

## What others can do:

- ✓ **Listen** to what I need. Sometimes, just listening is all you need to do.
- ✓ Provide me with soft music or my favourite tunes.
- ✓ Take me home when I am tired.
- ✓ Try to understand my point of view.
- ✓ Do not make requests of me when I am tired.
- ✓ Realize that activities can tire us very easily and we can be over-stimulated.
- ✓ Try to reduce the amount of stress around me.
- ✓ Realize that I am entitled to CHOOSE MY PAIN. There are things we choose to do, such as attend a special event, where we know we are entering an uncontrolled environment with many triggers. We make a conscious decision to do this even though it will cause us to experience a trigger. Allow me to choose and decide to go anyway.

**“Keep this in mind that we ourselves do not always have control over what is happening and things can change quickly.”**

(Gail Robinet, B.A., M.Div., Burford, ON)

## SUGGESTED RESOURCES

### Articles

Agli, O., Bailly, N., Ferrand, C. (2015). Spirituality and religion in older adults with dementia: a systemic review. *International Psychogeriatrics* (27)5:715-25.

Daly, L. Fahey-McCarthy, E. Timmins F. (2019). The experience of spirituality from the perspective of people living with dementia: A systematic review and meta-synthesis. *Dementia* 18(2):448-470.

### Books

Power, G.A. (2014). *Dementia beyond disease*, Health Professions Press.

Devi, G. (2017). *The spectrum of hope: An optimistic and new approach to Alzheimer's Disease and other dementias*. Workman Publishing. [Note: also available in large print edition]

Furman, R. (2020). *A healthy brain for life: How to prevent Alzheimer's, dementia, and memory loss*. Revell Company.

McFadden, S. (2020). *Dementia-friendly communities: Why we need them and how we can create them*. Jessica Kingsley Publishers.

Lokvig, J. (2016). *The Alzheimer's and Memory Café: How to start and succeed with your own café*. Endless Circle Press.

Taylor, R. (2007). *Alzheimer's from the inside out*. Health Professions Press.

### Documentary

"Alzheimer's: What You Can Do," 2021.  
Virginia Public Media (PBS, NPR)

[vpm.org/dementia-documentary-series](http://vpm.org/dementia-documentary-series)

### Websites

The Alter program was created in 2019 at Georgia State University to address the lack of resources and awareness around dementia in African American and faith communities.

[alterdementia.com/](http://alterdementia.com/)

American Heart Association diet focuses on food that are beneficial for brain health.

[www.heart.org](http://www.heart.org)

Dementia Alliance International is an independent self-advocacy organization of people with dementia.	<a href="http://www.dementiaallianceinternational.org/">www.dementiaallianceinternational.org/</a>
Dementia Friendly America provides tools and resources for communities interested in becoming dementia friendly.	<a href="http://www.dfamerica.org/">www.dfamerica.org/</a>
Dementia Mentors is about helping those living with dementia understand that there is still life after the diagnosis.	<a href="http://www.dementiamentors.org/home.html">www.dementiamentors.org/home.html</a>
International Association of Indigenous Aging (IA2) works to identify and implement the most effective solutions to the most significant issues facing American Indians, Alaska Natives, and Indigenous people around the globe.	<a href="http://iasquared.org/">iasquared.org/</a>
Memory Café Directory provides a list of memory cafés around the country.	<a href="http://www.memorycafedirectory.com/what-is-a-memory-cafe/">www.memorycafedirectory.com/what-is-a-memory-cafe/</a>
MIND diet focuses on foods that are beneficial for brain health.	<a href="http://www.medicalnewstoday.com/articles/mind-diet#summary">www.medicalnewstoday.com/articles/mind-diet#summary</a>
National Institute on Aging provides articles, studies, and tips on exercise.	<a href="http://www.nia.nih.gov/health/exercise-physical-activity">www.nia.nih.gov/health/exercise-physical-activity</a>
SilverSneakers is a health and fitness program designed for adults 65+.	<a href="http://silversneakers.com">silversneakers.com</a>
Sleepfoundation.org provides educational, evidence-based information on sleep	<a href="http://www.sleepfoundation.org">www.sleepfoundation.org</a>

# SECTION 3: Emotional, Psychological and Functional Health

## 3.1 Your Overall Well-Being

Before being diagnosed with dementia, you may not have given much thought to actively supporting your well-being. Generally, people think of well-being in terms of physical health, but well-being is broader and includes social, psychological/emotional, and spiritual dimensions as well.

All dimensions of well-being are vital, important, and interconnected. Think about a time when you were at odds with someone important in your life and how it made you feel. You may have felt fine physically but unsettled emotionally and this affected your overall state of well-being. There are many ways well-being can be disrupted, including not feeling personally safe or financially secure.

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The Preamble to the Constitution of the World Health Organization notes that well-being includes *“a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”*

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Discovering you have dementia can certainly be a blow to your sense of well-being. You will need to become intentional about maintaining your well-being. It will require active work on your part. For most of us, this does not occur naturally. The good news is the rewards are more than worth your effort.



## A Holistic View

Throughout human history, people have recognized the connections between mind, body, and spirit. Ancient practices such as meditation and prayer not only calm our thoughts and emotions but have been shown to support our physical health, lowering blood pressure, reducing stress hormones, and boosting our immune systems.

Many of us have experienced these mind-body-spirit connections, whether it's having butterflies in our stomach or trembling hands when we're nervous or feeling a lack of energy or changes in appetite when we're depressed. Our mood or mental state can affect our bodies, and vice versa. Developing habits that nurture health in mind-body-spirit aids in our overall well-being. For example, exercise can help our mental outlook, and becoming absorbed in music or a good conversation can distract us from physical ailments and lift our spirits.

Unfortunately, when doctors deliver a diagnosis of dementia, they often say that there's no treatment and nothing you can do. "It would be good if instead they'd say, 'You'll have some challenges. Here's what we can do to manage symptoms and have a quality of life that you enjoy. Let's figure out what you enjoy now and what sparks joy for you, so we can build upon that,'" says Colin Milner, CEO of the International Council on Active Aging. His organization's members include 10,000 senior living communities.

*I use the analogy of a Christmas tree to describe that my dementia symptoms affect some aspects of my abilities, but many other important abilities remain. "A Christmas tree may have many lights and ornaments. Imagine that some of the lights don't work and a few of the ornaments have been removed. The Christmas tree is still beautiful and serves a purpose."*

**Laurie Scherrer, Manual Guide**



Advocates for improving the quality of life for people living with dementia argue that too much focus has been placed on pharmacological “fixes,” and not enough attention paid to enhancing well-being and quality of life. If you focus on cognitive losses and inabilities, you miss focusing on what you can do, how you can compensate for changing abilities, make accommodations, and have a positive attitude. Being proactive is transformative.

Dr. Jason Karlawish stresses that our well-being also depends on the world around us. In his book *The Problem of Alzheimer’s*, he describes dementia as a “humanitarian problem,” not just an individual challenge. “Imagine a world reconfigured to support changing cognitive abilities. Some of these innovations will be technological fixes to the environment, sort of sliding doors and voice recognition devices for the mind; others will be changes in the ways we interact with, look out for, and support each other. Imagine a revolution in technology, society, and our culture,” he writes. In an interview, he notes that we need resources to “accommodate” our brains. These include everything from sidewalks and walkable communities, to social structures to support care partners, to access to brain-healthy food.

“Dementia is a challenge that engages many people across multiple disciplines. It’s affecting society broadly,” he says.

## 3.2 A Framework for Emotional and Psychological Well-Being

“It is important to let go of a deficit-based approach to supporting people living with changing cognitive abilities and move to a strengths-based, proactive approach,” notes Allen Power, MD, in his ground-breaking book *Dementia Beyond Disease — Enhancing Well-Being*. Drawing on a framework developed by the nonprofit The Eden Alternative, Dr. Power explores seven domains of well-being:

- ◆ **Identity** — personhood, which is both sacred in itself and a reflection of how others view us. Our identity emerges from our life history and all the unique experiences we have had
- ◆ **Connectedness** — a sense of belonging and involvement, being connected to those around us, to our home and belongings, and to nature, embracing creativity, spirituality, love, and hope
- ◆ **Autonomy** — choice and freedom, self-determination, not being coerced or constrained
- ◆ **Security** — freedom from anxiety or fear, safe (both physical safety and emotional security), living with privacy and respect

- ◆ **Meaning** — purpose, feeling needed and useful, making a difference
- ◆ **Growth** — changing, learning, developing, evolving, expanding
- ◆ **Joy** — happiness, delight, contentment, pleasure

The deep cultural stigma associated with dementia and the related fears and anxiety about what the future holds can undermine a sense of well-being. Stigma also contributes to self-isolation or to friends and family treating us differently. There can be frustration and sadness about not being able to perform activities in ways that once were routine. Changes in the brain may also contribute to depression and anxiety.

With intention and support, people living with dementia can help maintain their psychological and emotional well-being. “Improving people’s experience of dementia means improving the support they get to process how they feel, and how they understand and think about the condition, their future, and their relationships. Maintaining a sense of control, identity, and connection is a key focus as dementia progresses,” notes the British Psychological Society.

*One of the issues that I have with my family is when they say “Oh, we can’t do that because she’ll get too confused or might not be safe. We can’t go to the boardwalk because she might wander away” — instead of finding accommodations or ways we can do that safely. I say to them, you’re looking at my inabilities instead of abilities.*

**Anne (who asked not to be named)**

Sherrie Dupuis of University of Waterloo in Canada notes that stigma, combined with a narrow biomedical view that sees the person as the disease, combine for a one-two punch to someone's psychological and emotional health. People living with dementia have told her research team that one of their frustrations is having dementia described as purely a cognitive issue. "Yes, dementia has cognitive components, but it's also experienced emotionally. We live in emotional ways. We all do as human beings. We need to reflect and teach about the experiences of dementia that can engage with emotions," she says.

One of the most important things in ensuring your emotional well-being is having a sense of purpose and making a contribution. (See [The Importance of Having Purpose and Goals](#) in Section 1.12, page 73.) "For all of us, well-being is impacted if we don't have a sense of purpose," says Angela Lunde of the Mayo Clinic. "Unfortunately, people living with dementia are especially susceptible to having their sense of purpose taken away."

"We have a sense of purpose in our younger years that changes as we age and even more so if we have a disease that causes dementia," adds Angela's colleague at the Mayo Clinic, Jodi Melius, RN. "That doesn't mean a person with dementia has to give up on a life with purpose, but they may need to think about it in a new or different way."

## Maintaining Self-Confidence

Related to having a sense of purpose is self-confidence. "Often people living with dementia feel like they can no longer do certain things", says Angela Lunde. "This makes sense because if others don't believe in us; we lose confidence in ourselves."

Others — even those close to you — may make assumptions about what you can and cannot do. Try not to let that undermine your sense of self-worth. Be clear about your choices and preferences and let others know that you'd rather make a mistake than not try at all.

"Self-confidence can be optimized in persons with dementia when those around them stop making assumptions based solely on their dementia diagnosis, and when they focus on strengths rather than their deficits. If friends and family offer encouragement, persons living with dementia are much more likely to remain confident in their abilities, maintain activities, and even learn new things," she stressed.

At the same time, she adds, "Keep in mind that having dementia sometimes means letting go of things, such as driving. However, people living with dementia can continue to do many things especially with some adaptations and accommodations, or with a little assistance from others. Accepting assistance can be hard, but if it allows you to continue doing something you love, then assistance is a good thing."

## Does Your Environment Support Your Well-Being?

You may find that you are much more sensitive to your environment than you were in the past. Too much stimulation may be disorienting and upsetting. Too little stimulation can be boring and upsetting in a different way.

Your ability to filter out noise may alter. Going to a party with many loud voices around you can make it very difficult to concentrate or to have a good time. Be intentional about choosing your surroundings. If you love going to restaurants, for example, search for places that are quiet, or go at off-times when commotion is reduced. Some people have found that their favorite places will accommodate them by reserving a quieter table or suggesting the best time to come.

As your symptoms advance, you may find that sounds become more confusing — so that gunshots on a television show may sound as if they are outside your door. Pay attention and choose what is soothing or comforting to be around.

Your sense of smell or taste may also change. Some studies have found that losing your sense of smell is very common in most types of dementia and in Parkinson's disease. Aging itself can affect our sense of smell and taste.

Scents can also trigger pleasant memories — or unpleasant. The aroma of baking bread or a garden rose may be a source of great delight. Other scents may remind you of unpleasant encounters and be repugnant.

Some people living with dementia, because of changes in the brain, may hallucinate smells, like smoke or perfume, that are not there. Or they may hallucinate the sound of footsteps. This is more common in Lewy body dementia or Parkinson's disease but can occur with Alzheimer's as well. Other senses too can be affected. (See [Creative Practices](#), Section 3.7, page 222.)

Remember, whether it's physical or emotional comfort, ask for what you need. Don't be embarrassed or uncomfortable stating how you're feeling.

## When to Seek Professional Help

Sorting out manageable problems from mental illness that needs treatment, such as clinical depression, can be challenging. Many people living with dementia find that getting professional counseling or therapy is beneficial. Having a caring professional who can help you gain perspective or figure out strategies for managing problems is well worth the effort.

It may be difficult to find mental health professionals who are trained in supporting people living with dementia and their care partners. However, what is most important, says Angela

Lunde, is to find someone who will listen, validate your experience, and whom you can connect with and trust.

If you are experiencing mental illness or psychological problems, going on medication may not be the first or best choice, says Allen Power, MD. “Antidepressants can be tried and may be helpful if clinical depression is present. However, some people living with dementia have a type of apathy in their demeanor that can look like depression but is not amenable to the drugs.”

Be sure to check with your neurologist if another healthcare practitioner prescribes medication. If you have Lewy body dementia, for example, some prescription drugs, including anti-psychotics, could be dangerous. (See also [Medications and Medications to Avoid](#) in Section 5.4, page 280.)



## ***When Thoughts Turn to Suicide***

***Susan Wehry, MD, Contributor***

*Depression can be treated, and suicide is preventable*

Nearly 46,000 Americans died by suicide in 2020, according to the Centers for Disease Control and Prevention (CDC). Significant rate differences are found depending on age, gender, ethnicity, and race, but suicide occurs in all demographic groups. Specific suicide rates for people living with dementia are not known.

Thinking about suicide is common. One in 10 Americans say they have thought seriously about taking their own lives. What makes some people go on to die by suicide? The reasons are unique to each individual. Research shows that no one takes their life for a single reason. Life stresses combined with certain risk factors, such as childhood trauma, substance use, chronic physical pain, bipolar illness, and depression are strongly linked to suicidal thinking, attempts, and completions.

Whatever the unique circumstances, a sense of hopelessness is common among people who seriously consider and die by suicide. The dominant doom-and-gloom narrative about dementia may make people living with dementia especially susceptible to a feeling of hopelessness. In addition, societal stigma over the “burden” of dementia

and chronic illness on care partners may further instill hopelessness for people living with dementia. Research shows that when people living with dementia buy into these stigmas, they tend to avoid social interactions and become isolated. They are more likely to become anxious, depressed, and commit suicide. Fortunately, organizations such as the Dementia Action Alliance are effectively countering that stigma and supporting individuals with brain changes to thrive. This is not to minimize the real loss and challenges faced by people living with dementia, but only to say it is half the story.

Suicide is preventable. Asking someone directly if they're thinking about suicide won't "put the idea in their head" — most people are relieved when someone starts a conversation. Where depression is playing a role, getting treatment is critical: taking one's life is far too important a decision to make while depressed and depression is treatable. Getting someone through an intense moment of active suicidal crisis significantly reduces the risk they will die by suicide now and in the future. Most people who survive a suicide attempt go on to engage in life.

If you or someone you care about is talking about suicide, listen. Remind them they are not alone, and help is available. If they have a plan, find out if they have access to the means for carrying out that plan. Over half of suicide deaths in the United States are by firearms. Safely securing firearms can make the difference between life and premature death.

For more information, check out the American Federation for the Prevention of Suicide [afsp.org/](http://afsp.org/) or call or text 988 (formerly the National Suicide Prevention Lifeline and now the 988 Suicide and Crisis Lifeline). You can also reach the lifeline at t 1-800-273-8255.

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<sup>2</sup> Johnstone, M. (2011). Metaphors, stigma and the 'Alzheimerization' of the euthanasia debate. *Dementia*, (12)4, 377-393.

<sup>3</sup> Benbow, S. and Jolley, D. (2012). Dementia: stigma and its effects. *Neurodegenerative Disease Management*, 2(2), 165-172.

<sup>4</sup> Erlangsen, A., Zarit, S. and Conwell, Y. (2008). Hospital-diagnosed dementia and suicide: a longitudinal study using prospective, nationwide register data. *The American Journal of Geriatric Psychiatry*, 16(3), 220-228.

<sup>5</sup> Koyama, A., Fujise, N., Matsushita, M., Ishikawa, T., Hashimoto, M. and Ikeda, M. (2015). Suicidal ideation and related factors among dementia patients. *Journal of Affective Disorders*, (178)1, 66-70.



### 3.3 Intimacy and Sexuality



*Emily Franke, LSW, MSW, Contributor*

Living with dementia often alters sexuality and intimacy including those in long-time relationships. The following are some suggestions to help you discuss and handle issues that may arise around what can be sensitive topics.

#### Changes are Common

If you are living with dementia, you may worry that your spouse or significant other will not feel the same towards you. You may find that your own sexual desires have changed. Some people continue to experience an active sex life, while others have increased or decreased libido. Some people living with frontotemporal dementia, for example, because of changes in a particular part of their brain, experience an increase in sexual desire along with a lack of inhibition. (See [Frontotemporal Dementia](#), Section 8.9, page 414.)

*Intimacy, both emotional and physical, is a basic human need that does not go away simply because somebody has dementia. It is perfectly normal to still have desire — and it is perfectly normal to have desire fade.*

**Angela Lunde, M.A., Contributor**



Changes related to sex may be physical or emotional, which aligns with the different types of intimacy that all humans enjoy. Physical intimacy is about touch and closeness between bodies. In a romantic relationship, this closeness may include holding hands, cuddling, kissing, and sex. Your relationship doesn't have to be sexual or romantic to have physical intimacy — hugging friends and family is an example of non-romantic physical intimacy.



Psychological or emotional intimacy is the sense that you could be open and honest in talking with someone else about personal thoughts and feelings not usually expressed in other relationships. You may be psychologically intimate with friends or family in addition to your partner or spouse.

There may be several factors that are affecting the changes you notice related to sex and intimacy; this is normal. It may feel overwhelming trying to identify what is going on. But it's not always necessary to identify a specific cause to begin to address the overall issue of changes associated with sex. Approaching these changes with curiosity instead of judgment lends itself to finding solutions that work for you. When it feels overwhelming trying to figure out where to start, consider the **3Ts**:

- ◆ More **time**
- ◆ More **touch**
- ◆ More **talking**

**Time:** *Might mean initiating intimacy over a longer period including more foreplay both physical and emotional. Taking time to get comfortable and relaxed so that feelings of love and affection become the focus instead of focusing on performance (like achieving orgasm).*

**Touch:** *Refers not only to sexual touch (touching of genitalia) but also affectionate touch. Affectionate touch may include massage, kissing, light tickling, or touching other areas of the body such as the shoulders, back, or feet. It might also mean increasing time spent physically close to your partner, cuddling for instance, with no goal like having sex in mind.*

**Talking:** *Might be a wide variety of activities including discussing your concerns with your partner, your healthcare provider, or other supports in your life like friends or support group. We will dive into talking about it in the next section.*

## Talking about “IT”

Discussing sexual matters can be uncomfortable. Very few people look forward to having the “birds and the bees” conversation at any point in their lives. In her book *Dementia Reimagined*, Dr. Tia Powell notes that our culture is uneasy about older people having sex. “But the problem is even broader. There are prejudicial ideas about people with any sort of disability engaging in sex,” she writes.

For LGBTQ+ individuals living with dementia, there is an extra layer of prejudice. According to the Alzheimer’s Association’s 2018 *Issue Brief on LGBT<sup>1</sup> and Dementia*: “Gay, lesbian and bisexual older adults face the additional barrier of [healthcare] providers who do not recognize that many people are attracted to people of their same gender, or who harbor negative opinions about same-sex sexual contact. Healthcare providers need to examine their own beliefs and prejudices, as well as organizational policies. A same-sex sexual relationship may trigger the family’s or care partner’s biases toward or about the LGBT community.”

Whatever your situation or identity, try to be open and honest about your feelings, even though sex can be uncomfortable to talk about, even — or especially — with your partner.

## So, what can you do?

- ◆ Use “I” statements.
  - For example, “I feel worried that you might think my lack of desire is a lack of desire for you rather than a result of my diagnosis.” Instead of “You make me feel guilty for not having a desire for sex.”
- ◆ Try using “Ask, Tell, Ask” as a framework for starting conversations.
  - Ask for permission to talk about sex or intimacy.
  - Tell the other person what you are feeling or experiencing using “I” statements.
  - Ask what they think about that information or how they are feeling.

Frustration, guilt, anger, grief are all normal emotions when an intimate relationship changes. If you are feeling this way, your emotions are valid and worth discussing with your partner or support system.

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<sup>1</sup> LGBTQ+ is currently the term preferred by the LGBTQ+ community. When the Alzheimer’s Association’s paper was written in 2018, the preferred term was LGBT.

“I feel more guilt than anything,” says Jo (not her real name), who is living with dementia, about her lack of interest in having sex with her husband. “I feel guilty for more than one reason. I feel guilty because I have this stupid disease. Afterward, I feel awful because I’ve just been laying there. He’s understanding, but I know he’s frustrated. I don’t know how to talk to him about it.”

She is hardly alone. “People living with dementia have a sense of guilt and burden,” says Jodi Melius, who facilitates many support groups at the Mayo Clinic. “Try to find intimacy in other ways if sexuality is not a place of comfort.”

“My lack of interest started around the time of my cognitive problems, but years before I had a diagnosis,” says Celeste (not her real name). She said her sex drive went from a “7 down to 2” on a scale of 10. “I now have very little interest in intercourse, but more interest in hand rubbing or that kind of intimacy. I have not had a conversation about it. I feel like he might take it personally and feel like it’s him and not the dementia. I don’t want to hurt his feelings.”

People from the LGBTQ+ community who are living with dementia often experience these same challenges, though they can be heightened. A 2014 survey found that one in three LGBT older people are very or extremely concerned about “being lonely and growing old alone,” as compared to 19 percent of non-LGBT people.

## Seeking Medical Support

Many people as they age lose some of their sexual desire or function. Medication and medical problems, as well as age, can affect libido. But most people, both from the LGBTQ+ and heterosexual communities, continue to be sexually active, including those living with dementia. A 2018 study by researchers at the University of Chicago, for example, found that the majority of people living with dementia who are partnered and living at home are sexually active (59 percent of men and 51 percent of women).

Men living with dementia can experience changes in their sexual performance. “My issue is I cannot ejaculate when I am having sex with my wife. I get aroused but it is very hard to climax,” says Tom (not his real name). Women may experience changes in vaginal lubrication, increased or decreased sensitivity, or vulva and vaginal wall thinning and shrinkage (vulvovaginal atrophy). While some changes are normal and age-related, others may be related to medication or medical diagnoses.

“More than one-third of men and one in 10 women in the study’s dementia group reported bothersome sexual problems, but only 17 percent of men and one percent of women living with dementia talked to a physician about sex life changes that result from a medical

condition like dementia,” according to study author Stacy Tessler-Lindau, MD. If a physical or mental change is affecting your satisfaction with your sex life or is resulting in pain, talk to your medical providers.

There are options for specialized counseling to discuss topics like intimacy and sex. Ask your doctor for a referral or recommendation. You may find that your medical provider is not well-versed in the topic of sex, due in part to societal stigma. If you encounter this, don't be discouraged. Raise the topic in a dementia support group where you've established a sense of trust and can hear what others are going through. "Being able to express myself freely made me feel very comfortable that I wasn't alone," said Jo of her experience discussing this with other women who live with dementia. "Maybe I won't be so hard on myself."

Tip: Using "Ask, Tell, Ask" is a good way to start conversations with a medical provider also!

## Take Home Message

Whether or not you have a sexual relationship with anyone, maintaining physical and emotional intimacy with friends, family members, and others is critical to your well-being.

“

*Our love has never been stronger.  
The "wild monkey sex" is gone.  
But the tenderness, the touching,  
the waking up in the middle of  
the night together is there.*

**A care partner (who asked not to be named)**

”



## ***Finding Intimacy if You're Single and Gay ... or Anyone Else***

***John-Richard Pagan, Manual Guide***

Sex is a topic that comes up in support groups I lead. It's important to think about how sex and dementia relate to one another. What happens in Lewy body dementia, which I have, is that we have autonomic dysfunction. This can affect one's sexual drive. For some it's an overly active drive while for others we have a total disconnect from our physical sexual drive. This can be amplified by behavioral changes, which decrease emotional desire. How does that affect your sexual relationship — or does it?

When I was diagnosed originally with neurodegenerative disease and then with Lewy body dementia, I was with a partner who was half my age and who had a very strong sexual drive. My sexual drive completely dropped off — I had no sexual drive whatsoever. I felt like I had failed the relationship, and I couldn't provide what he needed. He would say, "It's okay and I'll work with it," but you could see it was really frustrating for him. I finally ended the relationship partly because of the lack of desire for sexual intimacy and because he was younger, and I questioned his ability to care for me if the time came. I believe in monogamy and I didn't believe in stepping out of the relationship [for sex], so that was not an option.

I got to a point where I thought a sexual relationship was impossible and, therefore, I would be by myself for the rest of my life. In talking with others about sex and relationships, I've found that for some it's true — it's all about the sexual drive, their libido. When that stops or decreases, that becomes a hindrance in the relationship. But for others, there's a recognition that there's something beyond the actual sexual connection for the intimacy of the relationship. Intimacy can include anything from cuddling to foreplay and just enjoying one another's company. I've become comfortable with that. And with thinking that a relationship is possible. I just need to be honest with the person I'm in a relationship with and let them know that I can only go as far as I can go.

I've talked to other people whose sexual drive was magnified after diagnosis. They wanted more sex than their partner did. I encourage them to be creative finding new ways to make it interesting for them and their partner, including seeing a sexual counselor to suggest new methods of enjoying the intimacy ever deeper.

Due to my spirituality, I've also come to a place where I trust my Creator that I will be exactly where I need to be regarding a relationship. My mother [my care partner] thinks I should not be in a relationship because of my dementia. I understand that. It's easy for children and parents of people living with dementia to think intimacy is over for that person. They want to take care of them, and they can't see that person being sexually active. In care communities, it's not uncommon to find that someone has crawled into another resident's bed for sexual intimacy.

Living with dementia doesn't mean that the drive for intimacy isn't there. I look forward to having another intimate relationship. I know it will probably be a lot more hugging, kissing, and holding hands and going for walks together or watching movies. I really feel the right person would be okay with that. I've gone from feeling hopeless to feeling hopeful.

As a former psychotherapist, I listened to people talk about their intimacy and sexual behaviors. It's nothing to be shameful of. Your physician may not be willing or comfortable talking about or asking about your sexual life. If that is the case, you could talk with a psychiatrist or therapist.

Intimacy and sexuality are natural parts of who we are — we're meant to be intimate beings and we're meant to be sexually active until we're not. There's no shame. We don't have to do something because we're submitting to our partner's needs. We can acknowledge where we're at and find new ways of being intimate. That was something I was really surprised at when I led the Lewy body dementia group — others who had lost their drive didn't know how to connect with their partner. Didn't you go to the beach or take long walks or hold hands when you were dating? Do the same things. Stimulate yourself in other ways. And go as far as you want to go comfortably when it comes to sex.

As a single gay man, my biggest challenge is how do I tell somebody that I have dementia — how do I date somebody and be completely honest? I can tell you that in the gay community, sex is a huge part. It is hard to find somebody who's willing to talk to you and doesn't want to immediately jump into sex. For me, some of it also has to do with, "Do I want to burden somebody else?" There is that word, burden. We try so hard not to use the word "burden," but it sits in the back of our minds, as people living with dementia. Do I have the right to burden someone else if my condition progresses over time? My dementia affects my ability to walk and my balance. I have a cane, and I have a walker I keep in my car. I'm not the guy you are going to take on long hikes! It leads me to pull back from social interactions, not taking a chance out of concerns of acceptance.

It's been challenging to be single. My spirituality is part of what keeps me sane. It gives me some peace and reminds me that if it's meant to happen it will happen. I work hard to accept that.

## 3.4 Functional Health



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Your “functional health status” refers to your ability to perform daily activities to meet basic needs and fulfill your usual roles. Prioritizing your functional health will help you maintain independence and dignity, and enhance the quality of your life.

To maximize functional health, you may want to consult with therapists, including physical therapists, occupational therapists, and speech-language pathologists. A good therapist will assess your condition and needs and help you develop strategies for maintaining your capacity to participate in day-to-day activities. This in turn will give you confidence in your abilities.

Therapists can also adjust your routines as needed. For example, Mr. Jones was worried about forgetting his daughter’s birthday. By working with an occupational therapist, he was able to create a manageable reminder system.

Your functional health status is an important factor not only in determining your overall health, but also for measuring your risk of having an adverse event, such as a fall. Therapists can identify risk factors to prevent or manage things like maintaining balance and strength and learning cognitive and word-finding strategies. They can also help you learn about the connection between sensory changes that you may be experiencing (vision, hearing) and your body’s ability to navigate spatially.

You can also get help in figuring out how to continue to pursue activities you enjoy and that give you meaning and purpose. An “occupational profile” is a summary of your history and experiences, patterns of daily living, interests, values, and needs, based on your cultural background. With your assistance, your therapist can create a comprehensive profile to provide you with individualized care.



## Independence and Confidence in your Body

Having confidence in your abilities is a life-long effort for many of us and is made more challenging for people living with dementia. You may have concerns about losing independence and personal autonomy. Here are some steps you can take:

- ◆ Reflect on your fears and concerns and identify your goals for the future.
- ◆ Educate yourself about dementia using manuals like this one and reach out to trained professionals to gain a better understanding of how dementia affects your body and life course.
- ◆ Have open discussions with family and friends about your fears of losing independence and personal autonomy. These discussions will help others know how to best support your goals.
- ◆ Find out what resources are available to help guide you and your family/friends through the course of your condition and to plan for ways to preserve quality of life.

To promote your independence and self-confidence you may want to participate in therapy and/or social groups that are geared toward promoting positive self-image. Continuing to acknowledge your strengths and abilities and prioritizing self-care are all important aspects of promoting a positive self-image, and especially important for people living with dementia. As abilities change with your symptoms, counseling and therapy can teach you coping mechanisms to deal with those changes. Some individuals opt to take a spiritual approach to their self-care and coping techniques, such as meditation, prayer, music, and mind-body centering.

As discussed earlier in this manual, trying new activities and interests also boosts confidence. New experiences promote learning and can stimulate the brain to grow and form new connections. Just as the phrase “use it or lose” promotes exercise to maintain muscle strength and stamina, the same applies to our brain functioning.

## Develop Good Routines and Stick to Them

Routines play an important role in helping you maintain functional health and independence. Developing a good daily routine that works for you early on in your diagnosis of dementia, and sticking to that routine, will help later when attention and forgetfulness may make daily tasks more difficult to complete. Writing down your daily routines and schedules helps promote consistency. Consistent routines, such as getting up at the same time every day, completing weekly chores on set days and times, and following the same grooming routine each morning and evening help reduce the chances of “missing” an important task and



reduce the chances of a functional decline. This predictability will help reduce confusion related to time and events, as well as improve short-term memory of events.

Success can be enhanced further by ensuring your family and friends understand how consistent routines can promote your independence and functional health. Occupational and physical therapists, as well as speech-language pathologists, can assist with creating daily and weekly routines or schedules. Mental health therapists also play an important role in helping to adapt these routines as your symptoms advance, to help you continue to thrive in your desired environment.



## ***Mix Up My Routine = Mix Me Up***

### ***Laurie Scherrer, Manual Guide***

*Her brother calls her every morning. For three days, he couldn't call.*

This insignificant little change threw me into four days of “Dementia Daze” (some call it a fog). Suddenly the “routine tasks” I performed every day were a challenge. I couldn't remember what I had done and still needed to do. Since I couldn't accomplish the “routine” tasks, the other tasks on my list seemed extremely overwhelming. Unable to process how to rearrange my day, I walked around in circles, pacing the room, trying to think it all through. The feeling of being lost triggered more confusion and frustration.

## What Types of Therapists Support Functional Health?



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### Physical Therapy

Physical therapy helps restore and maintain physical health. Among the treatments physical therapists provide:

- ◆ Gait training to improve walking abilities
- ◆ Physical exercise to improve strength, range of motion, and function
- ◆ Balance maintenance
- ◆ Wound care to improve skin integrity and promote wound healing
- ◆ Pain reduction
- ◆ Safety awareness and education
- ◆ Falls prevention strategies
- ◆ Activities to improve cardio-respiratory status

Physical therapists can help improve the lives of individuals living with dementia by finding strategies that focus on enhancing function, independence, and safety.

### Occupational Therapy

With strong knowledge of a person's psychological, physical, emotional, and social makeup, occupational therapists can evaluate how your condition is affecting your body and mind using a holistic perspective.

They provide a person-centric approach to ensure an individual's ability to live independently, safely, and to the highest potential including learning principles of work simplification. Additionally, occupational therapists can provide necessary family and care partner education. They will recommend additional support services if needed, such as a home health aide to assist with bathing or to assist with cooking, laundry, and grocery shopping.

## Speech-Language Pathology

Speech-language pathologists (SLPs) assess, diagnose, and treat speech, language, and swallowing disorders (known as dysphagia). A speech-language pathologist can assist you with word-finding, organizing thoughts, paying attention, remembering, planning, and problem-solving. For example, when working with a speech-language pathologist you may work on how to use memory aids and strategies for remembering details of an event, situation, or a person's name.

One common, evidence-based approach used by speech-language pathologists is called "spaced-retrieval with errorless learning," which helps you recall pieces of information. When using this approach, you and your speech-language pathologist will together determine an important piece of information that you would like to remember with greater ease, and then choose a target question to evoke a desired physical or verbal response. Next, your speech-language pathologist will systematically increase the time intervals between the questions, to create opportunities for recalling and learning the desired information. Together, you and your speech-language pathologist may use spaced retrieval to help you remember a specific phone number or a step needed to complete a daily task safely. They also might train your care partners to understand the technique.

Other areas might involve training and counseling on effective communication approaches to use with your partner/spouse, children, and friends. These approaches can reduce instances of communication breakdown and frustration. Simple strategies include reducing environmental distractions, like turning off the TV or radio, or facing each other when speaking or making sure that everyone in the conversation knows the topic and when it has changed. This may not always be easy for individuals having trouble with attention or hearing changes or if you're in a crowded room.

A speech-language pathologist can also assist with swallowing disorders, which occur in seven to 23 percent of older adults, and more so with people living with dementia.

## Tips for Dealing with Swallowing and Speaking Concerns

Dehydration, malnutrition, unintended weight loss, and respiratory infections can contribute to difficulty in swallowing. This in turn reduces quality of life and functional health.

Swallowing disorders are commonly the result of sensory or motor changes within the body's nervous system (or a combination of both). They may also be a result of a behavior, such as rapid eating or taking large bites that affect the control of chewing and swallowing.

A speech-language pathologist can work with you to address a swallowing disorder. They can help you compensate with strategies such as:

- ◆ Taking small bites or more frequent sips
- ◆ Learning exercises to restore and strengthen the muscles used with swallowing
- ◆ Changing your position when you eat or drink
- ◆ Modifying temperature, taste, or food texture and liquid consistency

An occupational therapist can help you learn to use adaptive silverware, cups, and other equipment.

Another common problem caused by age and/or medications is dry mouth (xerostomia). The effects of dry mouth can result in difficulty chewing, as well as swallowing food, liquids, and medications. You may consult with your physician or SLP on using different natural and over-the-counter treatments to address dry mouth.

The ability to communicate our thoughts and ideas is something we take for granted every day. The ability to talk is an intricate process beginning with thoughts in the mind that we formulate into words to speak. Your brain creates patterns that it connects and sends to your mouth to communicate. The process of speaking occurs with the use of many muscles in our face, lips, tongue, and throat, as well as muscles for breathing.

Changes in speech can occur in different types of dementia, and may be a result of a breakdown in the brain's ability to create and send the patterns to create sounds from your mouth. Muscle weakness or a combination of both brain changes and muscle weakness can also play a role. These changes may help in diagnosing what type of dementia you are experiencing.

As we get older and more sedentary, our breath becomes shallower, affecting our ability to project our voice and talk. Increasing your breath support may help you reduce fatigue when communicating, and enhance your ability to speak longer phrases and tell stories, by lessening excessive pressure on the muscles in your throat and mouth. In cases when speech becomes very difficult, a speech-language pathologist might recommend the use of technology to facilitate communication.

## Enteral Nutrition (Tube Feeding)

Currently, there is little evidence that tube feeding improves survival, quality of life, or pain for individuals living with advanced dementia. It's important to talk to your healthcare provider about the risks and benefits of alternative ways of providing nutrition versus a tube feeding, as well as making sure your family and support networks understand and respect your wishes in the later stages of dementia. Be sure to keep a written record of what you want and share it with your doctor, family, and care partners. (For more on [advance directives](#), see *Getting Your Financial and Legal Affairs in Order*, Section 4.8, page 251.)

## Maintaining Motor Control and Balance

Motor control refers both to your reflexes and to your ability to direct movements to complete tasks or stabilize your body in space. Balance (postural control) is the ability to maintain a center of gravity that allows you to stand upright and move around without falling. Good balance requires coordination of the brain, nerves (sensory and motor), bones, joints, muscles, ears (hearing), and eyes (vision). Another important part of balance is related to a term called "proprioception," which refers to the position of your body and how your body knows where it is in the world. Motor control and balance work together to help your body move and complete daily tasks.

As we get older, we tend to lose muscle mass and function. Physically inactive people can lose as much as 3 to 5 percent of their muscle mass each decade after age 30. This progressive muscle loss, as well as changes in the brain associated with dementia and aging, can affect your motor control, balance, strength, flexibility, and range of motion. This in turn increases the risk for falls.

To prevent muscle decline, incorporate physical activity into your daily routines. If you notice changes in motor control and balance, seek help from a physical or occupational therapist to reduce the speed of functional health decline. There may be ways to adapt your environment to help ensure safety and security, as well as promote independence and functional health, as your symptoms change.

The Seattle Protocols are an example of a set of effective exercise programs that have been researched. Originally developed to treat depression in people living with dementia, they have also been found to increase physical function and to improve mood and slow the development of advanced cognitive symptoms. According to an article in the *Journal of Nutrition and Healthy Aging*, the Seattle Protocols make exercise a "pleasant activity" and teach people living with dementia and their care partners strategies for successfully establishing and maintaining exercise goals.

## 3.5 Living Safely in Your Home

People living with dementia are four to five times more likely to fall than older people who do not have dementia. For those who fall, the risk of sustaining a fracture is three times higher for people living with dementia. Changes that increase your risk of falling include:

- ◆ Perception that affects judgment and the ability to reason
- ◆ Recognition of sensory input, such as sight, sound, and touch
- ◆ The ability to understand and express needs
- ◆ The brain's inability to coordinate movement and to communicate with the muscles to carry out day-to-day functions despite having the physical ability
- ◆ Misinterpretation of the environment, causing illusions and misperceptions regarding depth, light intensity, color, pattern, and temperature
- ◆ Loss of memory and challenges with new learning
- ◆ Difficulty in initiating tasks, leading to immobility

If you fall, these are the kinds of questions a healthcare professional will consider:

- ◆ Is there a reversible cause or is it related to another medical condition?
- ◆ Are you taking multiple medications?
- ◆ Are you experiencing medication side effects or interactions?
- ◆ Are you taking your medications as prescribed?
- ◆ Do you have changes in your vision?
- ◆ Has your mobility changed?
- ◆ Are you restless?
- ◆ Are you fatigued?
- ◆ Are you experiencing pain that you have not been able to communicate?
- ◆ Do you have adequate nutrition and are you drinking enough liquids?

## Things You Can Do

- ◆ Ensure adequate lighting (increase lighting, reduce glare, limit shadows)
- ◆ Keep pathways clear (declutter, keep floor surfaces level, dry, and non-slip)
- ◆ Remove area rugs
- ◆ Enhance accessibility (keep important items in consistent, visible, easy-to-reach places, lower bed height, use adaptive equipment)
- ◆ Increase bathroom safety (use a non-slip bathmat, a bath chair or bath bench, a handheld shower, and have an accessible emergency system close by such as Lifeline or cell phone)
- ◆ Grab bars (therapists can assist with appropriate location) by shower area and toilet
- ◆ Ensure safe footwear (buy shoes with Velcro closures, avoid walking indoors in socks or slippers, ensure outdoor footwear is appropriate for the weather)
- ◆ Reduce noise level (avoid sudden, loud noises)
- ◆ Use mobility devices correctly, if recommended (canes, walkers)

In addition, if you have a dog, have a routine for hanging up the leash. Or for a cat, consider moving the litter box to a higher surface to avoid tripping or excessive bending.

Be sure to ask your doctor if any of your medications might affect your balance and alertness.

## Home Safety

Remaining at home safely with as much independence as possible is the goal of many individuals living with dementia. You may find success in maintaining your independence by making simple modifications to your environment and routines. The following ideas may help reduce the chances of life-threatening or other critical situations occurring throughout the course of dementia. (For more on home modifications and safety tips from those living with dementia, see [Supportive Home Modifications](#), Section 4.7, page 246.)

- ◆ Installing automatic shut-off function for stove, microwave, electric kettle, or small convection/air fryer oven
- ◆ Keeping emergency phone numbers easily accessible (on the wall, back side of cell phone)

- ◆ Using your phone for safety (e.g., bringing it to the bathroom during shower, notifying family when you will be showering, buying a phone with a clip to keep it on you)
- ◆ Having an emergency alert button or smartwatch with falls impact detection
- ◆ Using a buddy system for safety checks (e.g., phone call check, set lunch date)
- ◆ Setting “location on” for smartphones
- ◆ Using medication tools such as an automatic pill dispenser or bubble-wrapped medications for each time of day (morning, noon, supper, and evening)

## Adaptive and assistive equipment

At some point, assistive or adaptive equipment will likely be useful to maintain independence and safety. Determining the correct equipment for your needs depends on the skills of an occupational therapist who can assess what will work for you and your lifestyle. This may help you avoid unnecessary costs and plan for the future.

### Adaptive and assistive equipment

- Digital or talking clock
- Grabber to help reach objects
- Smart devices with set reminders and checklists (Google Home, Alexa, iPad, tablet)
- Calendars and planners to promote organization and recall
- Sock aid or shoehorns
- Toilet risers
- Magnifying glasses or magnifying stands with light
- Seat cushions (promote positioning and comfort)
- Color contrast plates and dish ware
- Razor, brush, or comb extension handle



## 3.6 Mind-Body Practices



*Julia Wood, OTR/L, Contributor*

Mind-body practices are techniques designed to enhance the mind's positive impact on the body. These include behavioral, psychological, social, expressive, and spiritual practices such as yoga, meditation, tai chi, and biofield therapies. These approaches are becoming increasingly popular, with many having reported benefits for managing symptoms associated with various chronic diseases.

### Reflective Exercise

Reflective exercise forms combine deep breathing, meditation, and any form of movement to obtain a state of deep relaxation. The most common forms are yoga and tai chi, which have been studied over the last decade to see if they can positively impact changes in cognitive, physical, or psychological outcomes in individuals living with dementia. More research is needed, but studies have shown positive results in a variety of outcomes including improved balance, improvements in various aspects of cognition, improved performance of activities of daily living, increased endurance, improved confidence and self-esteem, increased quality of life, and decreased care partner stress.

**TAI CHI** is a self-paced form of gentle physical exercise and stretching. It involves a series of movements performed in a slow, focused manner and accompanied by deep breathing. Each movement flows into the next without pause, ensuring that your body is in constant motion. Tai chi is low impact and puts minimal stress on joints and muscles, making it generally safe for all ages and fitness levels. Tai chi is inexpensive and requires no special equipment. You can practice tai chi anywhere, indoors or outside, alone or in a group class.

**YOGA**, which means union, is most commonly associated with the physical practice of postures woven together and coordinated with the breath. Yoga practice is generally intended to improve flexibility, coordination, and balance; build strength; calm the mind; and relax the body. Yoga can be adapted to a variety of abilities and ages, making it accessible for most people.

## Mindfulness and Meditative Techniques

These age-old practices are based on Eastern traditions that focus on self-regulatory techniques to help one maintain attention and awareness. These interventions share a goal of working to “be in the moment” without judgment. Research over the last 20 years has shown a variety of positive effects from mindfulness-based interventions for people with dementia including improved sleep, better mood, cognitive improvements, structural brain changes suggesting neuroplasticity (the brain’s ability to change and adapt), and increased quality of life.

## Biofield Therapies

These therapies are based on the belief that human beings are fields of energy that are in constant interaction with others and the environment. These interventions involve modification of the human energy field by directing healing energy through the practitioner’s hands. They include Reiki, Therapeutic Touch, and Healing Touch. They most likely impact well-being by promoting relaxation and reducing stress and anxiety. More research is needed, but studies have shown decreased agitation and improved mood, following participation in biofield therapies for people with dementia.

### **REIKI**

Reiki is an energy healing technique that promotes relaxation and reduces stress and anxiety through gentle touch. Reiki practitioners use their hands to deliver energy to your body, improving the balance and flow of your energy to support healing. Studies suggest that Reiki may create feelings of peace, relaxation, and well-being. During a typical Reiki session, you lie on a massage table fully clothed as the Reiki practitioner gently places their hands on or slightly above your body in specific energy locations.

### **THERAPEUTIC TOUCH**

This is where the practitioner hovers their hands over the body to correct or balance energy fields. Studies suggest that therapeutic touch may help reduce pain and lessen anxiety. Typical sessions are similar to Reiki.

### **HEALING TOUCH**

Healing Touch uses gentle hand techniques thought to help re-pattern an individual’s energy field, and accelerate healing of the body, mind, and spirit. The goal of Healing Touch is to purposefully use the energetic interaction between the practitioner and the individual to restore balance to the energy system. This non-invasive technique employs the hands to clear, energize, and balance the human and environmental energy fields, thus affecting physical, mental, emotional, and spiritual health.

When seeking activities to assist you in living well with dementia, mind-body therapies can provide a personalized, low-cost strategy with no documented side effects. More research is needed to understand how they may benefit individuals living with dementia but, given the scope of evidence, these mind-body approaches offer potential symptom management for those living with dementia, care partners, and healthcare providers to explore.

*Art is a way to communicate when words don't work. People's spirit really shines through. I've had powerful moments of connecting with people who were communicating and experiencing life differently. People living with dementia have helped me learn more and more about the enduring personhood and the whole rainbow of ways that people can connect, can share their spirit, their creativity, their memories, beyond one person alone with their database of memories.*

**Beth Soltzberg, MSW, MBA, Contributor**



### **3.7 Creative Practices**

Throughout this manual you will find examples of how creative practices expand and deepen the well-being of people living with dementia. Cynthia Huling Hummel, for example, discovered mask making and painting, and finds great satisfaction in pursuing art. Her masks were displayed in the National Art Museum in Stockholm, Sweden.

You can tap into creativity in boundless ways, from gardening to cooking, dancing, writing poetry, knitting, playing an instrument, singing, collage, and pottery. Here are some examples:

## **MOVEMENT-BASED GROUPS**

Movement-based groups, including those that are designed specifically for people experiencing cognitive change, can be fun, challenging, and creative. These can be exercise or dance groups. There is some evidence that physical exercise and movement not only improve physical functioning but also mood. Exercise may also help slow the progression of cognitive changes. (See [Pillars of Well-Being](#), Section 2.2F, page 101.)

## **DANCE**

Dance can support expression if speaking becomes difficult. Dance uses gestures and rhythmic movements as a form of expression that can amplify or replace traditional ways of communicating. By engaging the body as a form of expression, dance can promote and extend a feeling of connection to self and others. In this way, dance can serve as a form of language.

Dance is both a good way to exercise and a creative outlet for people living with cognitive change. Many people become incredibly involved in the rhythmic activities that dance provides. Studies suggest that dance may benefit cognitive function, maintain motor function, and improve quality of life, although more research is needed. One 2021 “meta-analysis” of 14 studies in the journal *Frontiers in Aging Neuroscience* found that “dance interventions may positively affect cognitive function, rote memory, immediate recall, delayed recall, and attention in patients with [mild cognitive impairment].”

## **THEATER, DRAMA, AND STORYTELLING**

These are beneficial for people living with cognitive change, according to several studies. These practices promote social interaction and emotional relief in a failure-free setting. Visual arts and storytelling are often combined.

## **CREATIVE WRITING and POETRY**

These tap into different ways of communicating how we see the world. There are groups especially for individuals living with cognitive changes.

## **MUSIC**

Whether singing with a choir, listening to recorded or live music, or playing a musical instrument, music is pleasurable and good for the brain. When playing

a musical instrument and singing, we utilize our procedural memory. This may be better preserved than short-term memory and is beneficial regardless of our abilities. Popular videos show individuals with advanced symptoms of dementia who continue to perform ballet or play the piano with amazing ability. These videos also illustrate the connection between music and muscle memory (movement).

## LEISURE ACTIVITIES

Leisure activities also can be both fun and therapeutic. Examples include doing puzzles, reading, gardening, participating in sports, and joining organized group discussions. Whether you do these independently or with some assistance, they can be beneficial.

## SENSORY STIMULATION

This is a way to engage in creative practices even if your symptoms advance. For example, one man had long been in a bell choir. As his condition worsened, he moved very little. However, because of his long-term and procedural memory, when a white glove was put on his hand, he knew that it was time to play in the bell choir. As the music played, he knew from a gestural cue (touch) to ring the bell and play his part. This made him and his family happy, knowing that he was still able to participate in a favorite activity.

Another example of sensory stimulation involved using the scent of roses to bring pleasure to someone with advanced symptoms of dementia. A husband was sure

*“On a Positive Note Chorus,”  
based in Neenah, Wisconsin,  
has been singing and performing since 2014.  
The chorus is made up of people living with  
dementia and their care partners.  
It’s an enormous gift to be with these folks.  
We want the community to see that folks  
living with dementia can bring joy to them.*

**Susan McFadden, PhD, Contributor**



his wife was unable to respond to him. He mentioned to the occupational therapist that his wife had always loved roses. The therapist suggested he bring his wife a bouquet. She showed him how to bring the roses within his wife's field of vision and then close to her nose. His wife moved her head toward the rose, attempting to smell it. She smiled, held her husband's hand tight, and cried with happiness. So did he. Roses became an enjoyable part of their new routine.

TimeSlips is devoted to engaging people living with dementia and other elders in meaningful projects large and small. Using prompts and small-group connection, TimeSlips trainers help people living with dementia create stories and dramatic scripts, which they can then act out.

Its core values are:

- ◆ Saying, "Yes, and ..."
- ◆ Asking beautiful questions
- ◆ Giving proof of listening
- ◆ Opening ourselves to wonder
- ◆ Committing to rigor and the value of all human beings
- ◆ Finding meaning by connecting our personal expressions to the larger world

"The arts and creativity are an emotional and symbolic language. They open up people's expressive and communicative potential." — *Anne Basting, PhD, founder TimeSlips, and a MacArthur Fellow*

*I like having music on.  
I like to dance around  
the house — but not sing!*

**Kim Reid, Manual Guide**





## ***The Arts and Personhood***

### ***Daniel Potts, MD FAAN, Contributor***

*Painting connected my father to his story*

“Art is an appeal against vanishing.” — Lynn Casteel Harper, *On Vanishing*

I grew up musical. My mother was a voice and piano teacher. I became a neurologist, but I really didn't appreciate the usefulness of the arts in healthcare until my Dad was diagnosed with Alzheimer's. He attended adult day care, and was exposed to both expressive arts therapies and the use of arts and creativity. That exposure really gave Dad his life back and enabled us to have a relationship with him that we were struggling to have. I cannot emphasize enough how thankful we are for that.

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The arts gave him an outlet to  
express himself better,  
to make himself known,  
to deal with these emotions,  
to take him back to parts  
that were healing to him.

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We did not think he was an artsy person. He was not creative, not musical, he didn't sing. He was gifted with his hands but did not create art. When he started attending Caring Days Adult Day Care, he was struggling with language, dealing with his emotions, and communicating with family and friends. The arts gave him an outlet to express himself better, to make himself known, to deal with these emotions, to take him back to parts that were healing to him.

He met George Parker, who was a volunteer artist with an innate understanding of how to share his art with others and pull out their gifts and talents. George began by showing them pictures he had created. Once people got into it, he let them paint what they wanted.

Dad started out copying things, then he began painting things in his mind — his father, his father's shoes and hats. Dad grew up sawmilling. He painted logs, wood rings, trees, people he had relationships with early on, workers in the sawmill. It was just fabulous. It validated Dad, it gave him something to be proud of. It connected him with his story, and it seemed to satisfy and give him peace. We think it made him more communicative, more able to pay attention. It was just easier to be with Dad. It really was amazing.

It taught me so much. I had been looking at Dad from the point of view as a physician, seeing losses and inabilities. This showed me giftings, the freedom to express what was inside. That led me to a deeper appreciation of the concept of personhood. I realized it's still there, but we have to change the way we look for it. We have to change ourselves.

What does this mean — scientifically, neurologically, spiritually, philosophically? I've explored that for 15 years. I've met with people who know a lot about this. We went on to start a foundation, Cognitive Dynamics. When we developed our programs, we thought most of it was about art and creativity. But it's really not. The art has value of its own, but I see it primarily as a means of shoring up personhood and enabling relationships. By shoring up personhood, we allow that individual to continue to express what's inside of them and tap into that which makes each one of us a person and share that, and by means of that sharing to build relationships.

To see some of Lester Potts's art and to learn more about the arts and people living with dementia, visit Cognitive Dynamics Foundation: [cognitivedynamics.org](http://cognitivedynamics.org)



## SUGGESTED RESOURCES

### Articles and Reports

Alzheimer Society of Canada, (2018). Dementia, intimacy and sexuality. [alzheimer.ca](http://alzheimer.ca)

British Psychological Society. (2016). Psychological dimensions of dementia: putting the person at the centre of care. [www.bps.org.uk](http://www.bps.org.uk)

Hwang, P.W. and Braun, K.L. (2015). The effectiveness of dance interventions to improve older adults' health: a systematic literature review. *Alternative Therapies in Health and Medicine*, (21)5 64-70.

Kontos, P., Grigorovich, A. (2018). Integrating citizenship, embodiment, and relationality: towards a reconceptualization of dance and dementia in long-term care. *Journal of Law, Medicine & Ethics* 46(3), 717-723.

Liu, C., Su, M., Jiao, Y., et al., (2021). Effects of dance interventions on cognition, psycho-behavioral symptoms, motor functions, and quality of life in older adult patients with mild cognitive impairment: a meta-analysis and systematic review. *Frontiers in Aging Neuroscience*, (13): 706609.

Teri, L. Logsdon, R., McCurry S. (2008). Exercise interventions for dementia and cognitive impairment: The Seattle Protocols. *Journal of Nutrition, Health and Aging*, (12)6 391-394.

Taking Charge of Your Health and Wellbeing website, Earl E. Bakken Center for Spirituality & Healing, University of Minnesota. [www.takingcharge.csh.umn.edu/explore-healing-practices/what-are-mind-body-therapies](http://www.takingcharge.csh.umn.edu/explore-healing-practices/what-are-mind-body-therapies)

### Books

Basting, A. (2021). *Creative care: a revolutionary approach to dementia and elder care*. Harper One.

Jewell, A., editor. (2011). *Spirituality and personhood in dementia*. Jessica Kingsley Publishers.

## SECTION 4: Life Affairs

After you've received a diagnosis of dementia, you will need to think about practical matters related to the future. This section covers some of the big considerations that people are often concerned about, such as employment, driving, and health insurance. Other considerations may not be as obvious, like whether your home will work well for you as your symptoms advance. Legal and financial planning are key, no matter your income. It's important to have the paperwork in place and to decide who will make decisions or carry out tasks like bill-paying if you are unable to. These and other day-to-day considerations are covered in this section.

### 4.1 Cognitive Changes and Your Job

Many people continue to work after being diagnosed with dementia. Just because you get a diagnosis does not mean you must quit your job or retire immediately. Many accommodations can be made to allow individuals to continue to be successful. Working with your human resources department or your direct supervisor can be helpful. Perhaps cutting back hours or adjusting responsibilities can allow you to continue to be productive, have a sense of purpose, and earn income.

If you are still working, you are probably wondering how long you can continue to do so. Deciding when to stop and when to tell your employer can be challenging.

Giving up your job will affect your finances, and it may change whom you regularly engage with, and how you fill your time. It may also affect your self-confidence and identity. Allen Power, MD writes in his book, *Dementia Beyond Disease*, our culture highly values a strong work ethic. "... our work ethic has elevated productivity to the extent that those who cannot produce as much ... are devalued, even if they have previously spent decades of their lives in highly productive work."

If you are just noticing cognitive changes, you might consider creating "an occupational living will." In his book, *The Problem of Alzheimer's*, Dr. Jason Karlawish tells the story

of a colleague who created this novel tool. He wrote down how he wished to proceed if he developed cognitive impairment, and he shared this with his colleagues. He asked them “to make a fair and reasonable assessment of his work performance and to share their observations with him. If these observations trigger a concern, a plan is in place for a formal assessment with a physician,” Dr. Karlawish writes. The colleague even made a video speaking to his future self, saying his wishes as far as work and his abilities to perform his job.

Whether it’s concerns about working or driving, having a few trusted people in your circle who will be honest with you is invaluable. Cynthia Huling Hummel noted, “I have a ‘circle of care’ — that is, a few dear friends who have agreed to ‘hold up the mirror’ (so to speak) to help me to recognize that my abilities have changed. They will let me know when I may be lacking in capacity to make wise decisions.”

Often one of the first places cognitive changes are noticed is in the workplace. Sometimes you will notice the change; other times it is coworkers or colleagues.

Common examples of activities in the workplace that you may have uncustomary difficulty with:

- ◆ Processing numbers if this had been a strength
- ◆ Remembering decisions made at meetings and who attended
- ◆ Understanding verbal instructions
- ◆ Managing multiple tasks simultaneously
- ◆ Remembering meetings or appointments
- ◆ Concentrating
- ◆ Losing confidence in making decisions

It is common for people to misidentify these signs as stress or due to a heavy workload. Being overworked, not getting restorative sleep (see [restorative sleep](#), *Pillars of Well-Being*, Section 2.2E, page 97), and feeling distressed can certainly cause temporary lapses in cognitive abilities; however changes associated with dementia are different. If challenges persist, contact your primary healthcare provider to discuss your symptoms and concerns.

If it is determined that you are living with a form of dementia, you will have many decisions to make, including when you share this information with your employer. You may have concerns about sharing your diagnosis with others due to the stigma associated with dementia. As noted in [Tell People or Not](#) (see Section 1.15, page 80), Dr. Gayatri Devi warns that your employer and coworkers may begin to view you through “Alzheimer’s-colored glasses,” assuming that you are incapable of work, even if up until now you had been given strong evaluations.

As the late Richard Taylor, a renowned advocate and author of *Alzheimer's From the Inside Out*, said in an interview, "Ideally, an employee would be told: 'These are not the kinds of errors we generally see in you. But we're still committed to you as an employee — we have a lot of investment in you. This is a new problem for us to solve. You want to keep your job and we want to keep you. How can we partner with you?'"

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Try to make a plan for  
financial security event if it  
may change as the  
disease progresses.

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In truth, this may be unlikely to happen. Because of the stigma, many experts caution that employees diagnosed with dementia need to proceed carefully. Consider how losing your job or retiring may affect matters such as health insurance and your income. Try to make a plan for financial security even if it may change as the disease progresses. If you feel your continued work would endanger others, you must take measures to ensure safety.

Among other suggestions from Dementia Australia about next steps:

- ◆ Have a dress rehearsal with family or friends for how you will tell your employer
- ◆ Discuss the possibility of adapting aspects of your job to make it possible for you to continue
- ◆ Think about who needs — or doesn't need — to know at your workplace
- ◆ Identify one or two trusted people who might be willing to help you with specific parts of your job
- ◆ Know how much medical leave you have, as well as any disability benefits

## Americans with Disabilities Act and Your Job

What about the Americans with Disabilities Act (ADA)? Does it offer protection to employees living with dementia? In theory, yes. In practice, far too many employers view a dementia diagnosis as a reason to force an employee into retirement.

The ADA prohibits discrimination against people living with disabilities in several areas, including employment, transportation, public accommodations, communications, and access to state and local government programs and services. The ADA was established to ensure that individuals living with disabilities are not discriminated against. The ADA defines disability as “a physical or mental impairment that substantially limits one or more major life activities.”

Much depends on your symptoms and the nature of your work. The ADA does not go by diagnosis but by functional impairment. If an employee can complete their work requirements with reasonable accommodation, they should be protected under the ADA. For someone living with dementia, this could include a flexible schedule, desktop reminders, or some assistance from a co-worker. Richard Taylor continued teaching at the college level for a few years, with support from his teaching assistant.

The Job Accommodation Network (JAN), a service of the U.S. Department of Labor, cites some general examples of reasonable accommodations. These include restructuring jobs; making worksites and workstations accessible; modifying work schedules and responsibilities; and providing specialized equipment. Employers are required to provide an accommodation unless it would cause undue hardship for the employer, which is assessed on a case-by-case basis.

If you are unable to work due to your dementia diagnosis, you may be eligible for Social Security Disability Insurance. This is for people who have paid into the Social Security system but who have not reached their full retirement age. (Social Security is gradually increasing the full retirement age. To see a calculator, go to [www.ssa.gov/benefits/disability/qualify.html](http://www.ssa.gov/benefits/disability/qualify.html).) Once you have reached your full retirement age, then your benefits convert to regular Social Security. (For more on SSDI, see [Insurance](#) in *Getting Your Financial and Legal Affairs in Order*, Section 4.8, page 263.)



## ***She Loved Her Job, But ‘Then Things Changed’***

### ***Laurie Scherrer, Manual Guide***

*Learning from others with disabilities*

Laurie Scherrer had worked her way up the career ladder and enjoyed the challenges of the business world. Through her skills in computer programming, training, and management she rose to the position of Vice President and Director of Information Systems at a bank. “I had a knack for almost any computer programming and for bringing projects from conception to success,” she says.

Eventually, she found she no longer enjoyed managing employees. She discovered a new career passion: sales. Her warm personality and financial skills made her an excellent sales person. She loved her work and earned good money.

Her final and favorite job was selling mobility vans for people living with physical disabilities. “I really loved that job,” she says, “But then things changed.”

She found she could no longer do basic arithmetic. “We were at a convenience store one day. I was picking up something small to buy, and I remember not knowing how to count the money.” At the same time, she found that she was turning from a “people person” to someone easily agitated by others.

She lost her job selling mobility vans. But she learned something important that she carried forward. “I watched the way these people with physical disabilities found strategies to continue to live and to overcome their challenges. Many had such an ‘I can do’ attitude which focused on their abilities rather than their disabilities. After my diagnosis, that resonated with me. If they can find ways to adapt and find strategies to live positively, then so can I.”

## 4.2 Dementia and Driving

Driving is a fundamental part of our culture. Driving is equated with the freedom to go wherever and whenever we please. Our love affair with cars has been written into popular songs since the 1950s, from “Route 66” and “Little Nash Rambler” to “Truckin’” and “On the Road Again.” For many, cars are a primary way to get groceries, go to doctor’s appointments or church, commute to work, and travel on vacation.

Nearly 90 percent of adults in the U.S. have a driver’s license. According to the American Public Transportation Association, 45 percent of Americans have no access to public transportation, so it’s no small consideration to contemplate no longer being able to safely drive.

When someone is diagnosed with dementia, losing their ability to drive is one of their and their family’s first concerns. Some people in the early stages can continue to drive safely. Others have visual-spatial problems early on or other cognitive symptoms that make driving a hazard.

Driving is a complicated process and different parts of the brain control different aspects. Remembering how to operate a car is part of our procedural or implicit memory. So too is riding a bike or tying our shoes. Navigating where to go is controlled by a different part of our brain where declarative or explicit memory is stored. Thus you might be able to brake and steer properly but get lost going to your daughter’s house.

If you or your care partners have concerns, it’s a good idea to get an independent driving evaluation. According to the American Automobile Association (AAA) there are two types: clinical driving assessments are conducted by occupational therapists (\$200–\$400) and driving skills evaluators are licensed and certified by states (\$100–\$200). For more information, visit [exchange.aaa.com](http://exchange.aaa.com).

If you are still able to drive safely, have your driving reevaluated every six months or so as your symptoms may change.

The Alzheimer’s Association identifies the following signs of unsafe driving:

- ◆ Failing to observe traffic signs
- ◆ Making slow or poor decisions in traffic
- ◆ Driving at an inappropriate speed
- ◆ Becoming angry or confused while driving
- ◆ Hitting curbs
- ◆ Using poor lane control

- ◆ Making errors at intersections
- ◆ Confusing the brake and gas pedals
- ◆ Returning from a routine drive later than usual
- ◆ Forgetting the destination you are driving to during the trip

You may be able to recognize some of these signs on your own or need to rely on others in your life to share with you their experiences of your driving. Again, having a few trusted people in your circle can be very helpful and keep you from getting defensive. Listen to their judgment. While some care partners are overprotective when it comes to driving, they are likely thinking not only of your safety, but of other people's safety, whether as passengers, occupants of other cars, or pedestrians. It is best to err on the side of caution and be in control of making the decision to stop driving.

Regardless of when you stop driving, you need to make a plan. Think about what you use your car for and how you will continue to have access to those products, services, and activities when you can no longer drive. Even if you believe you can drive safely for the foreseeable future, it is a good idea to plan ahead.

Fortunately, we live in a time when there are many more options than in the past, although in rural communities some of these may not be available.

- ◆ Groceries and carryout meals can be delivered, either by the supermarket or restaurant, or by a delivery service. You will typically need to order these on your computer or smartphone. Most delivery services charge extra, so be sure you know what you're signing up for.
- ◆ Online shopping is now standard for basically anything you want or need. Whether through [amazon.com](https://www.amazon.com) or thousands of other retailers, nearly 70 percent of Americans have used online shopping, and 25 percent do so monthly.
- ◆ Taxis and driving services such as Lyft or Uber can transport you anywhere in your area, including to the airport. Generally these services are requested through a smartphone, although some taxi companies still use phones. (That said, some low-income communities report that it's more difficult to get driving services in their neighborhood.) If you can afford it, there are also private drivers that you hire directly or through a company.
- ◆ Public transit may be an option, either bus or subway. In the early stages, you may be able to manage this on your own, or ask a friend or care partner to go with you at least a couple of times so you can be comfortable with the bus routine.
- ◆ Contact your local area agency on aging or Eldercare Locator ([eldercare.acl.gov](https://eldercare.acl.gov)) to find out what transportation options there are for you.



- ◆ See if your community has a Village, a neighbor-helping-neighbor organization aimed at allowing people to age in place. They usually have a pool of volunteers available to provide free rides. A map of Village locations can be found at the Village to Village Network, [vtvnetwork.org](http://vtvnetwork.org).
- ◆ If you are part of a faith community, ask if any members of the congregation would be willing to pick you up for services and meetings you wish to attend.
- ◆ Ask friends and family if they'd be willing to help you out with rides from time to time. Offer to treat them to lunch or a movie in exchange for a ride.
- ◆ Investigate services — such as hairdressers/barbers or veterinarians — that will come to you. They may not be as expensive as you think.
- ◆ As your symptoms advance, your care partner could look into home medical and dental services. Many are covered by Medicare or other insurance, depending on your condition. Even hospital care is beginning to be provided at home in some areas.

“I voluntarily gave up driving in 2010 but I know how gut-wrenching it is for many people, especially men,” says Manual Guide Jim Mann. Having a plan and being proactive may help ease some of your sadness and worry about giving up your license.

Jim advises, “Be creative about getting out. If you are no longer able to drive, continue living. Start walking more in your community. Perhaps there is a small group of people who meet for coffee that would welcome you to join and offer to pick you up. Above all, know your world has not collapsed.”

## 4.3 Making Air Travel Easier

A good example of how a disability frame can be helpful is the Dementia-Friendly Airport [www.dementiafriendlyairports.com/about-us.html](http://www.dementiafriendlyairports.com/about-us.html) initiative. Launched in 2018, the Dementia-Friendly Airports Working Group is a collaboration of professionals, academics, and volunteers, including people living with dementia and care partners. Unlike some disabilities, such as those affecting mobility or vision, dementia may not have visible signs, such as a wheelchair or service dog, especially with early symptoms. The working group's efforts include training airport staff to understand “hidden disabilities” and to create policies and spaces that will support people living with dementia.

Among the recommendations for airports:

- ◆ Use signs, photos, and videos to make their processes and services clear to passengers.

- ◆ Provide quiet areas for travelers to wait for flights and calm routes through the airport, avoiding hectic retail shops and restaurants.
- ◆ Train staff to recognize a badge or lanyard indicating a passenger is living with dementia and allowing someone to accompany them to the gate.

As dementia becomes recognized as a disability, many other public places may be more open to measures such as setting aside quiet areas or having clearer signage. (For more on [dementia-friendly initiatives](#), see *Community Supports*, Section 2.4B, page 122.)

Unfortunately, most airports are not yet dementia-friendly places. For people living with dementia, airports are at the top of the stress meter. Airports are very noisy places, often with competing overhead announcements about things that travelers need to pay attention to, such as a gate change or flight cancellation. Besides the noise overload, airports provide visual overload. There is a lot of signage to navigate — check-in, baggage drop-off, baggage claim, wide assortment of gates, TSA screening, travel advisories, advertisements, and much more. The auditory and visual overstimulation adds to the general level of stress experienced when needing to fly.

Manual Guides Laurie Scherrer, Barney Nelson, and Mark Timmons offer the following recommendations when you need to fly:

## Booking the Flight

- ◆ It may cost a little more but opt for *Priority Boarding*. This allows you to board the plane before most of the other passengers. It's easier to find your seat, stow your luggage, and settle in before the plane starts filling up.
- ◆ **Two weeks before your flight**, contact Special Services for the airline your flight is booked on and request wheelchair assistance. While you may be physically able to walk, having wheelchair assist provides you with the means for help navigating TSA security and getting you to your departure gate. Some people living with dementia have balance challenges and cannot use escalators or stairs. Using wheelchair assistance bypasses the need to use escalators or stairs. Having this support helps reduce your stress.

## Preparing for the Flight

- ◆ Buy a clear plastic pouch with a strap that can be worn around your neck. This provides you with a safe place to keep your drivers license or other form of picture ID, boarding pass, mask, and other items you readily need. It is very easy to set a boarding pass down to do something and then forget about it. If you have a process to keep things handy and safe, you are much less likely to lose or misplace important items.
- ◆ Add a set of earplugs to your pouch. If/When the noise becomes overwhelming, earplugs help dim the noise.

## Checking In

- ◆ Plan to arrive at the airport early. This will help reduce your stress if extra time is needed for anything unexpected.
- ◆ Check in at the counter instead of a kiosk. When you get to the counter, let them know that you requested and need wheelchair assistance in case this information doesn't come up with your reservation information.
- ◆ Confirm that you can board the plane early.

## Navigating TSA Security

- ◆ Inform the TSA officer that you or your travel companion is living with dementia. They can help provide assistance during the screening process, including not separating you from your travel companion. If special screening or a luggage check is required, ask to have it done in a private area. Being in a private space gets you out of the way of other travelers and the hecticness of the general screening area.
- ◆ If you are traveling alone, TSA offers a program, TSA Cares, that allows you to have someone help you through security and to your departure gate. You can call TSA at (855) 787-2227 or go online at <https://www.tsa.gov/contact-center/form/cares> to request this assistance. **If you need this assistance, set it up three days ahead of your flight.**

## At the Gate

- ◆ If you use wheelchair assistance, don't forget to tip the assistant. Often these service people depend on tips to augment low pay.
- ◆ Sit at the least crowded location near the gate you can find so you can escape some of the noise and confusion.
- ◆ If you need to use the restroom it is very easy to get turned around. Use the restroom closest to your gate. Look for a landmark just before the restroom that can help you know which direction to go in when you leave.
- ◆ Write down your gate number and keep it in the pouch with all your ID.
- ◆ If possible, have someone wait for you outside the restroom and hold all your belongings except your ID Pouch.

## Boarding the Plane

- ◆ When you board the plane, provide the flight attendant with a card that explains you are living with dementia, and may need some assistance and support during the flight.



## ***Airports through a Disability Lens***

### ***Chuck McClatchey, Manual Guide***

*What 'dementia-friendly' could mean for travelers*

Manual Guide Chuck McClatchey has been on committees to help both the Las Vegas and Kansas City airports become dementia-friendly. He was part of Dementia Friendly Southern Nevada's Community Awareness program, which was the first in the country to be implemented at an airport. He worked with the Cleveland Clinic to develop a training program for airport employees. "We wrote the lesson plan from scratch," Chuck says.

"We had three in-person training sessions, and then COVID hit. We tried with virtual, but it was not the same as in-person training," he says. "I was amazed. Every person participating was involved in it. No one seemed to be sitting there because they had to be there. Surveys said it was really great."

In addition to learning about dementia, the training gave employees a chance to learn how stressful airports can be. Finding a family bathroom or simply a quiet place to sit is a challenge. "We talked about if they see somebody that looked lost, how to approach them, and how to communicate with care partners and people with dementia."

In Kansas City, a new airport was being built, and Chuck was on a committee to give them ideas about dementia-friendly design. Having a designated quiet place for families is ideal, whether it's for people living with dementia or parents with children who have autism. "One of the care partners flew with his wife, who was living with advanced symptoms of Alzheimer's. They were walking in the airport and she froze. The carpet color went from beige to black and she was afraid to step on it. We advised them not to have such a stark contrast in the carpet. Additionally, black flooring can be perceived as a hole. The Detroit airport has strobe lights — that doesn't help. Loud music when people are trying to concentrate on where they are going isn't good either."

## 4.4 Managing Your Schedule

There are many ways to manage your daily schedule, both through your computer or smartphone, or through simple creative strategies that work for you.

To begin, try to create a daily routine that you stick to. This will help you manage your time and reduce stress. Most people living with dementia find that a regular routine is helpful. Even if you've been a spontaneous person in the past, you might feel better with a more fixed routine, as far as when you arise, mealtimes, a balance of activity and rest, and bedtime.

For example, what times of day do you have the most energy? Make your schedule accordingly. "I've learned to expect to be surprised," says Manual Guide Mark Timmons. "I never know what dementia is going to throw at me from one day to the next. I used to be surprised at how downhill my brain function gets late in the afternoon. Now I know to schedule as much as I can in the mornings and early afternoons."



### ***A Simple Way to Organize Your Week***

***Rev. Dr. Cynthia Huling Hummel, Manual Guide***

*Planning ahead reduces stress*

Cynthia Huling Hummel developed a clear, hands-on way to keep her week straight. "Living alone, I don't have someone who will remind me of my day-to-day activities," she says. "But I have a great system in place. To organize my week, I have my 'memory bench.' Several years ago, I purchased an inexpensive bench as a way to get organized and keep track of my different appointments and activities. You could also repurpose an old table or invest in a "cubby hole" system like kids have in school.

The point is to have an area to lay out your week.

"Having a visual reminder of my week on the bench helps me stay on track each day. I made signs for my bench for each day of the week. Every Sunday night, I lay out the coming week's activities. For example, if I plan to go to the pool on Monday, I put my pool bag in the Monday section of the bench. I also check to make sure that everything I need is in that bag. I learned that the hard way, by forgetting to pack a towel one day

and having to put on my clothes over a wet bathing suit. If I have a dentist appointment on Friday, I put a note in the Friday pile with the time — and an extra toothbrush. Having an object there is a GREAT cue for me.

“I try and visualize (literally!) what I will need each day. That way, I am not searching for my swim goggles in my swim bag on Monday at 6:30 a.m. If I am speaking at an event on Thursday, I will put my presentation in the Thursday pile. Every night, I will write out a reminder for the next day that I will see while I have my coffee — Today, is MONDAY — get going. This system works great for me, but if it’s too much for you to lay out the entire week, you might try it on a day-to-day basis — that is to say, before you go to bed at night, think about what you will need for the next day and lay it out in a place where you will see it.”



Some people find that simple post-it notes help. The Alzheimer’s Society of Canada suggests putting post-it notes in places where you know you will look (such as on the bathroom mirror). Take the note down once you have done what it says, to prevent you from doing it twice and to avoid confusion. Erasable whiteboards, displayed in the kitchen or main hallway, are another handy tool that you can update throughout the day.

Jim Mann asked a tech-savvy friend to get his computer and phone systems set up to help him stay organized. “Use your smartphone calendar and alarms,” he advises. “When I’m somewhere and a new appointment is made, I put it immediately in my phone. I also make use of the phone calendar’s two warning times so you can be reminded of an appointment, for example, 60 minutes prior and again at 10 minutes. Depending on the tasks to complete for a meeting, I will sometimes have the first alarm set one week before and then reset it.” (For other ideas on [tools to manage your time](#), see *Technology Supports*, Section 6, page 303.)

Jim also has a simple way to keep his bedtime routine straight. “Before I go to bed, I take a light sleeping pill, a nose spray, and an anti-asthma inhaler, in that order. I would get confused because I would do this out of order, and it would cause great frustration. I finally developed a solution.” He places on his nightstand the three items, each sitting on a small card marked — 1, 2, 3 — to remind him of the order. The cards also have a picture of a city

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*Even if you've been a spontaneous person  
in the past, you might feel better  
with a more fixed routine,  
as far as when you arise, mealtimes,  
a balance of activity and rest, and bedtime.*

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in moonlight, so he'll know that these are things to take at night.

As symptoms advance, you might find it helpful if your care partner writes down a daily schedule that works for you. In consultation with her father, Jennifer Carson created binders explaining in everyday language what Lewy body dementia is, the family's person-centered philosophy, and details about how her father can best have a smooth day in a calm environment. She made two binders, one for direct care partners and one for extended family and friends. The binders include a section on his daily schedule, beginning with his regular wake-up time of 8 a.m., with a cup of coffee through sleep at 10 p.m. In between are times of activity and rest, meals, medications, and stress-free, quiet evenings.



## 4.5 Managing Your Stuff

People living with dementia often find that a well-ordered, decluttered home environment works best for them. It can help reduce confusion and stress, and you don't waste your time trying to find things that are not in easy view. As you declutter, you want to keep treasured items and not get rid of things you still enjoy.

You might want to enlist the help of a friend, family member, or professional organizer/declutterer to help you gradually sort through your belongings. Do a little at a time. One tried-and-true technique is to have three boxes to put things in: one for trash; one for items that you want to keep; and one for clothes, objects, or books to donate to charity or give to someone you know. This can be a satisfying way to revisit your things and focus on what you truly appreciate having. It's also satisfying to give away items that you no longer need but will be useful or enjoyable for someone else.

## 4.6 What About Pets?

A beloved pet is good for our well-being. Pets offer mutual affection and a reason to get out of bed. Their care can give our life purpose. They also make us smile or even laugh out loud. And petting them can be soothing.

More than two-thirds of U.S. households have pets. According to the U.S. Department of Health and Human Services, "Interacting with animals has been shown to decrease levels of cortisol (a stress-related hormone) and

**Laurie  
Scherrer's**



**TIP** **STORE CHRISTMAS THINGS** — decorations, scrapbooks, and other storable things — in clear plastic bins that are labeled with an image of the item, making them easy to find

**TIP** **USE SMALLER CLEAR BINS** in the kitchen pantry, labeled with images of the contents (Laurie came up with this trick, after adding flour to a dessert when she meant to use confectioner's sugar.)

**TIP** **PLACE CANNED FOODS** facing front on the shelf

**TIP** **ARRANGE SPICES** in alphabetical order

**TIP** **KNOW THE SIZE OF YOUR SHEETS** by sewing or safety-pinning a large tag off the middle of the bottom end of the sheet, noting what size the sheet is (king, queen, full, twin) (The tag at the bottom lets you know easily which direction to spread the sheet.)

lower blood pressure. Other studies have found that animals can reduce loneliness, increase feelings of social support, and boost your mood.”

People with advanced symptoms of dementia frequently respond positively when dogs or cats are present. A number of clinical trials of pet therapy for people living with dementia have shown benefit, although more research is needed.

Manual Guide Laurie Scherrer has a service dog named Lil Dawg. Lil Dawg is Laurie’s close companion and brings her much joy. As a service dog, she also looks out for Laurie’s well-being. “Lil Dawg knows some sign language. She is trained to go get Roy [Laurie’s husband] if she feels I am in distress, if I fall, or if I give her the command. She knows I have a difficult time in the shower sometimes, so she sits outside the shower and tells Roy when I am ready to get out. A couple times she came into the shower when she sensed I needed help.”

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*It’s good to make a plan  
for who will care for your pet  
if you are no longer able to.  
Perhaps an animal-loving friend, relative,  
or neighbor would be willing to  
make the commitment to care for your pet.*

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Manual Guide Dave Baldrige says he and his two dogs are “radically bonded.” Like other canine search-and-rescue dog handlers, “We tend to develop close relationships with our animals with sophisticated levels of understanding.”

His 8-year-old border collie, Duer, (Gaelic for “hero”) is from a top herding line in Scotland. “He’s changed from a wild and crazy young guy to being my constant caregiver. He follows me everywhere. Border collies are far smarter than me,” he says.

Dave has serious balance problems as one of his dementia symptoms. To exercise the dogs, he takes his electric wheelchair to a park. “Their daily care is critical,” he says. “Sometimes it’s hard for me to remember if I fed them or not. But they remind me!”

Caring for his dogs is his “reason for staying alive. I don’t want them to find new homes, although I know they may have to,” he says.

As Dave suggests, you may find that you need to make adjustments in order to continue to care for your pet. For instance, Terry Berry lives alone with her dog but close by her two daughters. Her daughters noticed the dog was losing weight and realized their mother was forgetting to feed the dog. Their ingenious strategy was to use an empty mayonnaise jar and mark the outside with permanent ink to show “full” and “half” levels. Every morning Terry fills the jar to the “full” level with dog food and gives the dog half of the jar of food. She leaves the jar on the kitchen counter to serve as a reminder and in the evening gives the other half of the food in the jar to her dog for dinner. She leaves the empty jar on the counter so the next morning she’ll see the empty jar and be reminded to fill it up and start the cycle again.

In her book *The Spectrum of Hope*, Dr. Gayatri Devi writes, “I believe very strongly in the therapeutic power of animals.” She brings her two dogs to her office daily and she has found her patients living with dementia love seeing them. “Lola and Huck are a memorable and treasured part of my office team.”

She also supports her patients adopting a cat or an older rescue dog, “because animals can both keep their owners more active and offer a sense of connection and intimacy.”

As with other aspects of life, it’s good to make a plan for who will care for your pet if you are no longer able to. If your pet has accidents in the house, or experiences unusual weight loss or gain, it may be a sign that you are not able to keep up with their care. Perhaps an animal-loving friend, relative, or neighbor would be willing to make the commitment to care for your pet. If you are able to set aside some funds to go towards its care, that may help you to find someone.

## 4.7 Supportive Home Modifications

If your plan is to stay in your own home for the time being or for the long haul, you may need to consider some home adaptations to make sure that your residence still works well for you. It’s a good idea to ask an occupational therapist to conduct an assessment to make sure that your home is safe and not an obstacle course. Some symptoms of dementia, such as visual and spatial changes, may make it more difficult for you to navigate around your home. One particular concern is falls, as discussed below.

“Fortunately I live in a house that’s very user-friendly with ledges and walls I can lean on,” says Dave Baldrige, who does not have a care partner. “Keeping my balance is a matter of constant focus. So far, so good.”

## Making Your Home Falls-Proof



*Jill Bjerke, B.S., D.C., CAPS Founder, Contributor*

We all want to live in a safe home. You may find that your vision, balance, and spatial awareness change as a result of dementia. Falls are a particular concern. Each year three million older people are treated in emergency rooms because of fall injuries, according to the Centers for Disease Control and Prevention. What can you do to ensure your home continues to be a safe environment for you?

Below are some tips that apply to all types of homes, whether a house, condominium, apartment, mobile home, or senior living residence. They are the basic, most critical steps to help prevent falls as you grow older or your symptoms advance.

- ◆ Wherever possible, have at least one zero entrance (flat threshold) to your home. Likewise, within a home, install a mini-ramp for thresholds over one inch (13 mm) to reduce trips and to allow continuous movement of walkers and wheelchairs. Note: If a threshold is a trip/fall hazard, apply fluorescent tape to it for quick identification.
- ◆ Bathroom, kitchen, door, and furniture should have “C” or “D”-style knobs. Round hardware can be difficult to grip.
- ◆ Pathways throughout the home should always be clutter-free and furniture should be arranged for easy passage.
- ◆ Remove common trip and falls hazards from the floors: throw/area rugs, extension cords, shoes, clothing, magazines, pet toys, magazines, etc.
- ◆ Furniture, beds, and toilets, as well as any other item that you sit on, should have arms and should be at an appropriate height for stability for sitting and rising. Leather or vinyl fabric is preferred for furniture as it is easier to push yourself on and off of. Furniture should be well-anchored.
- ◆ Install motion sensor nightlights in every room and hall, if possible, especially in your bedroom and bathroom.
- ◆ Install grab bars in appropriate places in the bathroom, including around the toilet and in the shower area.
- ◆ Post emergency numbers and addresses in critical areas for quick access in emergencies.

- ◆ Install smoke/CO2 detectors near the kitchen, furnace, and sleeping areas per local zoning codes. Unless the individual detector has a 10-year battery life, batteries should be checked a minimum of every three months. In addition, it is vital that ALL residents of the home can hear the alarm in all portions of a home, including when someone removes hearing aids at night. You may also want to invest in a weather radio to receive notification of an imminent weather hazard so that you can take appropriate safety action.
- ◆ Three sources of lighting are recommended in every room: natural, ambient (i.e. wall-mounted), and task, such as a reading light.
- ◆ All stairs should have stable, continuous handrails on both sides and non-slip tread surfaces. Treads should be no more than 7-3/4" high and, if interior, have a light switch at both the top and bottom of the staircase. Fluorescent tape should be used on tread edge for those with vision or stability difficulties.

Home safety is an ongoing process. Having a home assessment done on a regular basis can help you identify changes or alterations that need to be made.

If modifications or changes are required, there are many professionals who can perform what is needed, such as Certified Aging in Place Specialists, handymen, remodelers, and contractors. There are also a variety of funding sources for assistance in paying for such services.

Home safety is the first step to a healthy home!

## Home Safety Tips — From People Living with Dementia

We asked the experts — people living with dementia — what they have learned about living safely and well in their homes. Here are their ideas:

### General Home Safety — Throughout the Entire Dwelling

- ◆ Make sure carbon monoxide, smoke detectors, and fire extinguishers are easily available, visible, and up-to-date. Check manufacturer-suggested replacement and expiration date, as well as fire safety suggestions. Most require batteries to be replaced every two years and systems replaced every 10 years.
- ◆ Ensure a Quick Dial 911 or alarm is visible and accessible with a large display in all main rooms.

- ◆ Eliminate all possible tripping hazards. Specifically watch for:
  - Throw rugs
  - Wires or cords
  - Clutter (books, papers, small furniture, or knickknacks)
- ◆ Anchor or secure furniture as much as possible. If I start to lose my balance I will grab for the closest object. It is important that most objects will support me.
- ◆ Provide chairs with arms for support and to help me get in and out easily.
- ◆ Keep all passageways and walkways well lit.
- ◆ Place nightlights in every room.
- ◆ Install timers for lights to automatically turn on at dusk. Shadows and darkness can cause a distraction or confusion — especially during the change from day to night. Proper lighting is essential to avoid shadows and falls.
- ◆ Keep all cleaning products (potential hazard) in one location and labeled. Important: these products should NOT be placed in the bathroom where I may also keep my mouthwash or other areas where I may keep products that are placed in my mouth.
- ◆ Store medications away from food. Pills should not be placed next to my stash of treats — if I am confused the colorful pills may look like my M&Ms.
- ◆ Eliminate clutter as much as possible — clutter can cause confusion.
- ◆ Ensure all shelves and storage are at an easily accessible height to avoid the need to climb.
- ◆ Stairs are less of a hazard when fully carpeted (not throw rugs).
- ◆ Install railings on all step-down areas including porch and step-down rooms — when possible hang a plant or other object at eye level to draw attention to the height.
- ◆ [Smart911.com](http://Smart911.com) is a good safety website to sign up for.

## Bathroom:

- ◆ Ensure proper lighting.
- ◆ Only use electric heat items with automatic shut-off (for example, a curling iron).
- ◆ Place large color-coded (red for *hot*, blue for *cold*) stickers to mark *hot* or *cold* faucets.
- ◆ Mark the water knob positions (nail polish works well) for comfortable temperatures.
- ◆ Install grab bars/guard rails throughout the room (toilet, shower, bath) to provide extra stabilization.
- ◆ Provide textured mats or stickers on slippery surfaces.
- ◆ Raised toilet seats may be appropriate to help with sitting and standing.
- ◆ Post a hygiene checklist by the sink and in bathing area with appropriate steps for grooming in each area. This encourages following the same routine daily.
- ◆ Provide unique color and shape bottles to differentiate the content (i.e. shampoo and conditioner should be a different shape and color) or large labels. (See photo above)



## Kitchen:

- ◆ Avoid flat-top stoves, which can be a hazard especially when the adjustment is finger motion rather than knobs.
- ◆ Stove knobs should match the pattern of the heating element and not go straight across. (Knobs placed in a moon shape are often more accurate to the location of the burners.)
- ◆ Be prepared to remove stove knobs if needed for safety.
- ◆ Use appliances with automatic shut-off when possible.
- ◆ Have good lighting for food preparation.
- ◆ Mark refrigerated items with the date they should be disposed of; marking leftovers is especially important.
- ◆ Keep medications and vitamins away from eating and food areas.

**Bedroom:**

- ◆ Keep a strong nightlight on all night.
- ◆ Ensure that the passage to bathroom facilities is well lit.
- ◆ Proper height bed should be verified to ensure easy access, neither too high nor too low to comfortably get in and out.
- ◆ Verify proper size and fit of blankets and sheets — too long can cause legs to get tangled and create a fall hazard.
- ◆ Avoid heated blankets unless they have an automatic shut-off timer and are closely monitored for heat accuracy, electric failure, and cords/wire placement.
- ◆ Eliminate clutter from floors and tabletops.
- ◆ Provide a chair with arms near bed for dressing ease.

## 4.8 Getting Your Financial and Legal Affairs in Order

When people receive a diagnosis of dementia they often are told by their doctor to “get your affairs in order.” The following four pages are the ABCs of what that means, courtesy of the National Institute on Aging, National Institutes of Health.



# AgePage

## Getting Your Affairs in Order

*Ben has been married for 47 years. He always managed the family's money. But since his stroke, Ben is not able to walk or talk. His wife, Shirley, feels overwhelmed. Of course, she's worried about Ben's health. But, on top of that, she has no idea what bills should be paid or when they are due.*

*Across town, 80-year-old Louise lives alone. One night, she fell in the kitchen and broke her hip. She spent a week in the hospital and 2 months in a rehabilitation nursing home. Even though her son lives across the country, he was able to pay her bills and handle her Medicare questions right away. That's because, several years ago, Louise and her son made a plan about what he should do in case Louise had a medical emergency.*

### Plan for the Future

No one ever plans to be sick or disabled. Yet, it's this kind of planning that can make all the difference in an emergency.

Long before she fell, Louise put all her important papers in one place and told her son where to find them. She gave him the

name of her lawyer, as well as a list of people he could contact at her bank, doctor's office, insurance company, and investment firm. She made sure he had copies of her Medicare and other health insurance cards. She added her son's name to her checking account and safe deposit box at the bank. Louise made sure Medicare and her doctor had written permission to talk with her son about her health and insurance claims.

On the other hand, Ben always took care of family money matters, and he never talked about the details with Shirley. No one but Ben knew that his life insurance policy was in a box in the closet or that the car title and deed to the house were filed in his desk drawer. Ben never expected that his wife would have to take over. His lack of planning has made a tough job even tougher for Shirley.

### What Exactly Is an "Important Paper"?

The answer to this question may be different for every family. Remember, this is a starting place. You may have other information to add. For example, if you have a pet, you will want to include the name and address of your veterinarian. Include complete information about:

#### Personal Records

- Full legal name
- Social Security number
- Legal residence

- Date and place of birth
- Names and addresses of spouse and children
- Location of birth and death certificates and certificates of marriage, divorce, citizenship, and adoption
- Employers and dates of employment
- Education and military records
- Names and phone numbers of religious contacts
- Memberships in groups and awards received
- Names and phone numbers of close friends, relatives, doctors, lawyers, and financial advisors
- Medications taken regularly (be sure to update this regularly)
- Location of living will and other legal documents

### Steps for Getting Your Affairs in Order

- **Put your important papers and copies of legal documents in one place.** You can set up a file, put everything in a desk or dresser drawer, or list the information and location of papers in a notebook. If your papers are in a bank safe deposit box, keep copies in a file at home. Check each year to see if there's anything new to add.
- **Tell a trusted family member or friend where you put all your important papers.** You don't need to tell this friend or family member about your personal affairs, but someone should know where you keep your papers in case of an emergency. If you don't have a relative or friend you trust, ask a lawyer to help.
- **Discuss your end-of-life preferences with your doctor.** He or she can explain what health decisions you may have to make in the future and what treatment options are available. Talking with your doctor can help ensure your wishes are honored, and the visit may be covered by insurance.
- **Give permission in advance for your doctor or lawyer to talk with your caregiver as needed.** There may be questions about your care, a bill, or a health insurance claim. Without your consent, your caregiver may not be able to get needed information. You can give your okay in advance to Medicare, a credit card company, your bank, or your doctor. You may need to sign and return a form.



## Financial Records

- Sources of income and assets (pension from your employer, IRAs, 401(k)s, interest, etc.)
- Social Security and Medicare/Medicaid information
- Insurance information (life, health, long-term care, home, car) with policy numbers and agents' names and phone numbers
- Names of your banks and account numbers (checking, savings, credit union)
- Investment income (stocks, bonds, property) and stockbrokers' names and phone numbers
- Copy of most recent income tax return
- Location of most up-to-date will with an original signature
- Liabilities, including property tax—what is owed, to whom, and when payments are due
- Mortgages and debts—how and when they are paid
- Location of original deed of trust for home
- Car title and registration
- Credit and debit card names and numbers
- Location of safe deposit box and key

## Legal Documents

There are many different types of legal documents that can help you plan how your affairs will be handled in the future. Many of these documents have names that sound

alike, so make sure you are getting the documents you want. Also, State laws vary, so find out about the rules, requirements, and forms used in your State.

*Wills* and *trusts* let you name the person you want your money and property to go to after you die.

*Advance directives* let you make arrangements for your care if you become sick. Two common types of advance directives are:

- A *living will* gives you a say in your health care if you become too sick to make your wishes known. In a living will, you can state what kind of care you do or don't want. This can make it easier for family members to make tough healthcare decisions for you.
- A *durable power of attorney for health care* lets you name the person you want to make medical decisions for you if you can't make them yourself. Make sure the person you name is willing to make those decisions for you.

For legal matters, there are ways to give someone you trust the power to act in your place.

- A *general power of attorney* lets you give someone else the authority to act on your behalf, but this power will end if you are unable to make your own decisions.
- A *durable power of attorney* allows you to name someone to act on your behalf for any legal task, but it stays in place if you become unable to make your own decisions.

## Help for Getting Your Papers in Order

You may want to talk with a lawyer about setting up a general power of attorney, durable power of attorney, joint account, trust, or advance directive. Be sure to ask about the lawyer's fees before you make an appointment.

You should be able to find a directory of local lawyers on the internet or at your local library, or you can contact your local bar association for lawyers in your area. Your local bar association can also help you find what free legal aid options your State has to offer. An informed family member may be able to help you manage some of these issues.

## For More Information About Getting Your Affairs in Order

### AARP

1-888-687-2277 (toll-free)  
1-877-434-7598 (TTY/toll-free)  
1-877-342-2277 (español/línea gratis)  
member@aarp.org  
[www.aarp.org](http://www.aarp.org)

### CaringInfo

1-800-658-8898 (toll-free)  
caringinfo@nhpco.org  
[www.caringinfo.org](http://www.caringinfo.org)

### Centers for Medicare & Medicaid Services

1-800-633-4227 (1-800-MEDICARE/toll-free)  
1-877-486-2048 (TTY/toll-free)  
[www.medicare.gov](http://www.medicare.gov)

### Eldercare Locator

1-800-677-1116 (toll-free)  
<https://eldercare.acl.gov>

### National Academy of Elder Law Attorneys

1-703-942-5711  
naela@naela.org  
[www.naela.org](http://www.naela.org)

### National Elder Law Foundation

1-520-881-1076  
info@nelf.org  
[www.nelf.org](http://www.nelf.org)

For more information on health and aging, contact:

### National Institute on Aging Information Center

1-800-222-2225 (toll-free)  
1-800-222-4225 (TTY/toll-free)  
niaic@nia.nih.gov  
[www.nia.nih.gov](http://www.nia.nih.gov)

Visit [www.nia.nih.gov/health](http://www.nia.nih.gov/health) to find more health and aging information from NIA and subscribe to email alerts. Visit <https://order.nia.nih.gov> to order free print publications.



National Institute  
on Aging

NIH...Turning Discovery Into Health®

June 2018

## Ways to Simplify Your Finances

### CREDIT CARDS

If you have a number of credit cards, you may want to close all cards except two. One primary credit card is easier to keep track of than multiple credit cards. Keep the other credit card in a safe place, in case your primary card is lost and you need to charge something. Consider lowering the credit amount on the card as a measure of protection. You also may want to have a trusted family member or friend as the credit card company contact in case they need to get in touch with you.

### AUTOMATIC PAYMENTS

It can be beneficial to set up automatic payments through your bank for important bills, such as mortgage payments, insurance, utilities, and credit cards to ensure the bills are paid timely.

### ACCOUNT ALERTS

Check with your bank to see if they can set up an alert notice to let you know when a bank balance drops below a predetermined amount. The alert can be a good heads up that a deposit has not been made, if there is an overpayment, or some other irregularity.

## How to Choose a Financial Adviser

When selecting a financial adviser, consider:

- ◆ Professional credentials
- ◆ Work experience
- ◆ Educational background
- ◆ Membership in professional associations
- ◆ Areas of specialty

Make sure to ask the financial adviser if he or she is familiar with elder care or long-term care planning.

Qualities of a good financial adviser:

- ◆ **They ask the right questions** — A good advisor knows how and when to ask the important questions that encourage clients to open up so that they can gather all the information they need to create a financial plan.
- ◆ **They pay attention to and act on the information you provide** — A financial advisor should always listen to what clients have to say, prioritize their objectives, respect the chosen level of risk they are comfortable with, and tailor recommendations to suit these factors.
- ◆ **They treat clients with courtesy and respect** — If you feel as though you or your loved one are not being heard, understood, or treated with respect, seek financial advice elsewhere.
- ◆ **They explain things until you understand** — A good financial advisor will take as much time as necessary to explain a proposed plan or transaction and make sure their clients understand exactly what is going to happen and what risks and benefits are involved.

*I was a ways down this path,  
and I knew things were happening.  
I took special care to get my affairs in order —  
my advance directives, my house payments,  
all the financial stuff I got in order.  
I'm maintaining communication  
with my friends and my daughter.  
I have a good plan in place.*

**David Baldrige, Manual Guide**





## Top 10 Financial Scams Targeting Seniors

Financial scams targeting seniors are prevalent and costly. The FBI estimates that seniors lose more than \$3 billion each year to fraudsters. Scammers go after seniors because they believe older adults have a significant amount of money sitting in their accounts.

It's not just wealthy seniors who are targeted. Low-income older adults are also at risk of financial abuse. Unfortunately, it's not always strangers who perpetrate these crimes. Over 90 percent of all reported elder abuse is committed by an older person's own family members, most often their adult children, followed by grandchildren, nieces and nephews, and others.

Financial scams often go unreported or can be difficult to prosecute as they are considered a "low-risk" crime. However, they're devastating to many older adults and can leave them in a very vulnerable position with little time to recoup their losses.

Learn how to identify and stop the most prominent scams so you can protect yourself and your loved ones from financial fraud.

### 1. Government impostor scams

Government impostors call unsuspecting victims and pretend to be from the Internal Revenue Service (IRS), Social Security Administration, or Medicare. They may say you have unpaid taxes and threaten arrest or deportation if you don't pay up immediately. Or they may say your Social Security or Medicare benefits are in danger of being cut off if you don't provide personal identifying information (that can then be used to commit fraud). Government impersonators often "spoof" the actual phone numbers of the government agency or call from the same area code (202 for Washington, DC).

### 2. The grandparent scam

The grandparent scam is so simple and so devious because it uses one of older adults' most reliable assets, their hearts. Scammers will place a call to an older person and say something along the lines of: "Hi Grandma, do you know who this is?" When the unsuspecting grandparent guesses the name of the grandchild the scammer most sounds like, the scammer has established a fake identity without having done any background research. Once "in," the fake grandchild will ask for money to solve some unexpected financial problem

(overdue rent, car repairs, jail bond) and will beg the grandparent not to tell anyone. Because scammers ask to be paid via gift cards or money transfer, which don't always require identification to collect, the senior may have no way of seeing that money ever again.

### **3. Medicare/health insurance scams**

Every U.S. citizen or permanent resident over age 65 qualifies for Medicare, so there is rarely any need for a scam artist to research what private health insurance company older people have in order to scam them out of some money. In these types of scams, perpetrators may pose as a Medicare representative to get older people to give them their personal information, or they will provide bogus services for elderly people at makeshift mobile clinics, then bill Medicare and pocket the money. Medicare scams often follow the latest trends in medical research, such as genetic testing fraud and COVID-19 vaccines.

### **4. Computer tech support scams**

Computer technical support scams prey on people's lack of knowledge about computers and cybersecurity. A pop-up message or blank screen usually appears on a computer or phone, telling you that your device is compromised and needs fixing. When you call the support number for help, the scammer may either request remote access to your computer and/or that you pay a fee to have it repaired. The Federal Trade Commission (FTC) found that seniors who fell for this scam lost an average of \$500 each to computer tech support scams in 2018.

### **5. Sweepstakes and lottery scams**

This simple scam is one that many are familiar with, and it capitalizes on the notion that "there's no such thing as a free lunch." Here, scammers inform their mark that they have won a lottery or sweepstakes of some kind and need to make some sort of payment to unlock the supposed prize. Often, seniors will be sent a check that they can deposit in their bank account, knowing that while it shows up in their account immediately, it will take a few days before the (fake) check is rejected. During that time, the criminals will quickly collect money for supposed fees or taxes on the prize, which they pocket while the victim has the "prize money" removed from his or her account as soon as the check bounces. Unlike some of the other scams noted here, lottery and sweepstakes scammers can sometimes collect thousands of dollars from their unsuspecting victims.



## **6. Robocalls/phone scams**

Robocalls take advantage of sophisticated phone technology to dial large numbers of households from anywhere in the world. Robocallers use a variety of tactics to cheat their victims. Some may claim that a warranty is expiring on their car/electronic product and payment is needed to renew it. One popular robocall is the “Can you hear me?” call, where when the senior says yes, the scammer hangs up after recording their voice, thus obtaining a voice signature to authorize unwanted charges on items like stolen credit cards.

## **7. Romance scams**

As more people use the Internet for dating, con artists see an opportunity to find their next victim. Romance scammers create elaborate fake profiles, often on social media, and exploit seniors’ loneliness. In some cases, romance scammers may (or pretend to) be overseas, and request money to pay for visas, medical emergencies, and travel expenses to come visit the U.S. Because they drag on for a long time, romance scammers can get a lot of money from a senior—the FTC found that in 2019 alone, seniors lost nearly \$84 million to romance scams.

## **8. Internet and email fraud**

While using the Internet is a great skill at any age, the slower speed of adoption among some older people makes them easier targets for automated Internet scams that are ubiquitous on the web and email programs. Pop-up browser windows simulating virus-scanning software will fool victims into either downloading a fake anti-virus program (at a substantial cost) or an actual virus that will open up whatever information is on the user’s computer to scammers. Their unfamiliarity with the less visible aspects of browsing the web (firewalls and built-in virus protection, for example) make seniors especially susceptible to such traps.

Phishing emails and text messages may look like they’re from a company you know or trust. They may look like they’re from a bank, a credit card company, or an online store. Phishing emails request your personal information, such as a log-in or Social Security number to verify your account, or ask that you update your credit card payment. Then they use that information to steal your personal and financial information.

## 9. Elder financial abuse

Unlike many of the other scams, elder financial abuse is carried out by someone a senior knows. This can be a family member, friend, power of attorney, or caregiver. These trusted individuals try and gain control of a senior's money, assets, and credit. They also may withhold needed care in order to retain control over the person and their assets. Seniors who are living with a disability or dementia are a higher risk.

## 10. Charity scams

Charity scams rely on seniors' goodwill to pocket money they claim they're raising for a good cause. Some scammers may use a name similar to a legitimate charity. They often capitalize on current events, such as natural disasters, and may set up a fundraising page on a crowdsourcing site, which don't always have the means to investigate fraud. Charity scammers may insist you donate immediately, sometimes with a payment method that should be a red flag—e.g., gift cards or money transfer.

## If you suspect you've been the victim of a scam ...

Don't be afraid or embarrassed to talk about it with someone you trust. You are not alone, and there are people who can help. Doing nothing could only make it worse. Keep handy the phone numbers and resources you can turn to, including the local police, your bank (if money has been taken from your accounts), and Adult Protective Services. To obtain the contact information for Adult Protective Services in your area, call the Eldercare Locator, a government sponsored national resource line, at: 1-800-677-1116, or visit their website at: [eldercare.acl.gov](https://eldercare.acl.gov)

You can also report scams online to the Federal Trade Commission.

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SOURCE: National Council on Aging, "Top 10 Financial Scams Targeting Seniors," February 2021, [ncoa.org](https://www.ncoa.org), reprinted with permission.

## ***Beware of Financial Scams: One Family's Story***

Janet first realized her husband James (not their real names) was having some cognitive problems when he fell for a complex financial scam over the phone. It began with a "computer technician," who identified himself as being with Microsoft, saying he had to conduct an online inspection of James's computer. That led to more calls from men convincing James that they needed his help to apprehend two high-placed security executives, one with Capitol One (his bank) and one with Microsoft. They told him if he told anyone, it would ruin their chances of catching the bad guy.

As luck would have it, Janet was out of town then, as was the regular bank manager who knew James. When he went to his branch bank to set up a wire transfer of \$50,000 to a bank in Kathmandu, Nepal, no one questioned it. He had been instructed to say he was taking his family on vacation there.

When Janet returned home she was immediately suspicious, and got on the other line when the thieves call again. It was clear to her that something was amiss when "Daniel Smith" and "John Morgan" spoke in heavily accented English with many grammatical mistakes.

By then it was too late. The bank opened an investigation, but the \$50,000 was gone forever. "The scammers made James feel as if he was helping the 'good guys' apprehend a 'bad guy,' and he wanted to be a good citizen," Janet says. She adds that he would have never fallen for it in the past, as he was a savvy communications specialist with his own consulting firm. That was when she first became aware of his cognitive problems.

## Insurance (Health, Disability, Life, Long-Term Care, Veteran's)

For many of us, understanding insurance is confusing in the best of times. There are four major areas of insurance to know about — health insurance, life insurance, long-term care insurance, and homeowner or renter insurance. They all can have an impact on your finances. Let's start with health insurance.

### Health insurance

The U.S. has a complicated healthcare system that is a mix of private and public insurance. If you are under 65, medical insurance premiums are generally paid for by you or your employer, or both. There are several types of medical insurance, including "fee-for-service," in which each doctor's visit or test is paid for directly, or "managed care," which has a flat-rate monthly premium that covers most of your medical care. The Affordable Care Act ("Obamacare") offers subsidies for health insurance, for those who are eligible based on their income. Millions of Americans, though, still do not have insurance. And according to a 2022 study by Kaiser Health News and NPR, 100 million people in the U.S. are saddled with medical debt, including many who have insurance.

### Medicare

Those who are living with a disability, are 65 or older, or are on kidney dialysis are eligible for the federally-funded Medicare system. Part A covers hospital care, Part B is medical insurance, and Part D is drug coverage. There are also Medicare Advantage Plans which are a type of managed care. (To learn more, visit [medicare.gov](https://www.medicare.gov))

#### Medicare Supplement Insurance (Medigap)

Generally speaking, Medicare pays for approximately 80 percent of your medical bills. To cover the remaining 20 percent, many people who have Medicare pay for a private supplemental insurance policy. There is a range of policies and prices. It is best to sign up for Medigap within the first six months after turning 65. After that, you can be refused insurance for preexisting conditions or expect to spend more on premiums. (For more information, see [medicare.gov](https://www.medicare.gov))

#### Medicare Part D (drug coverage)

Neither Medicare nor Medigap pay for prescription drugs. For that, you need to sign up for Medicare Part D. It is best to sign up for this insurance when you first sign up for Medicare, or you will pay a penalty. Costs of Part D depend on which drugs you take, and can change from year to year. (To learn more, visit [medicare.gov](https://www.medicare.gov))

Does Medicare cover long-term care costs?

No, Medicare only pays for short stays in skilled nursing facilities or home healthcare if three conditions are met:

- ◆ You were admitted to the hospital for 3 days or more (see box).
- ◆ Within 30 days of that hospital stay, you were admitted to a Medicare-certified skilled nursing facility.
- ◆ You require skilled nursing, physical therapy, or other therapy services as prescribed by your doctor.

If all those conditions are met, Medicare and Medicare Advantage will pay some of the costs up to 100 days in a skilled nursing facility. After 100 days, you're responsible for 100 percent of those costs. For more details, visit [medicare.gov](https://www.medicare.gov) and look for Medicare Coverage of Skilled Nursing Facility Care.

### ***The Three-Day Prior Hospitalization Rule***

For your stay in a skilled nursing facility (nursing home) to be covered by Medicare for up to 100 days, you first must have been hospitalized for three consecutive days. Hospitals count your admission day but not discharge day. They do not count time spent in the emergency room or time you're being observed before being admitted. Keep this in mind if the hospital wants to discharge you in less than three days to either rehab or a nursing home. (To learn your rights, visit the Center for Medicare Advocacy at [medicareadvocacy.org](https://www.medicareadvocacy.org))

### **Medicaid**

Medicaid is a program jointly funded by federal and state governments. It is administered by each state. Medicaid pays for medical care for people with very low income and asset levels, and long-term care for people who meet low income/asset criteria. Medicaid also is available to people younger than 65 if they meet disability qualifications. (To learn more and to find out how to contact your state Medicaid office, visit [medicaid.gov](https://www.medicicaid.gov))

## Social Security Disability Insurance (SSDI) and Dementia

This federal government program provides workers younger than age 65 Social Security disability payments. The government deems dementia a disability, as far as eligibility for Social Security Disability Insurance (SSDI). This is a monthly income benefit given to qualified people who have paid into the system but who are not yet old enough to receive Social Security retirement benefits. People diagnosed with younger-onset dementia are included in the Compassionate Allowances Initiatives, intended to streamline the process for receiving SSDI benefits.

Included in this listing are those living with:

- ◆ Early-onset Alzheimer’s disease
- ◆ Adult-onset Huntington disease
- ◆ Creutzfeldt-Jakob disease (CJD)
- ◆ Frontotemporal dementia (FTD), Pick’s disease — Type A
- ◆ Lewy body dementia
- ◆ Mixed dementia
- ◆ Primary Progressive Aphasia (PPA)
- ◆ Progressive Supranuclear Palsy (PSP)
- ◆ The ALS Parkinsonism Dementia Complex

(For more information and to apply for this benefit, visit [www.ssa.gov/compassionateallowances/](http://www.ssa.gov/compassionateallowances/))

## **One Family's Story**

Manual Guide Kim Reid was among those who was able to receive SSDI without too much hassle. Her husband Robert shares their experience in an email:

"Honestly our experience was not as bad as most I have heard. Fortunately I had documented Kim's journey through the healthcare system very well, which made the application process easier.



My notes and copies of our after-visit summaries and diagnosis allowed me to provide more than enough detailed information for the several page application and supplemental documentation. The SSI web page and some Google research also helped.

Upon submission of the application for a lengthy review, we were only once asked to provide additional duplicate information and were Blessed with a first try approval. It was all done via mail with no in-person meeting for review and/or approval."

You may not have as smooth a time as the Reids. The coronavirus pandemic led to delays in many government services. Local offices are again open and hopefully delays will ease over time.

## **Supplemental Security Income (SSI)**

This federal government program provides a minimum monthly income for people who are age 65 or older, are disabled or blind, and have very limited income and assets. To qualify for SSI benefits, the person with dementia must meet the Social Security Administration's definition of disability. Some low-income people qualify for both Social Security Disability Insurance and Supplemental Security Income. (For more information, visit [ssa.gov](https://www.ssa.gov))

## **Life insurance**

Life insurance can be a source of cash. You or your care partner should review your policy and check with your insurance agent or insurer. Among other questions, see if you can waive your premium payments because of your disability.

## Long-Term Care Insurance

Long-term care insurance is designed to help pay for home care, assisted living, or nursing home care as someone's symptoms advance and they can no longer live independently without help. Some people have good long-term care policies through their employer's insurance plan. Others have individual or family plans that they have paid premiums on for many years. Only a relatively small number of people have long-term care insurance. In 2018, just 276,000 people in the U.S. received benefits from long-term care insurance and less than six percent of those 50 and older had a long-term care insurance policy.

Many private insurers have gotten out of the long-term care insurance market over recent years, and those who have remained frequently impose large boosts in premiums.

If you do have long-term care insurance, find out how much coverage you have, over how long a period. Does it pay for home care or only residential care? What portion of costs will they cover? This is important to know as you and your care partners plan for the future.

If you do not already have long-term care insurance, you will probably not be able to get it, once you have symptoms of dementia. If you do need to move to assisted living, a memory care community, or a nursing home, you will either need to pay out-of-pocket or, if you meet low-income requirements in your state, you may be eligible for Medicaid for nursing homes, and depending on the state, other kinds of long-term care.

## Veterans Benefits

Veterans living with dementia may be eligible for certain benefits and services from the U.S. Department of Veterans Affairs (VA). Some current and surviving spouses of veterans may qualify for limited benefits as well. The VA administers many different programs for veterans and their families, including healthcare coverage, pensions, caregiver support services, and burial benefits.

While eligibility requirements for each of these programs vary, understanding what resources are available through the VA is the first step toward better supporting a veteran with dementia (or a spouse) and planning for their future care needs.

The VA covers some memory care costs for qualifying military veterans. The following VA programs are the most likely to provide aid for memory care services:

- ◆ Home-based Primary Care offers home healthcare to veterans with complex medical needs that can't be handled in the clinic setting.
- ◆ Homemaker or Home Health Aide offers assistance at home to veterans who need help with activities of daily living, like bathing, toileting, and dressing.



- ◆ Respite Care provides relief for family members who are providing in-home care by sending temporary help when they need time away.
- ◆ Adult Day Health Care offers a place for people living with dementia to go during the day for life enrichment and social engagement.
- ◆ Spouses of military veterans living with dementia may also receive support through the VA Caregiver Support Program. (For more information, visit [www.caregiver.va.gov](http://www.caregiver.va.gov))

Through its extensive healthcare system, the VA can also help cover doctor's appointments, dental care, and vision care. Most people who served in active military service and did not receive a dishonorable discharge will qualify for VA benefits and should check with the VA as soon as possible. Some benefits may also be available for those who served in the Reserves. {For information on a range of benefits you may be eligible for, visit [va.gov](http://va.gov)}

### **Healthcare (Advance) Directive**

A healthcare directive lets you specify what kind of medical treatments you want or do not want at the end-of-life if you can't speak for yourself. It is sometimes called a Living Will or Advance Directive. It also gives you the opportunity to express additional instructions about your values, hopes, and concerns for all healthcare decisions, not just care at the end-of-life. You can change or cancel your directive at any time.

This is quite helpful for a patient with a progressive disease, like dementia, who may eventually need life-sustaining treatment. Because medical science has become so advanced, allowing life to be sustained long past the point that once would have been possible, individuals need to state before a serious medical event occurs how much intervention they wish to have. A living will or advance directive shows how much intervention the individual wants, so families are not left to make painful decisions when someone is seriously ill. With this document, the individual can make specific requests for what should and should not be done, rather than relying on family members to remember their wishes in an emotionally charged situation.

The requirements for creating an advance directive vary from state to state. Checking with an attorney is the best way to ensure that yours is in line with the laws of your state. But your advance directive will likely still be honored either in your state or another, as long as you have it written down. (For more information, see [American Bar Association](#) article in this section's Resources, page 272.) You can find these forms online as well. An advance directive can also help limit any disagreements between family members about what they think you would want.

## Dementia Health Care Directive

Many people have clear ideas about the medical care they would want if they were to develop dementia. But standard advance directives (living wills) do not cover dementia. Dementia is the most common reason people lose the ability to guide their own care, so expressing and documenting these wishes while you can is important. A Dementia Directive is a simple way to communicate your wishes if you are later incapacitated. Families often face difficult medical decisions if their loved one is living with dementia. Having a Dementia Directive or similar document to refer to can help them feel clearer that the decisions they make reflect what their loved one would have wanted. One common issue that arises is artificial feeding and whether you would want tube feeding if you can no longer feed yourself and appear uninterested in eating. (For more on [tube feeding](#), see *Functional Health*, Section 3.4, page 216.)

The Dementia Directive is a simple tool developed by a physician to help you plan for your end-of-life care, depending on whether you are experiencing mild, moderate, or advanced symptoms of dementia. (For more information, visit [dementia-directive.org](http://dementia-directive.org))

A Dementia Provision, created by the nonprofit Compassion and Choices, is another tool that can be used as an addendum to your Advance Directive. (For more information, visit [compassionandchoices.org/](http://compassionandchoices.org/))

Another document is called a Do Not Resuscitate order (DNR) or POLST (Physician's Orders for Life-Sustaining Treatment). If your heart stops beating or you stop breathing, you may not want intervention but instead would prefer a natural death. Without one of these orders, healthcare providers, including emergency rescue squads, will likely try to resuscitate you. Talk to your physician if you wish to have a DNR/POLST.

It is important that you give copies of your Health Care Directive and DNR/POLST to your care partners, your healthcare power of attorney, your physicians, and your attorney. Keep a card in your wallet that has the contact of whomever has your healthcare power of attorney. If you go to a hospital or long-term care facility, the directive should accompany you and be attached to your chart.



## ***How to Get Help When You Can't Afford It***

### ***Pat McHenry Sullivan, Contributor***

*Many free offerings will help reduce expenses*

My husband and I are among the vast majority of people who make too much for government health, housing, and other benefits, and way too little to afford market-rate dementia care or even personal care such as regular cleaning help. Some ways we thrive anyhow are:

- ◆ Networking, which led us to all the free programs we mentioned in our essay [\*Transforming the Narrative From Tragedy to Thriving\*](#) (see Section 7.2, page 341), including Moving Together, the GoldMind weekly arts lessons that come in the mail, and the free, thorough diagnosis and follow-up from University of California, Davis.
- ◆ Daring to ask for scholarships (for my husband John's improv training) and for medical financial assistance. Many, especially those from Kaiser Permanente, are very generous. Ours has eliminated most co-pays, starting when I got breast cancer, and he was diagnosed with mild cognitive impairment (MCI).
- ◆ Using the sharing economy through local and national list-servs to give and receive walkers and other medical equipment, exchange produce, give and receive household goods in top quality.
- ◆ Checking the many nearby senior centers where we can see free movies, attend free programs, go to the thrift shop, and connect with great resources.
- ◆ Living ecologically in a way that cuts expenses while helping to save the environment.
- ◆ Making the most of fix-it fairs (when COVID isn't preventing that).
- ◆ Making big pots of soup and other meals, then freezing portions for later use.
- ◆ Hanging out with other creative, ecology, and sharing-minded people who love helping each other and the earth thrive.

- ◆ Making the most of a superb city bus system and cheap taxi service for seniors. Several of the taxi drivers are so dependable they can take John to monthly medical services where my input isn't needed and return him safely. Meanwhile, I can get other important work done.
- ◆ Haunting Amazon and yard sales to create a library of DVDs John loves and can play on a portable player both to entertain and engage him and to increase my ability to work on non-care-partner tasks.

Another creative initiative is Co-op Day Care, an ancient and innovative concept that helps save money while increasing engagement. Inspired by parent-run cooperative schooling or after-school programs, the Institute on Aging in San Francisco opened a co-op day care program for people living with dementia, giving their care partners respite and connection to others in their situation. There's no charge, because care partners take turns helping to run the program. The program at the Presidio in San Francisco has been thriving for over a year. A new one is opening soon in West Oakland through the Institute on Aging.

House sharing is another option to consider. My husband and I are moving from California to Virginia, to share a home with my sister. She'll get my help to finish and publish a book — something I've done successfully for about a dozen people! She will provide backup and respite care for me. Sharing shopping and other chores will save us much time and energy. Thankfully, both of us are clear about what we want and need and are expert at setting boundaries. We are blessed with a creative, ethical approach to life that we got from our parents, then nurtured by ourselves and with the support of many others.

## SUGGESTED RESOURCES

### Articles

Sabatino, C. (2016). Can my advance directives travel across state lines? An essay on portability. *Bifocal* (38)1. American Bar Association, americanbar.org.

### Books

Devi, G. (2017). *The Spectrum of Hope: An Optimistic and New Approach to Alzheimer's Disease and Other Dementias*. Workman Publishing Company.

Karlawish, J. (2021). *The Problem of Alzheimer's: How Science, Culture, and Politics Turned a Rare Disease into a Crisis and What We Can Do About It*. St. Martin's Press.

Power, G.A. (2014). *Dementia Beyond Disease: Enhancing Well-Being*, Health Professions Press.

Prosch, T. (2013). *AARP The Other Talk: A Guide to Talking with Your Adult Children about the Rest of Your Life*, McGraw Hill.

Taylor, R. (2007). *Alzheimer's from the Inside Out*, Health Professions Press.

### Websites

Dementia Provision, created by the nonprofit Compassion and Choices, is another tool that can be used as an addendum to your Advance Directive

[compassionandchoices.org/](http://compassionandchoices.org/)

Americans with Disabilities Act, U.S. Department of Labor

[www.dol.gov/general/topic/disability/ada](http://www.dol.gov/general/topic/disability/ada)

Aging Life Care Association (also called geriatric care managers) is made up of professionals who practice a holistic, client-centered approach to caring for older adults or others facing ongoing health challenges

[www.aginglifecare.org](http://www.aginglifecare.org)

"At the Crossroads: Family Conversations About Alzheimer's Disease, Dementia & Driving," The Hartford Center for Mature Market Excellence

[s0.hfdstatic.com/sites/the\\_hartford/files/cmme-crossroads.pdf](http://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf)

"Compassionate Allowances", U.S. Social Security Administration	<a href="http://www.ssa.gov/compassionateallowances/">www.ssa.gov/compassionateallowances/</a>
"Disability Benefits," U.S. Social Security Administration	<a href="http://www.ssa.gov/benefits/disability/qualify.html">www.ssa.gov/benefits/disability/qualify.html</a>
Elder Locator a public service of the U.S. Administration on Aging connecting you to services for older adults and their families	<a href="http://eldercare.acl.gov/Public/Index.aspx">eldercare.acl.gov/Public/Index.aspx</a>
"Employment and Dementia," Dementia Australia	<a href="http://www.dementia.org.au/about-dementia/i-have-dementia/employment-and-dementia">www.dementia.org.au/about-dementia/i-have-dementia/employment-and-dementia</a>
Geriatrics and Extended Care, Department of Veterans Affairs (VA) — Veterans with dementia may be eligible for certain benefits and services	<a href="http://www.va.gov/GERIATRICAL/pages/Alzheimers_and_Dementia_Care.asp">www.va.gov/GERIATRICAL/pages/Alzheimers_and_Dementia_Care.asp</a>
Home Modification Information Network," University of Southern California Leonard Davis School of Gerontology	<a href="http://homemods.org/acl/hmin/">homemods.org/acl/hmin/</a>
Home Transitions Solution Group provides home assessment, remote home care, and medical data integration and other services	<a href="http://www.hometransitionsolutions.org/">www.hometransitionsolutions.org/</a>
Job Accommodation Network (JAN) is a source of free, expert, and confidential guidance on job accommodations and disability employment issues	<a href="http://askjan.org/">askjan.org/</a>
National Council on Aging, "Top 10 Financial Scams Targeting Seniors"	<a href="http://www.ncoa.org/article/top-10-financial-scams-targeting-seniors">www.ncoa.org/article/top-10-financial-scams-targeting-seniors</a>
Smart911.com is a national service meaning your Smart911 Safety Profile travels with you and is visible to any participating 9-1-1 center nationwide	<a href="http://www.smart911.com/">www.smart911.com/</a>
The American Automobile Association (AAA) — To learn more about clinical driving assessments, which can be conducted by occupational therapists or driving skills evaluators who are licensed and certified by states	<a href="http://exchange.aaa.com/safety/senior-driver-safety-mobility/evaluate-your-driving-ability/">exchange.aaa.com/safety/senior-driver-safety-mobility/evaluate-your-driving-ability/</a>

The Conversation Project, a public engagement initiative with a goal to have every person's wishes for end-of-life care expressed and respected

[theconversationproject.org/](http://theconversationproject.org/)

The Dementia Directive is a simple tool developed by a physician to help you plan for your end-of-life care, depending on whether you are experiencing mild, moderate or advanced symptoms of dementia

[dementia-directive.org](http://dementia-directive.org)

## SECTION 5: Medical Affairs

Once you have a diagnosis of dementia, what comes next? This section shares information that has been helpful to others as they navigate the complex healthcare system and consider their individual needs. This manual does not provide medical advice. For that, you should always speak with your physician and other healthcare team members. (For information on diagnosis and types of dementia, see [Identifying Cognitive Impairment/Dementia](#), Section 1.1, page 43, and [Learning About MCI and Dementia](#), Section 8, page 379.)

### 5.1 Health Goals

If you are on Medicare, your physician may ask during your annual wellness visit what your health goals are. You may not have given this much thought before. Or you may have thought about it like making a New Year's resolution: "Lose a few pounds." "Exercise more."

When diagnosed with a chronic health condition, such as dementia, it's a good time to determine what your health goals are. Think about your health goals broadly, not just medically. In "Discussing Goals of Care," in the online journal *UpToDate*, the authors suggest considering goals like "self-sufficiency, life enjoyment, connectedness and legacy, balancing quality and length of life, and a desire to be engaged in care decisions."

Some examples of goals:

- ◆ Have a healthcare team you trust.
- ◆ Limit exposure to things that cause you stress.
- ◆ Walk at least 30 minutes daily.
- ◆ Connect with people who matter to you.
- ◆ Do something that makes another person smile.



- ◆ Volunteer at something you find meaningful and interesting.
- ◆ Spend time in nature at least once a week.
- ◆ Take naps.
- ◆ Learn meditation and deep breathing exercises for relaxation.
- ◆ Have an evening routine to wind down.
- ◆ Be free from pain as much as possible.
- ◆ Make sure you are at the lowest effective dose of any medication.

Once you have decided on your goals, convey them clearly to your family, friends, and to your healthcare team so they will be better able to support you. Recognize that your goals will evolve with time.

Some people may be more comfortable conveying their goals verbally, others in writing. Barney Nelson, a Manual Contributor, for example, is conveying his goals in a video recording.

Allen Power, MD, adds that medical tests are not the only meaningful measure of health. “Those yardsticks are not the only yardsticks,” he says. “There are so many things the tests don’t measure. There’s no mental status test that asks can you play a song on the piano — and there are people with very advanced dementia who can play beautifully. We have to ask what makes life worthwhile for each person?”

For example, Terrie Montgomery wants to walk regularly and listen to the birds. Dave Baldridge wants to keep caring for his beloved dogs in his own home. Jim Mann wants to ride the city bus and go downtown by himself. These goals are not medical, but they are related to health. “That’s what keeps you going,” says Jim. “That’s what helps in your brain health.”

*I have returned to school to get  
a second bachelor’s in religious studies.  
I take one class as I feel able.*

**John-Richard Pagan, Manual Guide**



Being as self-sufficient as possible is a goal many people have. “We want people to try to take charge and step up and self-advocate and do what they can,” says Dr. Power. “Taking charge of your overall health is one way you can do that. By saying, ‘I do believe if I exercise, engage, keep going out and socializing, this can help me do better.’” That said, he added, sometimes a disease progresses more rapidly despite your best efforts. “If that happens, it doesn’t mean you failed.”

Health goals also encompass end-of-life decisions. Be intentional about your desires, write them down, and convey them to others.

## 5.2 Who Should Be on your Healthcare Team?

As described elsewhere in this manual, many different professions and practices can help you maintain your health and well-being. Most of these should be covered by insurance, but some may not be. If they are not covered, you may need to pay out of pocket or identify local resources that support your choices. For example, many Area Agencies on Aging offer brain health and exercise classes. You can find your Area Agency on Aging, online at the Eldercare Locator: [eldercare.acl.gov/Public/Index.aspx](http://eldercare.acl.gov/Public/Index.aspx). Be sure to check if you will need to pay out of pocket before making an appointment.

Your healthcare team members can include:

- ◆ **Primary care physician**, whose office may include a nurse practitioner or physician’s assistant who will sometimes see you. It is important to know that not all physicians have expertise in assessing, diagnosing, and supporting people living with dementia. Ideally your physician will be a geriatrician or have experience with older patients and be aware of special concerns like polypharmacy (too many medications). It is OK to ask if anyone in the practice has expertise with dementia.
- ◆ **Dementia specialist**, such as a neurologist, neuropsychiatrist, geriatrics psychiatrist, or neuropsychologist, who will be up to date on research and who ideally has a holistic view of treating dementia.
- ◆ **Other medical specialists**, such as a cardiologist or rheumatologist, depending on your medical diagnoses. Be sure that any medications or treatments from specialists are coordinated and approved by your primary care physician.
- ◆ **Pharmacist**, as another set of eyes on how multiple drugs might interact, and who should be familiar with medications’ side effects such as dizziness, confusion, or insomnia.

- ◆ **Dentist**, to help prevent gum disease and tooth decay which are much higher in older people than the general population. Some medications may give people dry mouth which can increase the risk of cavities.
- ◆ **Physical, occupational, and speech therapists**, who can each play an important role in promoting your functional health. (For more information, see [Functional Health](#), Section 3.4, page 210.)
- ◆ **Cognitive therapist**, who has expertise in cognitive skills training and other strategies for people living with cognitive impairment or dementia. Some people find cognitive therapy helpful.
- ◆ **Mental health practitioners**, such as a psychologist, licensed clinical social worker, marriage or family counselor, or pastoral counselor, for depression and anxiety, and to help you process grief or other complicated feelings about your disease.
- ◆ **Creative arts therapists**, including visual arts, drama, poetry and creative writing, music, and dance, who combine creative expression and counseling.
- ◆ **Creative artists**, who are not trained in counseling but who can guide and open up your creativity to promote personhood, communication, and well-being.
- ◆ **Complementary therapy practitioners**, whose training might include reiki, massage, compassionate touch, or aromatherapy, may be able to help address stress and pain and promote well-being. (For more information on complementary therapies and practices, see [Mind-Body Practices](#), Section 3.6, page 220.)

## 5.3 Making the Most of a Doctor Visit

Going to the doctor can be stressful for anyone, but may be more so for people living with dementia. Sitting in a crowded, often noisy waiting room; having blood drawn; and wondering about test results can produce anxiety. Doctors and care partners who feel rushed or are impatient may add to this anxiety. Preparing for a doctor's visit can help things go more smoothly.

Here are some suggestions:

- ◆ Bring someone with you. It is helpful to have another person listening to the same information and taking notes. This lets you focus on the doctor and what they are saying or asking.

- ◆ Keep a notebook handy at home. Jot down questions or concerns you want to ask your doctor during a future visit. Be sure to include any new symptoms or changes in existing symptoms.
- ◆ Before leaving for the doctor’s visit, review the notebook. Is there anything you want to add? Prioritize the items you want to address during the visit. Bring the list with you!
- ◆ Keep an up-to-date list of your medications. Include over-the-counter drugs, herbal supplements, and vitamins. Keep the list in your wallet or other convenient place where you know you will remember to bring it with you. Include the names and phone numbers of specialists you’ve seen since your last visit.
- ◆ If the office requires any paperwork, such as an updated medical history, try to get it completed ahead of time. Ask the office to mail it (or email it) to you. If you are comfortable using a computer, ask if you can fill out the information online. Be sure to let the office know of any change in your contact information or insurance.

*You have to be your own advocate.  
You have to speak up. You have to say  
‘Look, I’m a person. I feel like you became  
a doctor, you took an oath, so help me.’  
If we feel we’re not being treated fairly,  
we need to speak up.*

**Terrie Montgomery, Manual Guide**



- ◆ If possible, schedule the appointment during your best time of day. Ask if there is an option for a telehealth visit instead of an in-person visit. Being in the comfort of your own home can be easier for you.
- ◆ Allow plenty of time to get there and to park, so you won’t be rattled before you walk in.

- ◆ Bring a quiet activity along to pass the time while you're waiting: the newspaper, a crossword puzzle or sudoku, a book, or writing pad. If you have earbuds and a mobile device, you can listen to music you like and you know uplifts you.
- ◆ Ask the doctor to repeat or explain anything you do not understand.
- ◆ End the visit with a shared understanding of your goals of care and the next steps. This may include a new prescription, another appointment, a visit to a specialist, or practicing the strategies in your plan, such as good nutrition, deep breathing, and being outside.

## 5.4 Medications and Medications to Avoid

### Managing Dementia Symptoms: Medications

Medications are typically prescribed to treat the symptoms or the cause of an illness. The decision to prescribe a medication is based on an assessment of the likely benefits (efficacy) and the likely side effects or adverse reactions (risk). This is referred to as the risk/benefit ratio. More simply, the questions to ask about taking any medication are — Is it more likely to help than to harm me? Are the side effects worth it?

Medications prescribed for people living with dementia target symptoms rather than causes. So far, scientists have not found a drug or drugs that will prevent, reverse, modify, or cure dementia. Dementia is a complex syndrome with many causes (see [About MCI and Dementia](#), Section 8, page 379), and it is unlikely there will be a single approach.

Medications that address the cognitive symptoms of dementia “are palliative in nature,” explains Tia Powell, MD, “They can give some people some relief for some period of time but they are generally pretty modest. They are not disease-modifying therapies.”

The following are the medications approved by the U.S. Food and Drug Administration for dementia:

#### **CHOLINESTERASE INHIBITORS**

Donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne) work by boosting levels of a chemical involved in memory and judgment. Although primarily used to treat Alzheimer’s disease, cholinesterase inhibitors might also be prescribed for other dementias, including vascular dementia, Parkinson’s disease

dementia, and Lewy body dementia. Cholinesterase inhibitors are approved for all level of symptoms of Alzheimer’s disease. Side effects can include nausea, vomiting, and diarrhea.

### **MEMANTINE (NAMENDA)**

Memantine works by regulating the activity of a neurochemical, glutamate, that is also involved in learning and memory. Memantine is approved for moderate to advanced symptoms of Alzheimer’s and in some cases is prescribed with a cholinesterase inhibitor. A common side effect of Memantine is dizziness.

### **ADUCANUMAB (ADUHELM)**

In 2021, the FDA approved the first drug to reduce beta-amyloid plaques in the brain that are associated with Alzheimer’s disease. The hope is that by reducing these plaques, patients will experience less cognitive and functional decline. The evidence so far is that it is not effective.

The FDA’s approval was controversial. Some of FDA’s own scientific advisors resigned in protest of the fast-track approval, citing a lack of clinical evidence that it was safe and effective. There are several potentially serious side effects, including brain bleeds. And the cost of the drug is quite high.

In April 2022, the Centers for Medicare and Medicaid Services (CMS) announced it would only cover Aduhelm for patients who are enrolled in a randomized clinical trial. Many other major insurers also do not cover the drug.

At this writing, Biogen, the manufacturer of Aduhelm, was not able to enroll enough patients for one of the large-scale trials it had planned, and the trial was cancelled in June 2022. Another trial is ongoing.

Patients wanting to try the drug will need to pay the \$28,200 annual cost out of pocket, find an insurer willing to cover it, or join a CMS-approved clinical trial, in which case the drug costs would be covered by Medicare. The drug requires a monthly infusion given by IV and regular monitoring with CT scans because of the risk of brain bleeds.

Medications are sometimes used to treat symptoms other than cognitive symptoms, such as treatments for insomnia, anxiety, depression, and agitation. Remember the general rule — ask how likely these drugs are to work, and if the benefits outweigh the risks and side effects. Ask about alternatives. Non-pharmaceutical treatments for all of these symptoms are available. (See [Supporting Your Well-Being](#), Section 2, page 85.)

It's important to keep in mind that polypharmacy (simultaneous use of multiple drugs) is a serious problem for many older people, whether or not they are living with dementia. According to the Centers for Disease Control and Prevention (CDC), seven out of 10 adults aged 40 to 79 take at least one prescription drug, and one out of five take five or more drugs. The potential for drug interactions and side effects is quite high.

"Medications might be good, but every single medicine has potential side effects," says Anne Ellett, RN, MSN. "I ask people to look at the whole spectrum of what they're taking. In general, my approach is less is more. If you're on more than five things, you do have adverse events. It's not unusual for older people to be on 10, 15 things a day, a combination of prescription and supplements — no wonder they're dizzy or don't have an appetite or have bowel problems. Ask your healthcare provider to look at the risks and benefits of all your medications."

Periodically review your medications with your doctor. Don't assume you need to stay on a drug forever.

## Medications to Avoid if Possible

- ◆ **Sleep aids** are used to help people get to sleep and stay asleep. People living with dementia should NOT use these drugs regularly because they make the person more confused and more likely to fall. There are lifestyle changes people can make to improve their sleep. (See [Get Restorative Sleep](#), Section 2.2E, page 97.)
- ◆ **Anti-anxiety drugs** are often prescribed for agitation. These drugs can cause sleepiness, dizziness, falls, and confusion. A better strategy is to address the trigger or unmet need that is causing the agitation. If an anti-anxiety medication is used, it should only be used for short periods of time.
- ◆ **Anti-convulsants** are drugs sometimes used to treat severe aggression. Side effects may cause sleepiness, dizziness, mood swings, and confusion.
- ◆ **Antipsychotics** are often prescribed for paranoia, hallucinations, agitation, and aggression. Side effects of using these drugs can be serious, including increased risk of death in some older people living with dementia. In some instances, antipsychotics may be given for severe aggression if no other intervention has helped. There is no evidence antipsychotics are useful after about 12 weeks.

Dr. Allen Power pioneered efforts to treat people living with dementia, especially those in care homes, without the use of psychotropic drugs that affect mood and behavior. Too often, he argued, people with difficult behavior expressions are drugged into lethargy. Instead, he advises care partners and staff to try to identify the trigger or unmet need the person living

with dementia is struggling with that may be causing agitation or anger. (See [Coping with Expressions of Distress](#), Section 7.6, page 363.) CMS now tracks the use of antipsychotic drugs in nursing homes and has set a goal for their significant reduction.

## What about Supplements or Alternative “Cures”?

It seems almost every week there is a new claim for “how to prevent or cure Alzheimer’s disease” or some other form of dementia. We can’t cover them all so you will want to have a trusted source of information about these claims.

We recommend The National Center for Complementary and Integrative Medicine.

Here are a few tips from its website:

To date there is no convincing evidence from a large body of research that any dietary supplement can prevent worsening of cognitive impairment associated with dementia or Alzheimer’s disease. This includes studies of ginkgo, omega-3 fatty acids/fish oil, vitamins B and E, Asian ginseng, grape seed extract, and curcumin. Additional research on some of these supplements is underway.

Be suspicious of any product or therapy that claims to prevent or cure dementia. That said, a healthy lifestyle, having a sense of purpose, and staying connected to others may help reduce your risk of further cognitive impairment or slow its progression.

## 5.5 Prescription Assistance Programs

Prescription drugs can be very expensive. Even if you have signed up for Medicare Part D or other drug insurance, it may not adequately cover what your doctor prescribes. If you need help paying for prescription drugs, you might want to look into Patient (also called Prescription) Assistance Programs (PAPs).

According to the website [Needymeds.org](#), more than 375 PAPs operate in the U.S., helping more than 36 million people obtain pharmaceuticals. Some \$13 billion worth of prescription drugs are provided to low-income people at no cost. Some PAPs do not pay the full cost but will sell it to eligible patients at a discount. The programs are usually paid for by drug manufacturers, and, to a lesser extent, government and nonprofits. Generally, a PAP covers one particular drug; it is not an overall drug insurance plan.



PAPs do have their critics. Many manufacturers have a confusing application process. They may not be open about what criteria they use to determine eligibility. Critics caution that manufacturers also have their own agenda with a PAP, hoping to turn you into a loyal customer for their other drugs.

A fact sheet by *Consumer Reports* and Consumer Reports Best Buy Drugs offers these tips:

- ◆ Ask your doctor to prescribe a generic drug, rather than brand name, if the generic is equally effective and available.
- ◆ Ask your doctor, clinic, or pharmacist to recommend a PAP.
- ◆ Visit the website of the manufacturer of the drug to see if they have a PAP.
- ◆ Find out — if you can — what the income requirements are for a particular PAP. Income limits generally range from \$20,000 to \$40,000, depending on the size of your family. In addition, your assets may not exceed \$15,000 to \$20,000, not counting your home and one car.
- ◆ If your income or assets are too high and if you do not have drug insurance, you may still be able to get help from some programs.

Be wary of online companies that offer to help you with the application process — for a fee. There should not be a charge to apply for a PAP. Ask your healthcare provider to help you if the process is too confusing.

**Consumer Reports recommends:  
WEBSITES TO FIND A PAP**

- RxAssist, [www.rxassist.org](http://www.rxassist.org)
- Partnership for Prescription Assistance, [www.pparx.org](http://www.pparx.org)
- Needy Meds, [www.needymeds.org](http://www.needymeds.org)
- Medicare, [www.medicare.gov](http://www.medicare.gov) and search for Prescription Assistance Programs
- Medicare Rights Center, [www.medicarerights.org](http://www.medicarerights.org)

## 5.6 Cannabis and CBD

### Cannabis

Does cannabis (marijuana) hold promise for treating dementia? Scientists at Johns Hopkins University, Harvard University, and other major research centers are studying that question.

According to Harvard Health ([www.health.harvard.edu/mind-and-mood/the-effects-of-marijuana-on-your-memory](http://www.health.harvard.edu/mind-and-mood/the-effects-of-marijuana-on-your-memory)), "Cannabis contains varying amounts of the potentially therapeutic compound cannabidiol (CBD), which may help quell anxiety. However, there's no question that marijuana (the dried flowers and leaves of the cannabis plant) can produce short-term problems with thinking, working memory, executive function, and psychomotor function (physical actions that require conscious thought, such as driving a car or playing a musical instrument). This is because marijuana's main psychoactive chemical, THC, causes its effect by attaching to receptors in brain regions that are vital for memory formation, including the hippocampus, amygdala, and cerebral cortex. The extent to which long-term use of marijuana (either for medical or recreational purposes) produces persistent cognitive problems is not known."

As of June 2022, 37 states and Washington D.C. have legalized marijuana for medical purposes. In addition, 19 states and Washington, D.C. have legalized it for recreational purposes.

### CBD (Cannabidiol)

CBD is a chemical found in marijuana. CBD does not contain tetrahydrocannabinol (THC), the psychoactive ingredient found in marijuana that produces a high. CBD often comes as an oil, but it can also be formulated as an extract, a vaporized liquid, and an oil-based capsule. Food, drinks, and cosmetics are among the many CBD-infused products available.

Though CBD is often well-tolerated, it carries some risks. Side effects include dry mouth, diarrhea, reduced appetite, drowsiness, and fatigue. The U.S. Food and Drug Administration (FDA) warns that CBD can cause liver injury (as shown in some animal experiments in very high doses) and affect metabolism of other drugs you are taking, such as blood thinners. The FDA has not approved CBD for treating dementia.

Harvard Health cautions that there is some unreliability about the purity and dosage of CBD in products. A recent study of 84 CBD products bought online showed that more

than a quarter of the products contained less CBD than labeled. In addition, THC was found in 18 products. If you plan to use products containing CBD, talk to your doctor.

CBD has been found to help ease symptoms experienced by some people living with dementia, including:

- ◆ Anxiety
- ◆ Depression
- ◆ Agitation
- ◆ Insomnia
- ◆ Motor function problems

“For associated problems with dementia like anxiety, cannabis can help,” says Dr. Allen Power. It has also been found to ease pain and nausea associated with cancer and chemotherapy.

Research is ongoing as to the potential benefits of cannabis for dementia. The National Institute on Aging is funding a study to look at whether THC and CBD improve the quality of life for people living with dementia.

## 5.7 Transcranial Magnetic Stimulation

A treatment being studied for dementia is called transcranial magnetic stimulation (TMS). It is a noninvasive medical device that uses magnetic fields to stimulate nerve cells in the brain.

There are two types of TMS, the original type that gives repetitive magnetic pulses, and a newer version called Deep TMS. Both have been approved by the FDA to treat major depression that has not responded to medication, obsessive-compulsive disorder, and migraine headache pain. In some European countries, Deep TMS is also approved for a wide variety of other conditions, among them Parkinson’s disease and Alzheimer’s. Side effects are said to be mild, with the most common being headache.

In the U.S., TMS for dementia is considered “off-label” because it has not been approved by FDA for this purpose. Some neurologists do use it, including Dr. Gayarti Devi, who writes in *The Spectrum of Hope*: “I have spent a decade investigating the effects of TMS in patients living with dementia ... TMS increases cognitive reserve by increasing connections in targeted neural circuits.” She believes it can also help with dementia-related language problems.

Others say that it is too soon to know if TMS is safe and effective for treating dementia symptoms. A review in the journal *eNeuro* in 2020 called “Transcranial Magnetic Stimulation in Alzheimer’s Disease: Are We Ready?” concluded: “Although small clinical trials in [Alzheimer’s disease] have reported positive effects on cognitive outcome measures, significant knowledge gaps remain, and little attention has been directed at examining the potential influence of TMS on AD pathogenesis ... we caution that TMS therapeutic protocols established in young adults may have unexpected detrimental effects in older individuals or in the brain compromised by AD pathology.”

Neurologist Daniel Potts and others recommend that people living with dementia interested in trying TMS look for a clinical trial in which they can enroll.

## 5.8 Telehealth Visits

Telehealth has been around for decades, but it really took off during the COVID pandemic. A 2021 report by McKinsey found that the use of telehealth multiplied by 38 times from pre-pandemic figures. Some 40 percent of consumers said they would like to continue using telehealth, compared to just 11 percent pre-pandemic.

Among medical specialties, telehealth was used most widely in psychiatry. Since COVID, many doctors and therapists are using telehealth as insurance permits.

With telehealth you can be seen virtually by a healthcare provider, either online or over the phone, from the comfort of your home. It can also include using monitors to track things remotely, like blood pressure. The readings are sent automatically to your healthcare provider. As technology continues to improve, costs come down, and people grow more comfortable being in front of a video camera, telehealth will likely become increasingly common. Telehealth can be especially valuable in rural areas, where people often go long distances to be seen by specialists.

“Telehealth for people with early symptoms of dementia works as well as for anybody,” says Dr. Allen Power. “With certain symptoms, you need to be examined in person. Also, you might need some of the cues you get from a live conversation. Telehealth can be helpful to get an overall sense of how the person is doing and what they’re experiencing. With more advanced symptoms, telehealth becomes more challenging as some people living with dementia become confused with the telehealth online process. During the pandemic, some nursing homes tried to connect residents with their families using video. Some could do it, some could not.”

The National Institute on Aging is funding research on telehealth as a promising way to deliver healthcare to people living with dementia and their care partners, especially in underserved areas. According to NIA, “By making dementia care and education more accessible, telehealth can help manage dementia issues at home before a crisis happens. This, in turn, can lessen caregiver burden and stress and improve quality of life for people with dementia. Promising evidence suggests that telehealth dementia services may also reduce emergency department visits, which may help reduce the costs of dementia care.”

NIA cautions that insurance providers vary widely on their policies for covering telehealth, depending in part on state regulations. Be sure to check with your insurance provider before making a telehealth appointment.

## 5.9 Healthcare at Home

There is a growing movement to offer people a range of in-person medical services in their own homes — everything from house calls and dentistry to acute hospital-level care. This kind of delivery can be especially valuable for people living with dementia.

Much like telehealth, in-person healthcare at home was given a boost during the COVID pandemic, including for acute care. This was to reduce the spread of infection, a significant problem in hospitals, even before the pandemic. A 2015 study documented 687,000 cases of hospital-acquired infections, leading to 72,000 deaths. During COVID, the federal government gave a temporary waiver for acute-level hospital care to be delivered at home and still covered by Medicare and Medicaid. Major healthcare systems, including Kaiser Permanente and the Mayo Clinic, have formed an alliance to lobby for the waiver to be made permanent.

A 2020 clinical trial in the *Annals of Internal Medicine* found that costs for treating acutely-ill patients at home were 38 percent lower compared to a hospitalized group. The in-home patients received fewer lab tests, radiology exams, and specialist consultations, and they were less sedentary. Their readmission rates were also lower.

In addition to hospital-at-home, there is a move to go back to the future with traditional physician house calls. The American Academy of Home Care Medicine trains physicians and promotes home-based primary care. Technology, including portable devices, makes this type of medicine more affordable, with high quality results and high patient satisfaction. It also saves money. Over the first four years, the Independence at Home Demonstration project saved Medicare approximately \$63 million and delivered high-quality care. Most of the savings came from reduced hospitalizations and skilled nursing facility services. Visit [www.aahcm.org](http://www.aahcm.org) to find out if this type of home care is available in your area.

Other types of home health care, including services by nurses, occupational/physical/speech therapists, social workers, and spiritual care counselors, are available in some areas for people living with chronic conditions. Medicare will cover some of this care, including for people with advanced dementia and those who are homebound. (This coverage generally does not include long-term care by home-health aides, which is usually paid for out-of-pocket or with long-term care insurance.)

One company, DispatchHealth, operates in 24 states, as of June 2022. Its model is to send a two-person team (a physician's assistant or nurse practitioner and a medical technician) to your home when you call with a concern that might otherwise take you to an urgent care clinic or the emergency room. They will assess if you can be treated at home, or if you need to go to a hospital. The team can administer IVs, run lab work, change catheters, and many other procedures. The care is covered by Medicare, Medicaid, and many private insurers. For more information, visit: [dispatchhealth.com](https://dispatchhealth.com)

The Veteran's Administration has long offered a home-health care option to many veterans. The VA also pioneered programs to help compensate care partners. To learn more about these services, visit: [va.gov/geriatrics](https://va.gov/geriatrics)

## 5.10 Avoiding the Emergency Department

A visit to the emergency department (ED) can be stressful for all, especially for people living with dementia. The crowds, loud beeping, bright lights, and long waits can lead to increased agitation and stress.

Emergency department personnel may not be trained in dementia care. They are there to respond to a particular urgent problem. They may not be able to take the time to carefully listen to someone who has trouble communicating. Add to that the risk of infection, hospitalization, and hospital-related delirium. In short, avoid going to the emergency department if you can.

Studies have found that people living with dementia go to the ED often. According to a 2016 study by researchers at the University of Indiana School of Medicine, "... we found that older adults living with dementia who were frequent visitors to EDs and had higher numbers of comorbidities, received more costly care, were admitted to hospitals at higher rates, and had higher return rates than patients without dementia. Survival and ED return rates differed also according to the patients' dementia status" (meaning these rates were worse for people living with dementia).

The study continues: “To date, patients with dementia and other cognitive impairments have been recognized as more difficult for ED providers to assess and treat. We, however, know comparatively little about the decision making of emergency providers when treating this vulnerable population, the care preferences of patients with dementia and their caregivers who seek care in this environment, or alternatives that might be readily offered to patients with dementia who wish to avoid admission to the hospital from the ED.”

Of course, there are cases that are true emergencies, such as chest pain, signs of stroke, or excessive bleeding. Many problems can be handled in an urgent care clinic. These are smaller, less crowded and noisy, and lower cost than EDs. They can handle many non-life-threatening problems, such as:

- ◆ Allergic reactions and asthma
- ◆ Cuts and burns
- ◆ Falls, sprains, strains, and broken bones
- ◆ Colds and flus
- ◆ Sinus pressure and sinus infections (sinusitis)
- ◆ Strep throat
- ◆ Urinary tract infection

One of the best ways to avoid going to an ED is having a strong relationship with your healthcare provider. Being regularly seen can help nip problems in the bud. This can be made easier through telehealth or home visits, as discussed above. Discuss local alternatives to the ED in advance of a need with your healthcare provider.

It’s also a good idea to find out ahead of time if there are non-emergency services you can call in case you fall. Many fire departments, for example, will send help to safely lift someone who has fallen and get them settled. Call your fire department and ask if they have “non-emergency lift” or “lift service” help. Often this is given at no charge. In some areas, you can also access this help by dialing 311.

In an article in *Annals of Long-Term Care*, (“Dementia and the ER”), the author concluded: “Perhaps we need to reconsider whether the ED is an appropriate site of care for patients living with dementia. The expansion of house-call practices that bring both providers and technology to the patient, rather than the patient to the provider, may be an alternative to ER care. Providers should also consider earlier initiation of palliative care for patients living with dementia. These approaches might better serve patients living with dementia, their families, and the healthcare system.”

## 5.11 If You Have to Go to the Hospital

Sometimes going to the hospital is unavoidable. Whether it's through the ED or a planned hospital admission, there are many things you can do to prepare. Hospital staff and care partners offer the following tips to help things go as smoothly as possible:

- ◆ **Prepare a kit or folder ahead of time with key documents** including up-to-date medications list, list of medical problems and surgeries, your primary care and specialists' phone numbers (including after-hours), advance directives (including a do-not-resuscitate order if you have one), health-care power of attorney, and care partner contact information.
- ◆ **Create a document that lets the staff know** about the person living with dementia, including what is calming, what their bedtime routine is, what they prefer to be called, some basic biographical information, ways to communicate and so on. Have it in a handy place where staff and visitors can view it. The Dementia Action Alliance, in collaboration with people living with dementia, care partners, and dementia specialists, created a tool, "What Matters To Me," that is simple and easy to complete that provides the helpful information noted above. (See [What Matters to Me](#), Section 8, page 426.)
- ◆ **Ask your healthcare provider which hospitals they practice in**, and which have access to your medical records electronically. Plan to go to one of these.
- ◆ **When going to the hospital, have two people along**, if possible, in addition to the person living with dementia. One is responsible for driving and letting the other two off at the door. This person can also be there to help during the waiting time. If the care partner needs to deal with insurance forms and other details, the other friend or relative can focus on the person living with dementia.
- ◆ **Inform the staff that the person has dementia.** Let them know of any communication strategies that may help.
- ◆ **Consider bringing** eyeglasses and hearing aids, if used, eye mask for sleeping, ear plugs to soften hospital noises, and favorite calming activities, such as knitting, puzzles, adult coloring books, or headset with music.
- ◆ **Don't forget to bring a list of medications** and make it clear if the person needs to keep taking these while in the hospital.
- ◆ **If the person is on a regular diet** and not scheduled for any tests that must be performed on an empty stomach, have snacks and drinks that they would enjoy. Bring favorite dishes if they are not enjoying the hospital food.



- ◆ **Have the person choose one or two family photos** or scenic pictures to display.
- ◆ **Pack pajamas, slippers, and extra clothes**, so they don't have to wear a hospital gown.
- ◆ **Be aware that hospital staff likely have limited training in dementia**, so make them aware of any contraindicated medications, such as Haldol for people living with Lewy body dementia.

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*Being a calm and steady presence  
is the most important thing  
a care partner can do.*

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- ◆ **Encourage hospital staff to see the person as an individual** and not just a patient living with dementia who is confused and disoriented from the disease.
- ◆ **Ask the doctor to write an order** that says the person's vital signs do not have to be taken in the middle of the night unless there is an important medical reason to do so. Often these are done routinely. Sleep interruptions will increase the likelihood of agitation or delirium.
- ◆ **Have a friend or relative there around the clock**, if possible. This can help keep the person calm and well-hydrated. It also may prevent mistakes in medication or other problems from arising, to have an extra set of eyes there. If you are the only one available, take care of yourself. Take some time away from the hospital to get fresh air or go home for a nap. Be mindful of your own health.
- ◆ **Request the hospital chaplain visit** if you think the person living with dementia would find it comforting. You can also request other nonmedical volunteers, such as a book or art cart or a visit from a service dog, which some hospitals offer.

Being a calm and steady presence is the most important thing a care partner can do. That may go a long way towards helping your loved one weather a hospital stay.



## ***Delirium***

***Susan Wehry, MD***

*Even seasoned physicians can miss signs of delirium*

One of the biggest risks associated with a hospitalization is developing a delirium. Delirium is an acute change in mental status characterized by confusion, inattention, hallucinations, and fluctuations in consciousness. It is often missed, even by seasoned clinicians. This is particularly true if the person has underlying dementia because the symptoms are seen as just part of the dementia. Delirium in older adults is associated with an increased risk for cognitive and functional decline and death.

Dementia itself is a risk factor for developing delirium. So are taking certain medications and visual and hearing impairments. Delirium is typically caused by adverse reactions to anesthesia, alcohol withdrawal, drug-drug interactions, infections (skin, urinary, lungs), or electrolyte imbalances due to dehydration.

Ask if the hospital has adopted HELP (Hospital Elder Life Program), which is a delirium prevention initiative for older adult patients. Care partners will be familiar with symptoms that the person living with dementia usually experiences and can be invaluable in alerting hospital staff if there are changes in the person's mental status that may signal delirium. Care partners may need to be especially vigorous in advocating for an assessment for delirium. For example, the patient may be having hallucinations which have not been experienced before — insist the hospital assess for delirium. A simple tool called the "CAM" (Confusion Assessment Method) takes less than one minute to administer.

## 5.12 End-of-Life Planning

Dr. Jenny Randolph, in her research tracking 1,500 families living with Alzheimer's over a period of five years, found that less than 25 percent had a conversation about death. Talking about death and planning for it is generally considered morbid. Unfortunately, that is the influence of societal stigma. In actuality, death is one of the most intimate and personal life experiences.

Within hospice circles, it is often said that a person had a beautiful death. "A beautiful death" is unique for each person. For some, it is having people you are close to surround you with favorite music playing. For another, it may be having a spiritual guide present, or someone saying prayers, or reading treasured poetry, or simply sitting quietly by your side holding your hand.

If you have conversations about your ideal end-of-life scenario in advance and do some planning, others will know what you want and can help make it possible. Having end-of-life conversations does not need to be a depressing experience. Barney Nelson let his family know that he is videorecording his end-of-life thoughts and wishes. Once he is finished, he will gather his family so they can watch the video together and talk about it. Barney has a close and open relationship with his family and is comfortable talking about end-of-life issues.

Not everyone has a close family dynamic. In that case, it is better to limit the conversation to one or two family members with whom you have a close relationship. You may want to write a letter to other family members to caringly and kindly let them know your end-of-life wishes.

In 2010, a Pulitzer Prize-winning writer, Ellen Goodman, and colleagues launched a public initiative, the Conversation Project, to help people talk comfortably about their end-of-life wishes. There are many excellent resources on the Conversation Project website including a guide titled, "For Caregivers of People with Alzheimer's or Other Forms of Dementia."

Visit: [theconversationproject.org](http://theconversationproject.org)

Living with dementia adds a layer of complexity to end-of-life planning. Dementia can progress unpredictably, so when is a good time to plan? You should do this as soon as you feel comfortable and ready. What if you never feel comfortable or ready? If that is the case, you can enlist someone you feel comfortable with and ask for their help. This person could be a close friend, family member, clergy member, or a therapist, among others. Be upfront with the person that this is something you are struggling with. The resources from the Conversation Project can be a good way to start the process and discussion.

## ***End-of-Life Care for People Living with Dementia***

*Reprinted from the National Institute on Aging*

People often live for years with dementia. While it can be difficult to think of these diseases as terminal, they do eventually lead to death. Care partners often experience special challenges surrounding the end of life of someone living with dementia, in part because the disease progression is so unpredictable. Below are some considerations for end-of-life care for people with dementia.

### **Making medical decisions for people living with dementia**

With dementia, a person's body may continue to be physically healthy. However, dementia causes the gradual loss of thinking, remembering, and reasoning abilities, which means that people living with dementia at the end of life may no longer be able to make or communicate choices about their healthcare. If there are no advance care planning documents in place and the family does not know the person's wishes, care partners may need to make difficult decisions on behalf of their loved one about care and treatment approaches.

### **Questions to ask about end-of-life care for a person living with dementia**

[If you are] a caregiver, you will want to understand how the available medical options presented by the healthcare team fit with the needs of both the family and the person living with dementia. You might ask the healthcare team questions such as:

- ◆ Who can help me with end-of-life care for my loved one living with dementia?
- ◆ How will your suggested approaches affect their quality of life?
- ◆ What are my options if I can no longer manage the care of my loved one at home?
- ◆ How can I best decide when a visit to the doctor or hospital is necessary?
- ◆ Should I consider hospice at home, and if so, does the hospice team have experience working with people living with dementia?

## **Being there for a person living with dementia at the end of life**

As dementia progresses, caregivers may find it hard to provide emotional or spiritual comfort to a person who has advanced memory loss. However, even in advanced stages of dementia, a person may benefit from such connections. Sensory connections — targeting someone’s senses, including hearing, touch, or sight — may also bring comfort. Being touched or massaged can be soothing. Listening to music, white noise, or sounds from nature seems to relax some people and lessen agitation. Just being present can be calming to the person.

Palliative or hospice care teams may be helpful in suggesting ways for people living with dementia and their families to connect at the end of life. They also may be able to help identify when someone living with dementia is in the last days or weeks of life.

Signs of the final stages of dementia include some of the following:

- ◆ Be unable to move around on one’s own
- ◆ Become agitated or restless
- ◆ Be unable to speak or make oneself understood
- ◆ Have difficulty swallowing or be unable to swallow
- ◆ Develop an irregular breathing pattern
- ◆ Have a rattly sound to their breathing
- ◆ Have cold hands and feet

Though palliative and hospice care experts have unique experience with what happens at the end of life and may be able to give a sense of timing, it’s hard to predict exactly how much time a person has left.

## **Supporting dementia care partners at the end of life**

Caring for people living with dementia at the end-of-life can be demanding and stressful. Depression and fatigue are common problems for care partners because many feel they are always on call. Care partners may have to cut back on work hours or leave work altogether because of their caregiving responsibilities.

It is not uncommon for those who took care of a person living with advanced dementia to feel a sense of relief when death happens. It is important to realize such feelings are normal. Hospice care experts can provide support to care partners near the end of life as well as help with their grief.

## 5.13 Palliative and Hospice Care

If given the choice, everyone likely would want to die free of pain and in comfort. Most of us say we'd prefer to die at home, in familiar surroundings, and visited by loved ones. Whether you are in a hospital, a nursing home, or your own home, you will benefit by palliative or comfort care.

Palliative care specialists have expertise in symptom management, including pain and other kinds of discomfort. A palliative care team includes physicians and nurses specially trained in palliative medicine, as well as social workers, chaplains, and nutritionists.

When someone is approaching the last months of life, palliative care can transition into hospice care. A doctor will order hospice care if he or she expects you have less than six months remaining to live. Hospice care is paid for by Medicare and many other insurers. Knowing how long a person may live is not an exact science. If a person lives longer than six months, hospice can either be renewed, or discontinued for the time being.

Hospice care can be given in any setting — home, nursing home, assisted living, a hospital, or occasionally a residential hospice. Unfortunately, too often people are not offered — or will not accept — this benefit until the last few days of life. Sometimes, families or healthcare providers fear that offering hospice will make a patient lose hope. Discussing early on what your prognosis is and expressing what you want is key.

Hopefully, you have written down your wishes as far as end-of-life care. Otherwise, your care partners must make those difficult decisions on their own. It can get complicated if care partners disagree. Stating your wishes while you still are able is critically important. Five Wishes is an excellent resource. Visit: [www.fivewishes.org](http://www.fivewishes.org)

John and Susan McFadden have both worked closely with people living and dying with dementia for many years. They reflect on what is different about hospice care for those who can no longer speak for themselves.

"People [without dementia] are very good at talking about fears and hope, their images of death," says Susan. "You can't do that with a lot of folks living with advanced dementia. We never lose our need for touch and the comfort of someone holding our hands. People are using aromatherapy, trying to connect to people through other senses, and give them a sense of peace at the end."

"Hospice care is, or should be, a different experience for persons living with dementia," says John. "The origins of hospice care lie largely in the cognitive. 'Are you free from pain? Are you at peace with facing your death? Is there anything I can offer that would provide comfort?' When the dying person is living with advanced dementia, there needs to be

a shift to simply being present and accompanying the person on the journey. Many hospice chaplains now bring musical instruments rather than pamphlets, and focus on communicating calmness, peace, and joy, as much through appropriate touch as through words.”

John advises care partners and medical staff, “Rather than feeling like you’re helping someone prepare to die, move to just helping them find peace in the process of dying.”

## 5.14 Death with Dignity



*Susan Wehry, MD, Contributor*

What is meant by death with dignity? Usually, this phrase is used to describe laws that protect taking one’s own life with the assistance of another. It is also called medical aid in dying, assisted suicide, or physician-assisted suicide.

Some reject the idea that medical aid in dying should be considered assisted suicide at all. Instead, they look upon medical-aid-in-dying as just one of many end-of-life medical options. In this sense, medical aid in dying refers to the self-ingestion of lethal medication prescribed by a physician for the purpose of ending life. This is not the same as euthanasia. Euthanasia refers to someone else, such as a doctor, giving lethal medication to end someone’s life to end their suffering.

In 1997, Oregon enacted the first Death with Dignity Law. It allows terminally ill Oregonians to end their lives through voluntary self-administration of a lethal dose of medications prescribed by a physician for that purpose.<sup>1</sup> This law, The Oregon Death with Dignity Act, has become a model for legislation around the United States and is no longer restricted to in-state residents.<sup>2</sup> Although specific qualifications vary somewhat, they generally require that a person have a terminal illness and not be expected to live beyond six months. The person must ask for the medication orally and again in writing. Two physicians must confirm the person has the capacity to make the decision. The person also cannot be experiencing a clinically significant depression or other mental disorder that may interfere with their judgment. The decision must be voluntary. People living or dying with dementia are excluded from requesting lethal medication due to concerns about capacity and their ability to carry out the request independently. No state permits self-ingestion of lethal medication to be part

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<sup>1</sup> [Oregon DWDA \[https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/index.aspx\]](https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/index.aspx)

<sup>2</sup> [www.npr.org/2022/03/30/1089647368/oregon-physician-assisted-death-state-residents](http://www.npr.org/2022/03/30/1089647368/oregon-physician-assisted-death-state-residents)



of an advance care plan.

As of this writing, Washington, D.C. and eight states (Colorado, Hawaii, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington) and six countries (Spain, the Netherlands, Belgium, Luxembourg, Canada, and New Zealand) allow assisted suicide (as it is more generally referred to worldwide).<sup>3</sup>

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*Death with dignity speaks to  
the wish to preserve autonomy,  
a concern shared by people with and  
without dementia at the end of life.*

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The phrase death with dignity is also used another way. Death with dignity refers to the desire to preserve one's dignity until the last breath. Death with dignity refers to the wish most people have for a natural death, a wish often referred to as "letting die" without medical interference. Death with dignity also gives voice to the fear that without control over how and when one dies, one risks losing their dignity.

Death with dignity speaks to the wish to preserve autonomy, a concern shared by people with and without dementia at the end of life. According to Oregon's 2021 report on patients who used this law, the three most frequently reported end-of-life concerns were loss of autonomy (93 percent), decreasing ability to participate in activities that made life enjoyable (92 percent), and loss of dignity (68 percent). A little more than half of patients who requested lethal medication said they did not wish to become a burden on family members, friends, and caregivers.<sup>4</sup> People living with dementia may be especially attuned to concerns about autonomy throughout their changing brain journey. Many have the experience of decisions being challenged by care partners and health practitioners who question their capacity to make informed decisions. As more people living with dementia advocate for themselves, this may change.

Death with Dignity laws are very controversial, especially as they relate to people living with dementia. These laws raise ethical questions and may violate religious beliefs. Many express concern that a 'right to die' overseen by the state could become a 'duty to die' for economic reasons. In a recent press release, the Center for Disability Rights warned lawmakers that

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<sup>3</sup> Rada A G. Spain will become the sixth country worldwide to allow euthanasia and assisted suicide BMJ 2021; 372 :n147 doi:10.1136/bmj.n147

<sup>4</sup> [www.healthoregon.org/dwd](http://www.healthoregon.org/dwd) Public Health Division, Center for Health Statistics February 28, 2022

<sup>5</sup> [cdrnys.org/blog/press-releases/physician-assisted-suicide-deadly-for-disabled/](http://cdrnys.org/blog/press-releases/physician-assisted-suicide-deadly-for-disabled/)



New York's proposed Medical Aid in Dying legislation "is a deadly proposition that puts disabled people at risk."<sup>5</sup> Physicians too must grapple with what it means to prescribe life-ending medication. They must consider whether it violates their oath to do no harm or honors the obligation to do good and to respect patient autonomy.

A question worth asking: Does death with dignity require Death with Dignity laws? Dying with dignity is a complex and highly personal issue. People living with dementia who wish to thrive with dignity as well as die with dignity need to have lots of conversations with family, friends, practitioners, and care partners about what matters most to them about living and dying. What makes for a good life? What would make for a good death?

As mentioned in a prior section, these conversations need to be documented in the form of an advance directive. The proxy or surrogate decision-maker should be someone who is trusted and can be counted on to honor the person's choices and values. At present, it is not possible to request lethal medication in advance or to have a surrogate request it for a person living with dementia. It is possible to request a palliative care specialist be on your healthcare team and that comfort care be provided in advanced stages of dementia. It is possible to state whether or not you wish to receive antibiotics for pneumonia and to be permitted to refuse food and water. It is possible to request not to be resuscitated (DNR) in the event the heart stops.

Thinking and talking about the likely progression of brain changes over the course of dementia may not be easy. Nor is it easy to think and talk about our own mortality. The courage and willingness to do so now can help people living with dementia retain some control over conditions at the end of life and give comfort to themselves, their care partners, and their allies that their values and choices will be honored.

## SUGGESTED RESOURCES

### Articles

National Institute on Aging, "Telehealth: improving dementia care," 2020. [www.nia.nih.gov/news/telehealth-improving-dementia-care](http://www.nia.nih.gov/news/telehealth-improving-dementia-care)

Possin, K.L., et al. (2019). Effect of collaborative dementia care via telephone and internet on quality of life, caregiver well-being, and health care use: The Care Ecosystem randomized clinical trial. *JAMA Internal Medicine*. 179(12):1658-1667.

LaMantia, M.A., et al. (2016). Emergency department use among older adults with dementia. *Alzheimer Disease and Associated Disorders* 30(1) 35-40.

Segal-Gidan. (2018). Dementia and the ER — a toxic combination. *Annals of Long-Term Care*. [www.hmpgloballearningnetwork.com/site/altc/articles/dementia-and-er-toxic-combination](http://www.hmpgloballearningnetwork.com/site/altc/articles/dementia-and-er-toxic-combination)

Fenker, Richard. (2020). The red button: Creating good choices at the end-of-life for people living with dementia. Cimarron International Publishing.

Kenny, A. (2018). Making tough decisions about end-of-life care in dementia. Johns Hopkins University Press, Baltimore.

"End of Life Decisions — Honoring the Wishes of a Person with Alzheimer's Disease" is a free pamphlet available from the Alzheimer's Association website, alz.org. [www.alz.org/national/documents/brochure\\_endoflifedecisions.pdf](http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf)

### Websites

National Center on Complementary and Integrative Health — includes a summary of research related to supplements and dementia.

[www.nccih.nih.gov/health/tips/things-to-know-about-complementary-health-practices-for-cognitive-function-dementia-and-alzheimers-disease](http://www.nccih.nih.gov/health/tips/things-to-know-about-complementary-health-practices-for-cognitive-function-dementia-and-alzheimers-disease)

Harvard Health Publishing, "The effects of marijuana on your memory", 2021.

[www.health.harvard.edu/mind-and-mood/the-effects-of-marijuana-on-your-memory](http://www.health.harvard.edu/mind-and-mood/the-effects-of-marijuana-on-your-memory)

Aging Life Care Association (also called geriatric care managers) is made up of professionals who practice a holistic, client-centered approach to caring for older adults or others facing ongoing health challenges.

[www.aginglifecare.org](http://www.aginglifecare.org)

DispatchHealth offers medical support to patients no matter where they are in their healthcare journey, with services ranging from same-day, high-acuity care to a 30-day alternative to a hospital stay, all delivered straight to the patient's door.	<a href="https://dispatchhealth.com">dispatchhealth.com</a>
Geriatrics and Extended Care, Department of Veterans Affairs (VA) — Veterans with dementia may be eligible for certain benefits and services.	<a href="https://www.va.gov/geriatrics/">www.va.gov/geriatrics/</a>
National Institute on Aging, "Alzheimer's Disease Medications Fact Sheet," 2021.	<a href="https://order.nia.nih.gov/sites/default/files/2021-09/alzheimers-disease-medications.pdf">order.nia.nih.gov/sites/default/files/2021-09/alzheimers-disease-medications.pdf</a>
The American Academy of Home Care Medicine trains physicians and promotes home-based primary care.	<a href="https://www.aahcm.org/">www.aahcm.org/</a>
The Conversation Project a public engagement initiative with a goal to have every person's wishes for end-of-life care expressed and respected.	<a href="https://theconversationproject.org/">theconversationproject.org/</a>
Alzheimer's Association, "End of Life Decisions — Honoring the Wishes of a Person with Alzheimer's Disease."	<a href="https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf">https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf</a>
Alzheimer's Society-United Against Dementia, "How to know when a person with dementia is nearing the end of life."	<a href="https://www.alzheimers.org.uk/get-support/help-dementia-care/recognising-when-someone-reaching-end-their-life">www.alzheimers.org.uk/get-support/help-dementia-care/recognising-when-someone-reaching-end-their-life</a>
National Hospice and Palliative Care Organization has a webpage to locate a palliative care specialist or hospice.	<a href="https://www.nhpco.org/find-a-care-provider">www.nhpco.org/find-a-care-provider</a>

## SECTION 6: Technology Supports

*I find technology exciting and interesting, and I am always learning new ways to help me stay organized, safe, and entertained. Technology helps me enjoy and navigate life a little easier and can be especially helpful for those of us living with dementia and for care partners.*

Rev. Dr. Cynthia Huling Hummel, Manual Guide



Technology offers many beneficial ways to support the changing abilities that people living with dementia experience and helps them maintain their autonomy and independence for as long as possible. For care partners, technology can alleviate some of their worry and stress.

While technology can be a great support to maintain independence and enhance quality of life, it's important to note that technology can also present challenges. Even though it may seem that email and smartphones have been around forever, emails didn't become widely used until the late 1990s and the first iPhone came to market in 2007.

Since most people didn't grow up with technologies, many people 50 and over can have challenges using technologies optimally. This can be especially so for people living with cognitive impairment/dementia. New technologies are coming on the market continually

and many are being designed to be more user friendly to set up and operate. Don't be bashful about reaching out to a tech savvy friend, neighbor, or relative to help you with your technology.

There is a vast universe of technology products and apps available today. (App is short for an application that can be installed on your mobile phone or computer to carry out a specific task, everything from requesting a driver and ordering carryout food to identifying birds.) Below are five broad categories of technologies:

1. **Connection to others**
2. **Life enhancement and independence**
3. **Engagement and socialization**
4. **Safety and security**
5. **Health management**

## 6.1 Connection to Others

Technology provides an array of communication methods so people can keep in touch. Maintaining relationships with people who matter to you is important for your overall well-being. Staying connected helps keep you from becoming isolated and lonely. There are a number of ways to use technology to stay connected with others.

### Smartphones

Smartphones have changed how people live. Smart phones are cell phone or mobile phones with advanced features. You can use a smartphone anywhere your mobile phone carrier, such as AT&T, Mint, T-Mobile, and Verizon, has coverage, unlike landline phones that only have service inside your home. Smartphones also have built-in cameras to take pictures and videos, and can connect to the Internet to access online information, play games, and watch movies, among hundreds of other uses.

Another advantage of using smartphones for people living with dementia is the webcam feature which provides a way for you to see the person you are speaking with, as well as hear them. Being able to see and hear is helpful to process what is being said. The webcam feature is also helpful for people who use sign language to communicate.

Many people use their smartphone to communicate using the text feature. Text messaging sends written messages from one smartphone to another smartphone. The benefit of

texting is that it is a quick way to send short messages and responses, such as “I’ll be home in five minutes.”

It is important to recognize that most people living with dementia have spent the majority of their lives without smartphones, so using them is not intuitive and can cause some frustration and confusion. Because of the many benefits smartphones offer, it is worth the time investment to find a smartphone that can work for you. Smartphones that are basic and have adapted features, such as large buttons and simplified functions, can be a good choice.



## ***Ways I Use My Smartphone***

### ***Rev. Dr. Cynthia Huling Hummel, Manual Guide***

*I can organize my schedule, read the news, and visit my grandchildren*

If you don’t already have a smartphone, you might want to think about getting one. The cost has come way down and many of the phone companies offer a free smartphone with their service plans. Your smartphone is really a little computer that you can put in your pocket or purse that can help you throughout the day. There are many different brands of smartphones and most have the same basic features beyond being used to call people.

If you already have a smartphone that you would like to use for more than calling, you might want to ask a savvy friend to help you set up your smartphone. Alternatively, you can check with your local community center or library or OATS.org (Older Adults Technology Services; for more information, see [Resources](#) at the end of this section) to see if any classes are offered to help set up a smartphone. Teens can be a great resource, so you might check with your grandchild or a teenage neighbor.

**IMPORTANT:** You want to make sure you have the security features enabled on your smartphone to prevent someone from getting access to your personal information. Also, be careful of scammers who are always looking for ways to prey on easy targets.

I use an Apple iPhone that responds to my voice commands. I communicate throughout the day with my smartphone’s virtual assistant, Siri. You can select a male or a female voice, and can even change the type of accent. My sister’s phone, for example, has an

Australian accent. I think of Siri as a constant companion who helps me throughout the day, reminding me of what I need to do. I speak with Siri first thing in the morning and Siri is the last one I speak to at night.

Here are some of the ways that I use Siri throughout the day:

- ◆ I use Siri as my alarm clock not just in the morning but throughout the day. I can program Siri to set an alarm to remind me of a doctor's appointment that afternoon and a dinner date that night.
- ◆ Siri gets me to where I'm going without my having to rely on paper maps. I can program in an address and Siri guides me to my destination. I have certain locations that I have preset — so when I tell Siri to get me home, she knows my address and tells me step by step how to get there.
- ◆ I can check the weather on my phone by asking Siri. This is very helpful as I dress and plan my day. I have Siri set up to notify me of weather alerts so I don't get caught without my umbrella or snow shovel handy.
- ◆ I use the calendar app on my phone and Siri reminds me of upcoming appointments and meetings. Siri can give me a heads up that a meeting will be starting in X minutes.
- ◆ Did you know that Siri can activate the flashlight feature on an iPhone? For instance, I can say, "Siri, turn on the flashlight." Voila — the flashlight lights up!

Besides Siri, there are many other features on my smartphone that are a big help to me. I use my smartphone to pay bills and to stop and start the mail. I can use it to turn smart lights off (more on this later) and on in my home.

Here are other ways I use my smartphone to help me with my daily life:

- ◆ I use the voice app to send and check text messages and emails.
- ◆ I love to follow the news and instead of getting printed newspapers, I get *The New York Times* and local papers delivered right to my smartphone. I can also access the local, national, and international newsfeeds throughout the day.
- ◆ I attend virtual meetings from my phone, including virtual doctor's appointments.
- ◆ There are many helpful and free app programs you can easily install on your smartphone. My favorite app is Facetime, which lets me video chat with my grandkids.
- ◆ My smartphone is my camera and I take lots of pictures daily that I can easily share with my family and friends.

## VOIP (Voice Over Internet) to Connect with Others

Another way to stay connected is by using a service known as VOIP which stands for “voice over internet” protocol. You can use a smartphone, laptop, tablet, or desktop computer to connect with others over the Internet. Skype, Apple FaceTime, and Googletalk are some of the most widely used free software VOIPs. An added feature is that if the people you are connecting with also have the same VOIP software, the call is free anywhere in the world.

Smartphones and most laptops, tablets (touch-screen devices that are similar to a large smartphone), and desktop computers nowadays come equipped with webcams and built-in microphones and speakers. If you are using older model equipment that does not have a webcam, you may want to add a portable webcam so you can make video calls. Similarly, if your equipment lacks sound capacity, you may need to add a headphone and microphone. Portable webcams and microphones and headphones are fairly inexpensive.

## Email

Email is short for “electronic mail.” Email became widely used after the development of the Internet. Email allows people to send and receive written messages anytime anywhere in the world with an Internet connection. To use email, you need an electronic device such as a smartphone, laptop, tablet, or desktop computer, connection to the Internet, and an email account, such as Gmail, Outlook, Yahoo, iCloud mail, and AOL.

The following are some of the benefits of email:

- ◆ Emails can be sent anywhere in the world with an Internet connection at no cost.
- ◆ Copies of emails sent and received are automatically stored so that you can re-read them whenever you want.
- ◆ Email messages, unlike text messages, can be any length.
- ◆ You can start working on an email and finish it later.
- ◆ You can easily attach photos and document files to email messages.
- ◆ Email services include an email address book function, so you don’t have to remember people’s email addresses.
- ◆ You can “pin” or flag important emails to be able to find them quickly.



Despite best efforts, everyone ends up receiving spam or junk emails. Spam or junk mails are typically from companies wanting your attention and business. The major email accounts, such as Gmail, iCloud mail, and Outlook, have spam filter features to move these types of emails from your incoming email to a spam folder. Unfortunately, you will still end up with some unwanted email that you can simply delete.

## ***Four Signs That It's a Scam***

*From the Federal Trade Commission*

### **1. Scammers PRETEND to be from an organization you know.**

Scammers often pretend to be contacting you on behalf of the government. They might use a real name, like the Social Security Administration, the IRS, or Medicare, or make up a name that sounds official. Some pretend to be from a business you know, like a utility company, a tech company, or even a charity asking for donations.

They use technology to change the phone number that appears on your caller ID. So the name and number you see might not be real.

### **2. Scammers say there's a PROBLEM or a PRIZE.**

They might say you're in trouble with the government. Or you owe money. Or someone in your family had an emergency. Or that there's a virus on your computer. Some scammers say there's a problem with one of your accounts and that you need to verify some information. Others will lie and say you won money in a lottery or sweepstakes but have to pay a fee to get it.

### **3. Scammers PRESSURE you to act immediately.**

Scammers want you to act before you have time to think. If you're on the phone, they might tell you not to hang up so you can't check out their story. They might threaten to arrest you, sue you, take away your driver's or business license, or deport you. They might say your computer is about to be corrupted.

#### 4. Scammers tell you to PAY in a specific way.

They often insist that you pay by sending money through a money transfer company or by putting money on a gift card and then giving them the number on the back. Some will send you a check (that will later turn out to be fake), tell you to deposit it, and then send them money.

### What You Can Do to Avoid a Scam

- ◆ **Block unwanted calls and text messages.** Take steps to block unwanted calls and to filter unwanted text messages.
- ◆ **Don't give your personal or financial information in response to a request that you didn't expect.** Legitimate organizations won't call, email, or text to ask for your personal information, like your Social Security, bank account, or credit card numbers.

If you get an email or text message from a company you do business with and you think it's real, it's still best not to click on any links. Instead, contact them using a website you know is trustworthy. Or look up their phone number. Don't call a number they gave you or the number from your caller ID.

- ◆ **Resist the pressure to act immediately.** Legitimate businesses will give you time to make a decision. Anyone who pressures you to pay or give them your personal information is a scammer.
- ◆ **Know how scammers tell you to pay.** Never pay someone who insists you pay with a gift card or by using a money transfer service. And never deposit a check and send money back to someone.
- ◆ **Stop and talk to someone you trust.** Before you do anything else, tell someone — a friend, a family member, a neighbor — what happened. Talking about it could help you realize it's a scam.

You will need to manage your emails otherwise the volume of emails can become overwhelming. Move emails you want to keep to a **SAVED** folder. Delete emails you've read and don't need to save. When you hit "delete" the email goes into a **TRASH** folder. Routinely delete all the emails in the **TRASH** folder to free up space on your device.

Don't forget to run your security software to ensure that your device is virus free and to reduce the possibility of getting hacked. Ask for help if you don't know how to do this. If you are hacked, get professional help right away to protect your identity and your assets.

Contact your phone provider or the Federal Trade Commission site, [ReportFraud.ftc.gov](https://www.ftc.gov/Consumer/ReportFraud)

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*First thing in the morning and last at night, I check for any computer, smartphone, or app updates as this gives me confidence that hardware problems will not occur.*

*I like an empty in-basket so when I have replied, when I have taken appropriate action, or printed an important email for a more extensive action, I file it in the appropriate file. This reduces confusion and stress.*

*I don't have an Apple computer but I have an iPhone and iPad. I have the three devices synced so an appointment made in one syncs to the others. Likewise with my emails and files.*

*This makes my life so much easier.*

**Jim Mann, Manual Guide**



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## 6.2 Life Enhancement and Supporting Independence

Technologies are providing many life-enhancing benefits including helping to support our independence. Below are some of the technologies that offer helpful benefits for individuals living with dementia.

### Voice Activated Assistants

Voice activated assistants, such as Siri (from Apple), Google Assistant (from Google), and Alexa (from Amazon), can be used to play music and check the weather. Voice activated assistants can also be used to do all sorts of other things that are life enhancing and can help you maintain independence. Here is a sample:

- ◆ Answer your questions (everything from “where is Kathmandu?” to “what’s today’s date?” to “how do you say I love you in Spanish?”)
- ◆ Manage your calendar and remind you of events and appointments
- ◆ Create to-do and grocery lists
- ◆ Send text messages
- ◆ Provide reminders, such as where you put your keys
- ◆ Order things online to be shipped directly to you
- ◆ Turn on/off smart lights

Virtual assistants are accessible on smartphone, tablets, and computers, and on standalone devices, such as the Amazon Echo (Siri), Apple products (Alexa), and Google Home products (Google Assistant). According to a *PCMag* survey conducted in July 2021, the most commonly used virtual assistants are, in ranked order:

- ◆ Google Assistant (Google)
- ◆ Siri (Apple)
- ◆ Bixby (Samsung)
- ◆ Alexa (Amazon)
- ◆ Cortana (Microsoft)

*I use my smartphone calendar and alarms. When I'm somewhere and a new appointment is made, I put it immediately in my phone. I also make use of the calendar's two warning times so I can be reminded, for example, 60 minutes prior and again at 10 minutes. Depending on the tasks to complete for a meeting, I will sometimes have the first alarm set one week before and then reset it.*

**Jim Mann, Manual Guide**



## **Charging Pads**

It's easy to forget to charge smart devices, such as a phone, tablet, and watch, and to forget which cord charges which device. Charging pad devices can be a help with this. You simply lay your smart device on the charging pad to charge. The larger charging pads provide space for multiple devices at the same time. If you place the charging pad somewhere that's handy and visible, such as in the kitchen or next to your bed, you are much more likely to remember to charge devices — especially if you don't have to go searching for the power cords.



## ***Technology Helps Me Live Alone with Dementia***

### ***Mark Timmons, Manual Guide***

*I can ask Alexa a million times what day it is and she'll happily answer*

I live alone, so I have no one to remind me when it is time to take my daily medication. This is often a concern, as I always lose track of what time it is, what day it is, and even what year it is. Fortunately, I can use technology to help me manage my medication reminders and many other things.

I use a virtual digital voice assistant that recognizes spoken commands and can provide information. The virtual assistant I use is Alexa and it is available on Amazon's products. I have an Echo Dot in my bedroom, living room, and office. I have an Echo Show, a tablet device with a screen, on my kitchen table. Additionally, I have the Alexa app enabled on my smartphone. This set up provides me with access to Alexa almost anywhere I am.

Alexa is with me all day. For example, I get a daily wake-up call from Alexa. It's an easy set up.

1. "Alexa, set a wakeup call."
2. Alexa replies with, "OK, what time should I set your wake up call for?"
3. I answer, "6:30 a.m."
4. Alexa answers, "Your next 6:30 a.m. wakeup call is set. Do you want me to wake you up with the weather forecast for the day?"
5. I answer, "Yes."

Every morning Alexa wakes me up at 6:30 a.m., and then provides me with the current temperature and the weather forecast for the day.

I use Alexa for my medication reminders. I set this up through the Alexa app on my smartphone so I can direct Alexa to give this reminder to me on ALL of my Alexa devices. As a backup, I have a second reminder set up for 15 minutes later that simply asks, "Mark, did you remember to take your medication?"

I use an Echo Show because it has a screen so I can visually see things as well as hear things. For instance, I look at the Echo Show in the morning to see what is on my calendar for the day. While drinking my coffee I can follow things I like, such as a daily news briefing, sports scores, even Jimmy Fallon’s monologue.

Music plays a big part in my life. When I become confused or overwhelmed, music helps settle my brain and ground me. I use Alexa to play my favorite radio station, my favorite songs, a certain playlist, or my entire Spotify account on a specific device or on all devices at the same time! I really enjoy this because I can move from room to room listening and singing to the same song without missing a beat.

The lamps in my home all have LED “smartbulbs” that are compatible with Alexa. This means that I can program one, some, or all the lights to come on a certain time. I can choose the color and the intensity of the lighting as well. Using the app on my phone, I was able to set up a lighting routine with Alexa. At ten minutes before sunset, every day, my living room, office, hallway, and bedroom lights all turn on, at an intensity of less than 50 percent, in green. (I do not know why; I just like the color green.). I do not need to remind Alexa to do this — once programmed Alexa does the lighting automatically every day.

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*Music plays a big part in my life.  
When I become confused or overwhelmed,  
music helps settle my brain and ground me.*

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When I am ready for sleep, I can say, “Alexa, turn off all the lights” and my lights are turned off. If I forget to tell Alexa to turn off the lights, Alexa has learned my routines intuitively and will turn the lights off after I am asleep. The first time Alexa does this, Alexa will ask me the next day if this was the correct action to take. If I answer no, Alexa will keep the light on unless I tell Alexa to turn them off at night.

A benefit of Alexa for me is the lack of human emotion — especially aggravation. I can ask Alexa a million times what day today is, and she will happily answer every time. I have a reminder set up to remind me three times a day to write in my journal. Alexa is my go-to source for information about history, movies, music, famous people, news, sports.

I signed up for daily nutrition tips that I receive through Alexa. I can ask Alexa for a recipe and have it appear on my Echo Show screen. These are some of the ways I use Alexa, but this only scratches the surface of all the things Alexa can do.

## Ecommerce (Online Shopping)

The first major ecommerce platform consumers started using was Amazon. Amazon launched in 1995 primarily selling books online. In less than 30 years, online shopping has grown immensely, revolutionizing how people make purchases. According to Statista, 80 percent of the U.S. population shopped online in 2021.

Online shopping can be easy and convenient. Besides not having to leave home, online shopping offers access to a larger selection of items than stores, the ability to compare prices among sellers, and the opportunity to shop anytime, day or night. All you need is a device connected to the Internet, such as a smartphone, tablet, or computer, and a credit card.

According to the Federal Trade Commission, online shopping is the second most common area where consumers are impacted by fraud. Beware of scammers pretending to be legitimate online sellers that can abscond with your payment. For individuals living with dementia whose keen discernment skills may be diminished, it is recommended to shop online only with well known, reliable companies.

Always pay by credit card rather than a debit card. If you end up in a scammed situation, your credit card company can protect you and manage the fraud. **Never pay for anything online via a money transfer from your bank account.**

## Technology Assistance with Meals

### Grocery delivery

The revolutionizing of online shopping has also impacted grocery delivery. While not yet commonplace, purchasing groceries online is a growing trend. It saves going to a store, waiting in lines, and hauling the items home. With online grocery shopping, the groceries are delivered to your home. For people who don't drive, online grocery shopping is especially beneficial. Stores often charge a delivery fee making online grocery shopping more expensive, but the delivery cost and possible driver tip weighed against the maintenance cost of a vehicle (insurance, gas, tires, repairs, etc.) may make the delivery expense a bargain.

### Meal kit subscription services

Another growing food trend that makes eating at home easy are meal kit subscription services. While the meal kits are not technological, ordering them requires using a device connected to the Internet. Pre-ordered meal components are delivered to your home.



All of the ingredients needed for the meal are included in pre-measured portions with an easy-to-follow recipe to be assembled and cooked in your kitchen.

There are a number of companies offering meal kit subscription services, such as Blue Apron, Hello Fresh, Home Chef, and Freshly. There are a wide range of meal and diet choices at varying costs. For someone with dementia, meal kit services can be very beneficial. If assembling the meal is too complicated, you can order the meals and then invite a family member, friend, or neighbor over to help put the meals together.

### **Meal delivery from restaurants**

Another option for meals at home is to order fully prepared items from local restaurants and have them delivered to your home. Like meal kits, ordering meals for home delivery from restaurants needs to be done using a device connected to the Internet. (Note that there have been complaints that delivery services such as DoorDash and Grubhub have excessive fees — be sure to find out what the bottom line cost will be and if tipping is expected.)

## **Smartwatches**

Smartwatches became more commonly used once Apple's smartwatch hit the market in 2014. Since then, smartwatch capabilities and features have skyrocketed, and they now are basically wearable computers in the form of a watch. Think of things you can do on your computer, tablet, or smartphone; you can do these on your smartwatch as well.

There are some beneficial features of smartwatches. They can act as pedometers (to count your steps), fitness trackers including heart rate monitoring, and accelerometers for measuring how fast you are traveling.

If you're interested in buying a smartwatch, here are some things to consider:

- ◆ Comfort
- ◆ Size and display readability
- ◆ Battery life
- ◆ Water resistance
- ◆ Charging mechanism
- ◆ Price

## Wayfinding

Google maps is the most widely and commonly used Internet-based map and navigation app used worldwide. It is free and can be downloaded on your smartphone, tablet, or computer. Besides giving you directions, Google maps can help you locate nearby places (restaurants, banks, businesses, gas stations), get information (business hours, restaurant menus, distance between locations), and see the street view of sites, among many other uses.

Google map's blue dot feature is especially beneficial for people living with dementia. The blue dot feature can be used to mark where you parked your car, to share your current location with someone, and to let you know where you are if you get lost while out walking. It's an easy function to use. Open up the Google map app. A blue dot will appear on screen showing you where you are on the map. Tap that blue dot, and options will pop up that allow you to share your location with others or mark the place where you parked.

Other Internet-based free wayfinding apps include Waze and Apple map.

## 6.3 Engagement and Socializing

There is an amazing world of entertainment available online that offers a wealth of opportunities to learn new things, have fun, connect with others, and be stimulated.

You can access online activities using your smartphone, tablet, or computer.

Most likely you will need to download an app to access the engagement. Many engagement apps are available for free. The free versions often are accompanied by digital ads that can be confusing. Read reviews about the apps to identify ones that are highly rated, reliable, and work well for people living with dementia.

### Digital Photo Frames

A digital photo frame is a computerized device about the size of a picture frame that displays photos electronically in a slideshow-type format. You can set the slideshow of photos to display at whatever speed works best for you. The photos can be wonderfully entertaining and comforting.

Digital photo frames are an easy way to view lots of photos, plus they save the step of having to get photos printed. Some things to consider when purchasing a digital photo frame are:

- ◆ Battery or electrically powered
- ◆ Memory capacity
- ◆ WiFi connectivity
- ◆ Other features such as clock and calendar

## Games

Games on a tablet are a good way to introduce and encourage people to get familiar with the different finger movements on a touchscreen tablet. Games such as iFishPond, where you can touch the screen and make the water splash and go fishing are visually engaging, as are touchscreen games like Raindrops which plays musical notes or Fireworks that explode in color. You do not have to look for games that are specifically designed for people with cognitive impairment. Explore your interests to find games that are fun, interesting, and user friendly.

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*Explore your interests to find games that are fun, interesting, and user friendly.*

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Games can be a good way to introduce computers, as well as being fun. Search for websites that offer free versions of “traditional” games such as:

- ◆ Jigsaw puzzles
- ◆ Sudoku
- ◆ Crosswords
- ◆ Card games, such as Solitaire, Hearts, Gin Rummy

There are also digital games which appeal to the senses and can be fun and engaging. You can search online, using a search engine such as Google or Firefox, for games related to a person’s interests. Many games are free to access or download (though they may contain advertising) and most paid-for ones are low cost.

## Life Bios

Each of us has our own unique life story. Our lives are a collection of experiences that woven together make us who we are as a person. The process of developing your life story can be a wonderful activity for you to do and something precious for your family to have. You may want to invite a close friend or family member to help you write your life story. Besides being a fun way to spend time together, you can reminisce and jog each other's memories about your past.

There are many benefits to having a life bio, including:

- ◆ Life bios can serve as a way to remember aspects of your life that enhance your sense of identity.
- ◆ Life bios can help people develop closer relationships through sharing personal stories and learning some fascinating things.
- ◆ Life bios can be a way for non-family care partners to better personalize their support.

You can write your life story by hand, or type it on your computer. This makes it easier to share with others. There are online companies that can help you develop your life stories, such as LifeBio, 2nomi, and MemoryWell. You can also create your own; it does not need to be a major production. It can be a work-in-process project and not something that has to be completed all at once. The Dementia Action Alliance developed a free life bio template available online to make the process fun and easy.

## Robotic Pets

Robotic pets, such as cats and dogs, are becoming increasingly popular. Robotic pets are toy animals that have life-like features that include sound and movement, such as blinking or moving their heads. They are typically powered by batteries. Many robotic pets have sensors that respond to user movement and touch.

In 2018, New York State's Office for the Aging conducted a pilot study of robotic pets. Sixty older adults were provided with a robotic pet and tracked over a year. Seventy percent of the study participants felt less lonely at the end of the study. Then, in 2020 when New York's Department of Aging had to close its adult day programs due to COVID, the state provided over a thousand robotic cats and dogs to adult day program participants. A May 24, 2021, article in *The New Yorker* by Katie Engelhart noted that a few individuals living with cognitive impairment were disoriented by the robotic pets. One individual called her local aging department to report her cat wasn't eating. In general, though, people liked

the pets so much the batteries wore out. By April 2021, New York had given out 2,260 robotic pets and had ordered another thousand.

There is much research about the positive benefits of engaging with pets. While robotic pets are not a replacement for live pets, they can be wonderfully beneficial when having a live pet is not feasible or safe.

## Virtual Engagement

With smart devices growing more common and with screens for viewing, virtual platforms to share real-time content through the Internet evolved. Zoom, Microsoft Teams, and Facebook live streaming are some of the most well-known. A whole new world of engagement opened up with virtual technology. In addition to meeting others face-to-face on your screen, you can explore, learn, and experience a world of wonders from the convenience of your home.

There are countless virtual programs online — many for free — offering interesting, fun, and informational engagement. The following are some examples to get you started:

- ◆ Tour museums virtually through Google Arts & Culture, which teamed up with over 1,200 museums and galleries around the world to offer virtual tours and special online exhibits. [www.travelandleisure.com/attractions/museums-galleries/museums-with-virtual-tours](http://www.travelandleisure.com/attractions/museums-galleries/museums-with-virtual-tours)
- ◆ Experience some of the United States' best national parks from Florida to Alaska. [www.travelandleisure.com/trip-ideas/national-parks/virtual-national-parks-tours](http://www.travelandleisure.com/trip-ideas/national-parks/virtual-national-parks-tours)
- ◆ Watch the funny antics of sea otters playing or the hypnotic drifting of jellyfish from the Monterey Bay Aquarium. [www.montereybayaquarium.org/animals/live-cams](http://www.montereybayaquarium.org/animals/live-cams)
- ◆ Attend fun programs offered by the Dementia Action Alliance every weekday at 2 p.m. ET that are especially designed for individuals with cognitive impairment/dementia. [daanow.org/virtual-engagements/](http://daanow.org/virtual-engagements/)

## Virtual Reality

Virtual reality (VR) is a computerized system that allows users to view three-dimensional scenes by wearing a high-tech headset. Users are immersed in a virtual environment that can be explored and interacted with. People may be familiar with the concept of VR from video gaming. Now there are many applications for VR such as being able to enjoy realistic

travel experiences without leaving home. The virtual environment can be almost anything — limited only to the developer’s imagination. VR users can tour museums and historic sites, take a walk through foreign cities and parks, watch dolphins frolic in the ocean, and many more engaging and fun things.

Isolation and having fewer opportunities for socializing are commonly experienced by people living with dementia that can lead to becoming depressed and anxious. VR opens up a new way to engage with the world. Visiting a familiar place from the past can be comforting, touring a new city can be exciting and informational, and taking a walk along a beach can be calming. Experiences can be tailored to items of personal interest.

One small study conducted at a hospital in Kent, England, found that people living with dementia enjoyed experiencing 15-minute VR sessions and could choose among settings: a countryside, a sandy beach, a rocky beach, a cathedral, and a forest. The researchers found that these experiences helped trigger memories. (See [www.healthline.com/health-news/heres-how-vr-can-help-people-with-dementia#What-the-study-found](http://www.healthline.com/health-news/heres-how-vr-can-help-people-with-dementia#What-the-study-found))

## 6.4 Safety and Security

*There are so many products on the market now that make it easier to help you manage and keep safe in your home.*

Rev. Dr. Cynthia Huling Hummel, Manual Guide



### Digital Clocks with Date and Day of the Week

Feeling confused and disoriented are common symptoms experienced by individuals with dementia. This can include having trouble reading a regular clock face. A digital clock displays the time numerically (12:15) that may be easier to understand. Digital clocks that include the date (May 12, 2022) and the day (Thursday) are especially helpful.

Another helpful feature of digital clocks is the time display can easily be seen in the dark. If you wake up disoriented, seeing the digital clock display 3:00 am, for instance, can be helpful to know that it is not time to wake up yet.

## Kitchen Safety

It is easy to become distracted while working in the kitchen. There are a number of electronic devices that can help keep you safe from forgetting to turn off the stove or from leaving something cooking untended.

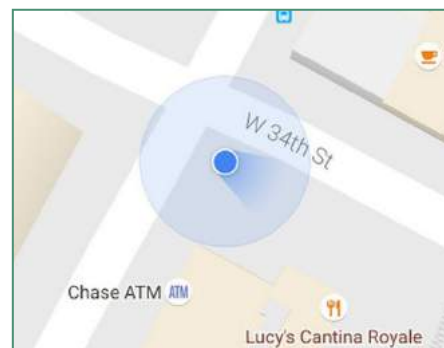
- ◆ Products such as CookStop use motion sensors to detect if there is no activity when the oven or stove is on and can shut them off.
- ◆ Electric tea kettles are a quick way to boil water. Make sure to get an electric tea kettle with an automatic shut-off feature.

## Location and Tracking Devices

### Location

Confusion and disorientation are common symptoms of dementia, especially if you are away from home. Online apps accessible on your smartphone or smartwatch can be very useful to help you maintain independence and safety while you're out.

As noted earlier, Google map's blue dot feature can be helpful. The blue dot feature can be used to mark where you parked your car, share your current location with someone, and let you know where you are if you get lost while out walking. It's an easy function to use. Open up the Google map app. A blue dot will appear on your screen showing you where you are on the map. Tap that blue dot, and options will pop up that allow you to share your location with others or mark the place where you parked.



### Tracking devices

If you have become disoriented while out walking, a family member and/or close friend may feel worried and concerned about your safety when you are away from home by yourself. One way to acknowledge their caring concern is to activate a free tracking app on your smartphone or smartwatch. This will relieve their worry, while allowing you to continue to be independent.

If you are a family member or friend, you might suggest this option. The individual will need to have some device with them when they leave the house that has technology that can transmit location, such as a smartphone or smartwatch. There are other options that offer location technology, such as wearing a pendant or using a SmartSole insert for shoes.

## Nightlights

Most of us need to use the bathroom in the middle of the night. It's not advisable to turn on lights to see the way as you don't want to become fully awake. Nightlights are important to have in your bedroom and bathroom. Nightlight technology has advanced to incorporate motion detection. If you plug in a nightlight in the bedroom, it comes on when it detects you getting out of bed. You can also have a motion detection nightlight in the bathroom. If you need to travel down a hallway to get to the bathroom, you will want a nightlight in the hallway as well.

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*Nightlight technology has advanced  
to incorporate motion detection.  
If you plug in a nightlight in the bedroom,  
it comes on when it detects  
you getting out of bed.*

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## Smart Home Technologies

If you are knowledgeable and savvy about technology, congratulations! You are well positioned for the 21st century and the ever-growing market of smart home products.

Not all of us, however, are savvy about technology, including knowing what products are available and would work best for your needs and lifestyle. If this sounds like you, there is good news. There are people/companies that offer consulting and installation services so you are able to utilize smart home technology to make your home life easier, securer, and safer. Having someone knowledgeable about smart home systems who can explain options and help you decide on products that best meet your needs and budget is a good investment. You don't want to end up buying products piecemeal only to find out they don't work together or do exactly what you thought.

A number of companies offer integrated suites of smart home technology products, including Google Nest, Amazon Smart Home, Apple HomeKit, and Samsung SmartThings Hub. Using the voice assistant or mobile app feature, the following are some of the things these systems can do:

- ◆ Activate smart lightbulbs and turn lights on and off and dim the lights
- ◆ Adjust the temperature inside the home



- ◆ Activate items using smart plugs such as coffee makers and music devices
- ◆ Make hands-free calls
- ◆ Set calendars and reminders
- ◆ Add items to a shopping list
- ◆ Activate smart home security including a security camera to see who is at the door
- ◆ Activate turning the TV on to a favorite program, changing channels, and controlling volume

As a security feature for falls or a health event, indoor camera systems can be programmed to send an alert notification to a family member's, friend's or neighbor's mobile device if there is no movement detected in a set period of time. There is more information on [fall safety](#) in the following section.

## 6.5 Health Management

### Fall Detection and Response Apps

Injuries due to falls are among the leading causes of hospitalizations for older adults. The World Health Organization reports that falls are the second leading cause of injury and deaths worldwide. The risk for falls increases the older we get as a result of decreasing physical mobility, strength and balance issues, poor vision, dizziness (side effect of some medications or blood pressure complications), and disorientation, among other causes. Technologies that can predict falls are in development.

If you do fall, what can you do? Most smartphones and smartwatches have gyro sensors that can detect when a fall has occurred. You can activate the fall detection setting on your smartphone or smartwatch. If you fall, the program is activated to send an alert to your emergency contact(s). There are also free apps that provide this feature, such as iFall (for Android users) and Google Maps. Remember, fall detection and alerts will only help you if you have the device on you. (For more on [falls](#), see *Supportive Home Modifications*, Section 4.7, page 246.)

## Medication Reminders

According to the Kaiser Family Foundation, 89 percent of adults 65 and older take prescription medications. Over half of those who take medications take four or more prescription drugs. Since memory loss is one of the main symptoms of dementia, remembering to take the correct medications on time can be challenging. There are many technologies that can help support you taking the right medications at the right time, including reminder systems, pill dispensers, and devices.

These are a number of apps to remind you when to take your medication and some apps can also remind you when to refill a prescription. Some of these apps are an audible reminder and others provide a visual alert. Medication reminder apps will not work if your phone has no signal, if you put your phone on silent, if your phone's battery runs out, or if you do not have your phone with you. There are also medication dispensers that will dispense the proper dose at the proper time, so that you don't take the medication more than once.

The following are some examples of apps that send you reminders to take your medications and can alert care partners about missed doses:

- ◆ MediSafe
- ◆ MangoHealth (for Android device users)
- ◆ RoundHealth (for iOS device users)
- ◆ DoseCast

## Medication Management



### ***A Survival Guide to Medication Management***

***Amy Goyer, Contributor***

Oct. 22, 2020, article reprinted with permission from AARP ([aarp.org/caregiving/health/info-2020/medication-management.html](https://www.aarp.org/caregiving/health/info-2020/medication-management.html))

One of my most time-consuming and stressful tasks as a care partner was managing multiple medications and supplements for my parents. Being responsible for getting their prescriptions filled and doggedly ensuring there were no adverse drug interactions or side effects was difficult. Tracking and sorting all of the pills, liquids, creams, nasal sprays, and eyedrops — and administering them all — was exhausting.

How did I survive? By finding practical ways to organize and track it all. Here are my top tips for making medication management easier.

#### **Organize for more than a week**

Many years ago I helped my parents get set up with pill organizers so that Dad, who had Alzheimer's disease, and Mom, who'd had a stroke, could better track their daily intake. For a time, Dad filled the boxes; my sister Susie filled them when it got too confusing and stressful for him.

When I moved to Arizona to care for my parents, I took over the task. I soon realized that by the time I got all the supplies out and filled one week's pillbox, it didn't take much more time to fill up a second week. Eventually I was filling two months' pill organizers at a time — a great time-saver that also made for fewer shopping trips or online orders.

The biggest problem I've had with pillboxes through the years has been finding a type that had individual compartments big enough to accommodate the plethora of pills my parents took. Before she passed away, Mom took various drugs five times a day (at one

time she had an alarming 23 medications, which I whittled down). I actually had to use two boxes for her — one with four compartments, plus a small, single-compartment box.

For Dad, who took pills twice a day, I used giant pill organizers with four rows. Each two rows held a week's meds. I'd fill four of those mega-organizers at a time, for an eight-week supply. Another time-saving option is presorted pill packets delivered directly from a pharmacy. Most of the major chains offer a 30-day supply, with each packet containing all pills to be taken with each dose.

There are also many technology-based pill organizers and dispensers that can help you plan.

## Create and maintain a list of meds

With a comprehensive list, it's less likely you'll forget anything while filling the pillboxes. It also helps ensure that any additional caregivers or an emergency-response person can easily find the information.

I recommend making a chart or spreadsheet, with at least these categories:

- ◆ Name of medication or supplement, and the strength (e.g., 600 mg tablets)
- ◆ Prescribing doctor's name and phone number
- ◆ Purpose (blood pressure, thyroid, dementia, blood thinner, pain, etc.)
- ◆ Dosage (for example: 600 mg, 1x/day; 25 mg, 2x/day)
- ◆ Comments (such as the generic name, special instructions, refill dates or auto-refill information)

I kept a copy of my list in a folder to bring for doctors' appointments or hospital visits. (Bonus: Medical staff will be thrilled and impressed that you have all of this necessary information at your fingertips. I received a lot of kudos from my parents' doctors over the years!)

## Take advantage of technology

Pillboxes and medication lists were my low-tech solutions, but I used some high-tech solutions, too. I made the meds list easily accessible at all times by creating it as a Word or Excel file on my computer, which I could access on my smartphone or tablet via a cloud storage app. (I used Dropbox, but there are several other free options.) I also kept a copy in my Evernote app and another in a caregiving app I used.

Some caregiving apps make the process easier by allowing you to add information about pills by simply taking a photo of the medication bottles (although I prefer to be able to add my notes and comments).

There are also amazing smart electronic pill organizers and dispensers that sound an alarm when it's time to take pills and send notifications to caregivers when meds have or have not been taken. Some of these devices hold multiple weeks at a time, but they may be limited to a certain number of pills in each dose.

Prices range from about \$15 for a simple pill organizer with alarms to more sophisticated dispensers that cost between \$150 and \$1,500. You can also set up motion sensors that notify you when your loved ones go to their pill organizers.

There are even robots that deliver medications in hospitals and long-term care facilities, so maybe one day we will all have one at home that can pop pills into our mouths!

**THE BOTTOM LINE:** Create a system, high-tech, low-tech or a combination of both, that works for you and your loved ones and ensures that the correct medications are being taken at the correct times. A little organization can save lives, ease pain and make everyone's life easier.

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Amy Goyer is AARP's family and caregiving expert and author of *Juggling Life, Work and Caregiving*. Connect with Amy on [amygoyer.com](http://amygoyer.com), Facebook, Twitter, in AARP's Online Community and in the AARP Facebook Family Caregivers Group.

## Medical Alert Systems



### ***How to Choose a Medical Alert System***

***Amy Goyer***

Oct. 22, 2021, article reprinted with permission from AARP ([aarp.org/caregiving/home-care/info-2017/medic-alert-systems-options.html](https://aarp.org/caregiving/home-care/info-2017/medic-alert-systems-options.html))

A medical alert system — often referred to as a personal emergency response system (PERS), medical emergency response system (MERS), health monitor or fall monitor — can provide increased independence for loved ones and peace of mind for family caregivers.

How do you find the one that's best for your situation? It can be complicated. Medical alert systems have evolved far beyond a basic, wearable device (like a bracelet or pendant) with a button that triggers a call to a response center in case of emergency.

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*Start by evaluating your loved ones' specific needs and abilities, present and future.*

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Now a medical alert device might include GPS, cellular connectivity, fall detection or prevention, in-home health and well-being monitors, activity trackers, movement sensors and more. Alert services might come with smartphones or as a feature of home security systems.

Start by evaluating your loved ones' specific needs and abilities, present and future. For example, if she has dementia, will she understand how to operate a system — or is something automatic, like a fall-detection device, more appropriate? Does he have a disorder that could hinder communication with a call center, like aphasia or hearing loss? Will limited fine motor skills make putting on a device or pushing a button too difficult?

Here are some key things to think about and questions to ask in choosing a medical alert system. Once you've made a selection, be sure to monitor how it is working. Don't hesitate to switch to another service if it isn't a good fit — it could save a life.

## What do you need it to do?

- ◆ **Fall detection.** Falls are perhaps the most common motivator for obtaining a medical alert system. Nearly 36 million older Americans a year experience a fall, and more than 1 in 5 falls causes an injury, according to the U.S. Centers for Disease Control and Prevention.
- ◆ **Call for help.** Devices with help buttons can connect the wearer to a live person at a response center or to emergency services such as the police or fire department. The button sends a signal to a base unit connected to a phone, which makes the call.
- ◆ **Medical monitoring.** Some systems can be set to monitor vital signs and provide medication reminders.
- ◆ **Cellular.** Mobile MERS can be used anywhere cellular service is available.
- ◆ **Location detection and tracking.** A device with GPS is especially useful if your loved one is still driving and relatively independent.
- ◆ **In-car.** These compact devices plug into your vehicle's 12V power outlet (what used to be the cigarette lighter) and have GPS capability. Some can be connected to a smartphone via Bluetooth.
- ◆ **Movement monitoring.** Motion detectors and beacons track movement in the home.
- ◆ **Daily check-in services.** Some monitoring companies will check in with your loved one every day, electronically or via a live phone call.
- ◆ **Activity and fitness tracking.** These have features like step counters to monitor healthy activity and fitness goals.
- ◆ **Virtual family connections.** Some systems enable users to make or receive ordinary calls, making it easy for family members and friends to check in.
- ◆ **Display time.** Alert devices might include a watch feature. Or vice versa: Some smart watches include health monitoring and fall-detection apps.
- ◆ **Home security monitoring.** The system detects danger from fire, smoke and carbon monoxide.

## What kind of equipment will work best?

- ◆ **Is it wearable?** You'll want a device your loved one finds comfortable. Look out for sharp edges, or strap materials that may irritate fragile skin. Also, is it attractive or unobtrusive enough that he or she will be willing to wear it?
- ◆ **Is it fully waterproof?** Can it be worn in the shower? Can it be fully immersed in water? Many falls happen in the bathroom and kitchen, so this is vital.
- ◆ **What's the range?** With an in-home system, find out how far the wearable help button can be from the base unit and still operate. That could be a real problem if, for example, your loved one falls in the yard or garage, or several rooms away from the base.
- ◆ **Is the speaker loud enough?** A care recipient with hearing loss might have trouble hearing the person at the response center speaking through the device or the base unit.
- ◆ **How's the battery life?** Also ask about the charging method and how you'll know if the battery is low.
- ◆ **Will it need technology updates?** If so, ask if the updates are implemented automatically or manually, and make sure you or your loved one is tech-savvy enough to manage them.
- ◆ **How do you set it up?** If there's a base unit or console, will you need more than one to cover the entire home and yard? Should the unit sit on a table or be wall-mounted? Is it plug-in or battery-operated? (If the former, does it have a battery backup if the power goes out?) Does it require a landline, and does it include cellular in case regular phone service is interrupted? Can you add stationary buttons around the home?
- ◆ **Is the system movable?** Not all medical-alert providers offer nationwide service (see below). If your loved ones move, can the system move with them?
- ◆ **Does it include a lockbox?** Some companies offer to install a lockbox that emergency medical personnel can access if they need to enter the home when the resident is incapacitated.
- ◆ **Can others connect via the device?** Some devices allow you to check in with your loved one through the alert system, using a monitoring app on your smartphone, tablet or computer.
- ◆ **Can it be added to a home security system?** Check with your home security provider. Be sure to ask if there is an additional fee.



## How do monitoring and response work?

- ◆ **Call routing.** Can you designate how you want various types of alerts/calls (urgent, nonurgent, emergency) routed? Is the system “monitored” (connected directly to a response center) or “non-monitored” (it dials numbers you designate, such as to a family member, neighbor or emergency services)? Some systems offer both options.
- ◆ **Response center.** Does the company operate its own response center or contract externally? Is the center certified? What’s the average response time? (It should be a matter of seconds.) Will your loved one be able to talk with a live person via the wearable device, and can the center communicate in your loved one’s preferred language if it is not English?
- ◆ **Customer service.** Quality customer relations are key. There should be a live person you can call 24/7 with questions about the service. You should also be able to contact the company via email or live chat. Look as well for an easy-to-navigate website with a comprehensive FAQ section.
- ◆ **Cybersecurity.** How does the company protect private information and prevent hackers from accessing your system?
- ◆ **False alarms.** It’s not uncommon for people to accidentally push the help button — is there a negative consequence if they do? Unlimited false alarms is a great feature.

## How much does it cost?

- ◆ **Fees.** Beware of complicated pricing plans and hidden costs like activation fees. Some companies include the cost of the device itself in the monthly service fee, while some charge extra for the equipment. Ask for a complete price breakdown; some features, such as fall detection, may cost more. Look for a company with no extra fees related to equipment, shipping, installation, activation, or service and repair. Watch out for offers of free service or “donated or used” equipment — they’re scams.
- ◆ **Contracts.** Don’t enter into a long-term contract. You should only have to pay ongoing monthly fees that typically range from \$20 to \$70 a month, depending on selected features. Be careful about paying for service in advance since you never know when you’ll need to stop it temporarily (due to a hospitalization, for instance) or permanently.

- ◆ **Guarantees and cancellation policies.** Look for a full money-back guarantee, or at least a free trial period, in case you are not satisfied with the service. And you'll want the ability to cancel at any time with no penalties (and a full refund if monthly fees have already been paid).
- ◆ **Discounts.** Ask about discounts for multiple people in the same household or for veterans. There might also be special deals available through membership organizations, health insurance or via a hospital, medical or care organization. See if the company offers reduced prices or a sliding fee scale for people with lower incomes.
- ◆ **Insurance.** For the most part, Medicare and private insurance companies will not cover the costs of a medical alert system (although some insurers offer discounts or referrals; check with your provider). In some states, Medicaid may cover all or part of the cost.
- ◆ **Tax deductions.** Check with your tax professional to find out if the cost of a medical alert is tax deductible as a medically necessary expense.

## Is it available where you live?

Many national companies offer medical alert services, but they may not all be available near you, so call and inquire about service areas. Local companies may be an option, too. In addition to companies that have been in the medical alert business for decades, technology and home security firms are now increasingly offering these services as well.

- ◆ **Do an online search.** Use keywords such as "medical alert systems," "personal emergency response systems," "fall detection devices" and "urgent response devices" along with the name of your city or state to find companies that serve your area. Check for customer reviews and complaints with the Better Business Bureau or your state's attorney general or consumer protection agency.
- ◆ **Contact your local Area Agency on Aging.** Find your local Area Agency on Aging via the federal government's Eldercare Locator and ask if it has a list of companies offering medical alert services locally. (I contacted mine, and it immediately emailed me a list of 16 national and local companies, including one that is offered through the agency itself.)
- ◆ **Check with your senior facility.** If you or your loved ones live in a senior community, it may offer an in-house or external medical alert system among

its services. Beware of facilities that only have pull cords in a few places throughout the room or apartment — people don't always fall or become ill within convenient reach of the cord.

- ◆ **Get referrals.** Ask friends and family members if they can recommend any medical alert systems they have used.

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Amy Goyer is AARP's family and caregiving expert and author of *Juggling Life, Work and Caregiving*. Connect with Amy on [amygoyer.com](http://amygoyer.com), Facebook, Twitter, in AARP's Online Community and in the AARP Facebook Family Caregivers Group.

## SUGGESTED RESOURCES

### General Supports

Older Adults Technology Services offers online classes to learn how to use technology	<a href="http://oats.org/world-class-programs/senior-planet-digital-2/">oats.org/world-class-programs/senior-planet-digital-2/</a>
Aging Connected helps older adults access affordable, accessible at-home internet if they don't have internet	<a href="http://agingconnected.org/">agingconnected.org/</a>
Cyber Seniors provides free technology support and training for older adults	<a href="http://cyberseniors.org/">cyberseniors.org/</a>
Tech Boomers specializes in free online courses for seniors	<a href="http://techboomers.com/">techboomers.com/</a>

### Charging pads

Belkin BOOST CHARGE™ Dual Wireless Charging Pads	<a href="http://www.belkin.com/us/chargers/wireless/charging-pads/boost-charge-dual-wireless-charging-pads/p/p-wiz002/">www.belkin.com/us/chargers/wireless/charging-pads/boost-charge-dual-wireless-charging-pads/p/p-wiz002/</a>
Samsung Wireless Charger Trio	<a href="http://www.samsung.com/ph/mobile-accessories/wireless-charger-trio-black-ep-p6300tbegww/">www.samsung.com/ph/mobile-accessories/wireless-charger-trio-black-ep-p6300tbegww/</a>

ZealSound Qi-Certified Ultra-Slim Triple Wireless Charger Station for Multiple 3 Devices

[www.amazon.com/Wireless-ZealSound-Qi-Certified-Ultra-Slim-Compatible/dp/B07D9KT4HP?ref\\_=ast\\_sto\\_dp](http://www.amazon.com/Wireless-ZealSound-Qi-Certified-Ultra-Slim-Compatible/dp/B07D9KT4HP?ref_=ast_sto_dp)

KeeKit 3 in 1 Wireless Charger, Foldable Magnetic Charger Station

[www.amazon.com/KeeKit-Wireless-Foldable-Magnetic-Charging/dp/B09Q58XSN9?ref\\_=ast\\_sto\\_dp](http://www.amazon.com/KeeKit-Wireless-Foldable-Magnetic-Charging/dp/B09Q58XSN9?ref_=ast_sto_dp)

Insignia™ - 20 W Qi Certified Dual Wireless Charging Pad

[www.bestbuy.com/site/insignia-20-w-qi-certified-dual-wireless-charging-pad-for-android-iphone-black/6409300.p?skuId=6409300](http://www.bestbuy.com/site/insignia-20-w-qi-certified-dual-wireless-charging-pad-for-android-iphone-black/6409300.p?skuId=6409300)

## Digital games and activities

### Apps

Fireworks Arcade is a free fun filled app for multi-touch and graphics (for both iOS and android devices users)

[www.bigduckgames.com/fireworks](http://www.bigduckgames.com/fireworks)

AquaLife 3D is a free app for users to create a 3D like aquarium (for both iOS and android devices users)

[www.fishgame3d.com/](http://www.fishgame3d.com/)

Joygage is an app that provides personalized on-demand activities and entertainment to people living with dementia

[www.joygage.com/](http://www.joygage.com/)

Lumosity app claims to improve brain function through the use of engaging brain exercises and activities

[www.lumosity.com/en/](http://www.lumosity.com/en/)

### Online Games

Jigsaw Planet — free online jigsaw puzzles

[www.jigsawplanet.com](http://www.jigsawplanet.com)

Solitaire— free online solitaire game

[solitaired.com/](http://solitaired.com/)

Word Search — free online word search puzzles

[thewordsearch.com/](http://thewordsearch.com/)

Chess — play chess online for free

[www.chess.com/](http://www.chess.com/)

## Digital photo frames

Aluratek Digital Photo Frame with Motion Sensor and 4GB Built-in Memory	<a href="http://aluratek.com/products/digital-photo-frames">aluratek.com/products/digital-photo-frames</a>
Feelcare Smart WiFi Digital Picture Frame	<a href="http://www.feelcaregroup.com/product.html">www.feelcaregroup.com/product.html</a>
Nixplay 10.1 inch Smart Digital Photo Frame with WiFi (W10F) - Share Photos and Videos Instantly via Email or App	<a href="http://www.nixplay.com">www.nixplay.com</a>
Atatat 10 Inch Digital Photo Frame	<a href="http://www.atatat.site">www.atatat.site</a>

## Fall detection and alerts

FallSafety Home is a free to download app (for both Apple and android users)	<a href="http://fallsafetyapp.com/fallsafety-home">fallsafetyapp.com/fallsafety-home</a>
Fall Detect App	<a href="http://aetsoft.net/products/fall-detection-app/">aetsoft.net/products/fall-detection-app/</a>

## Life Bios

LifeBio	<a href="http://www.lifebio.org/">www.lifebio.org/</a>
2nomi	<a href="http://2nomi.com/">2nomi.com/</a>
MemoryWell	<a href="http://www.memorywell.com/">www.memorywell.com/</a>
GreyMatters	<a href="http://www.greymatterstous.com/">www.greymatterstous.com/</a>

## Medication reminders

MediSafe	<a href="http://www.medisafe.com/">www.medisafe.com/</a>
RoundHealth (for iOS device users)	<a href="https://apps.apple.com/us/app/round-health/id1059591124">apps.apple.com/us/app/round-health/id1059591124</a>
DoseCast	<a href="https://apps.apple.com/us/app/dosecast-my-pill-reminder-app/id365191644">apps.apple.com/us/app/dosecast-my-pill-reminder-app/id365191644</a>
MyTherapy	<a href="http://www.mytherapyapp.com/">www.mytherapyapp.com/</a>

## Night lights

VONT Lyra LED Night Light	<a href="http://www.vont.com/product/plug-in-led-night-light-with-dusk-to-dawn-sensor/">www.vont.com/product/plug-in-led-night-light-with-dusk-to-dawn-sensor/</a>
GE Enbrighten LED Motion Sensor Night Light	
Motion Sensor Night Light	<a href="http://www.techsilver.co.uk/product/motion-sensor-night-light/">www.techsilver.co.uk/product/motion-sensor-night-light/</a> (NOTE: This is a British company. Click on US Dollars at top right to order.)
Sengled Smart Light Bulb	

## Smart home systems

Apple HomeKit	<a href="http://www.apple.com/shop/accessories/all/homekit">www.apple.com/shop/accessories/all/homekit</a>
Google Nest	<a href="http://store.google.com/us/?hl=en-US&amp;regionRedirect=true">store.google.com/us/?hl=en-US&amp;regionRedirect=true</a>
Amazon Smart Home	<a href="http://www.amazon.com/Smart-Home/b?ie=UTF8&amp;node=6563140011">www.amazon.com/Smart-Home/b?ie=UTF8&amp;node=6563140011</a>
Samsung SmartThings	<a href="http://www.smarthings.com/">www.smarthings.com/</a>

## Tracking devices

### Products

SmartSole is a GPS tracker sealed within a water-resistant, trimmable shoe insert	<a href="http://www.gpssmartsole.com">www.gpssmartsole.com</a>
Garmin Vivofit Fitness Band is a fitness band with built-in GPS	<a href="http://www.garmin.com">www.garmin.com</a>
AngelSense is a GPS tracker that provides a daily timeline of locations, routines and transit speed and sends an instant alert to care partners if their loved one is in an unfamiliar place	<a href="http://www.angelsense.com/gps-tracker-for-elderly/">www.angelsense.com/gps-tracker-for-elderly/</a>

Care Band Wearable is wearable, activity and location monitoring wristband to proactively manage dementia

[www.carebandremembers.com/products/](http://www.carebandremembers.com/products/)

## Apps

Life360 is an app that lets users share locations, group message, and call for roadside assistance. It has both the paid and premium services

[www.life360.com/intl/](http://www.life360.com/intl/)

Google Maps is a free app for real time GPS navigation and location sharing

[www.google.com/maps](http://www.google.com/maps)

iSharing is a free location tracking app to track family members real time and it comes with alerts

[isharingsoft.com/](http://isharingsoft.com/)

Boundary Care is a location-tracking app for iPhone and Apple Watch, specially designed to help care partners keep track of people living with dementia

[apps.apple.com/us/app/boundarycare/id1474130809?mt=8](https://apps.apple.com/us/app/boundarycare/id1474130809?mt=8)

## Virtual reality

Rendever platform and live programming delivers engaging group experiences using virtual reality (paid service)

[www.rendever.com/](http://www.rendever.com/)

MyndVR Headset and Tablet helps reduce anxiety, makes therapy fun and stimulates memory and cognition (paid service)

[www.myndvr.com/](http://www.myndvr.com/)

Meta Quest 2 is a standalone headset, simply slide it on and immediately ready to get started

# SECTION 7: Care Partnering

## 7.1 Care Partnering — Gifts and Challenges

This section of the manual is devoted to care partners and is mostly written by care partners with love, grace, humor, and creativity. The insights, experiences, and wisdom they share are good shoulders to stand on.

The manual uses the term “care partner” to acknowledge reciprocity, respect, and partnership in the relationship. With advanced symptoms you may not feel you are in a partnership. You may feel you are shouldering everything. But as many of the stories in this section demonstrate, even when symptoms advance, the person living with dementia has gifts to share — although in different and unexpected ways than before. Some of our contributors prefer to use the term “loved one” to refer to the person living with dementia. We recognize that some care partners have had fraught relationships, and they may be providing support more out of a sense of obligation or duty than love. We hope you can adapt the language and the lessons here to fit your own circumstances.

Care partners can be an adult child, a spouse/partner, a sibling, a grandchild, a parent (of someone living with younger onset dementia), another relative, or a friend. According to the Alzheimer’s Association in its 2021 report *Facts and Figures*, 11 million people provide unpaid care to people living with dementia. Of these:

- ◆ Roughly two-thirds are women
- ◆ Over half are adult children or in-laws
- ◆ Two-thirds reside with the person living with dementia
- ◆ Thirty percent are over the age of 65

The report notes that even as care partners describe high levels of depression and anxiety, many also express positive feelings about this role:

- ◆ Forty-five percent of care partners in a national poll said that caring for someone living with dementia was “very rewarding.”



- ◆ Many care partners describe feeling good about family togetherness and a sense of helping others.
- ◆ Those with support from other family members and friends expressed greater satisfaction than those without such support.

Dementia is known as a companion condition; it affects not only the person who is living with it, but also their family, friends, and the larger community. You unexpectedly are along on a journey of support that will be unique to you and the person in your life living with dementia. While it is not a chosen journey, with a positive and proactive attitude, it can be a time filled with many good things.

“Family care partnering can be cast in such a tragic way,” says Jennifer Carson, dementia specialist at the University of Nevada, Reno, and care partner to her father. “And sometimes it can feel like the 36-hour day. But where is the message about the possibility of growth or reciprocity or interdependence? There’s a lot of focus on care partner burnout, discussed widely in the literature. Having this kind of terminology doesn’t help bolster me as a family care partner. These messages are disheartening. They contribute more stress to my own thinking about my experience.”

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*Dementia is known as a companion condition;  
it affects not only the person who  
is living with it, but also their family,  
friends, and the larger community.*

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Sherry Dupuis, a dementia specialist with the University of Waterloo in Canada, observes the difference in perspective that she’s often found between the person living with dementia and the care partner. “I’ve been doing this a long time,” she says. “People living with dementia really want that positivity, that hope. They don’t want to think about the future. They plan for it and that’s important, but they want to get on with living their lives. For care partners, it’s a different experience. They wanted to focus on the negativity and how to cope which is completely understandable.” Navigating those feelings to strengthen and build relationships is critical for the well-being of all, she says.

We hope you find valuable strategies, wisdom, and inspiration from the following care partner narratives.

## 7.2 Transforming the Narrative from Tragedy to Thriving



*Pat McHenry Sullivan, Contributor*

“Thriving with dementia” is a notion I first discovered when I found the Dementia Action Alliance in late 2019, shortly after my husband John was diagnosed with dementia, likely Alzheimer’s with possible Lewy bodies.

On the site’s “Hear Our Voices” section, I heard many unique stories with common themes of how to find inspiration, hope, and solid support by being proactive with dementia. Here are some samples of insights:

*At first, the diagnosis led to despair. Then I faced the disease head-on and found many allies and resources.*

*Many of my allies live with dementia of different types. Others are care partners, meaning we all give to and receive help and inspiration from each other.*

*While dealing with dementia, I’ve mourned the loss of some cherished faculties. I’ve also developed resilience, empathy, creativity, and other gifts that too often get lost in our normally over-busy world.*

*If thriving is defined by doing the best we can for ourselves and others, standing together in authentic community, sharing sorrows and joy, being as creative and purposeful for as long as possible as well as possible, I thrive big time.*

*... Even when all I can give in the moment is our presence.*

Everyone has his or her own definition of what it means to thrive with dementia, and our definition is yet to be written.

Here are some measures that mean thriving to us:

Our marriage has never been richer. Much of the credit for this comes from our acceptance that “this too will pass,” and our agreement to seize the joy of today.

We accept the probability that if John lives long enough, one day his memory and language of words will fail.

That calls us now to expand and enhance ways to communicate through touch, silence, music, laughter, and other ways we don’t yet know. We hope that dedicated practice now will help us connect mysteriously even in later-stage dementia.

We take inspiration from former professional ballerina Marta Cinta González Saldaña, whose viral video shortly before she died in 2019 shows how she re-awakened to body and performance memories of Swan Lake to dance beautifully in her wheelchair. (See [www.youtube.com/watch?v=IT\\_tW3EVDK8](http://www.youtube.com/watch?v=IT_tW3EVDK8))

I'm inspired by care partner role models like the one in the Saldaña video: never controlling, attentive to cues as simple as Saldaña's hand motions to make the music louder. I'm to be with John not as a therapist, which I'm not, but simply to encourage him, human to human, to try again when it's emotionally or physically difficult.

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*'Keep on doing what you are doing,'  
the doctor told us.  
'It's working.'*

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Our vulnerability and deepening commitment to each other is a solid ground where intimacy grows. John's poor short-term memory erases details of what happens day to day and the names of the practices we use to enrich our lives, but the essence of what we do together — at least for now — he can remember.

John's neurologist recently confirmed that though John sometimes exhibits moderate-stage characteristics, he's still in the early stage of dementia — 14 years after he first was diagnosed with mild cognitive impairment.

"Keep on doing what you are doing," the doctor told us. "It's working."

Our doctor knew when he said "it's working" how much we have benefited from the work of DAA, Dementia Mentors, Re-Imagining Dementia, and a plethora of arts, spiritual, somatic, and other strategies. (For more on [Creative Things to Try](#), see Section 7.9, page 370.) He also knows that what we do to make ourselves and our marriage happier supports our medical and dementia needs, and vice versa.

**We can't possibly thrive alone or without blessings from others, including the natural world.** As you meet some of the allies and resources in our unintended spiritual, creative, and heroic journey, hopefully you will discover tips or ideas you can use now. You might also adapt or use them as a springboard to discover your own ways to thrive. Everyone's needs, dreams, hopes, and challenges are different. "If you know one person with dementia," it's often said, "you know one person with dementia." Also, "Nothing about us without us" reminds us not to assume as care partners that we know what's best for a person with dementia. Instead, we're guided to find our best way of providing person-centered care.

**We can overcome stigma and its impact by practicing blessing.** By “blessing,” I mean the simple act of seeing each other and ourselves as we are. Here’s an example of some steps in blessing:

- ◆ *I see you. I see you as you are, not as I wish or fear you to be.*
- ◆ *Seeing you, I engage with you and am willing to be impacted by you.*
- ◆ *Engaging with you, I call forth the best in you and for you.*
- ◆ *I am willing to roll up my sleeves and support your best life.*
- ◆ *You define and discern what is best for you for as long as possible.*
- ◆ *Through our engaged relationship, we both can thrive.*

When we are in a state of blessing, we’re present. Agendas, entrenched beliefs, and assumptions drop away. This supports creativity, playfulness, curiosity, wonder, intuition, and other natural gifts for making the most of life, individually and together. By contrast, the common curse of stigma makes it difficult or impossible to see each other as we really are, which means we can’t discover our best ways to thrive with dementia or even to manage it well.

The worst curses are not versions of “Damn you to this bad fate where the worst possible thing can happen to you,” but versions of not seeing and engaging with others.

Here’s an expression of that type of curse as applied to dementia:

- ◆ *I don’t see you or want to see you. I may ignore or look past you.*
- ◆ *I project upon you my fears and desires.*
- ◆ *Not seeing you as you are, I don’t engage with you.*
- ◆ *Not engaging with you, I don’t see or appreciate your worth.*
- ◆ *I don’t see your true needs, dreams, or potential.*
- ◆ *While doing “caregiving,” I am not really caring.*

Underlying this curse are projections of our own and others’ unwillingness to face such unspoken fears as “what if something like this happens to me? What if I’m shamed when people discover I have no clue about how to deal with dementia? What can I do to protect myself from being swallowed up by others’ needs?”

Habits of not confronting dementia worries can easily lead to shame and the story that dementia is necessarily a tragedy filled with doom and gloom. A few false assumptions that come from this narrative are:

- ◆ Dementia is either a rapid or dreadfully slow journey into a meaningless vegetative state.
- ◆ Having dementia is shameful, not to be discussed.
- ◆ There's little you can do to thrive with dementia other than hope for a cure.
- ◆ There's no such thing as care partners. The person with dementia is the receiver, their caregiver needs to serve to the point of martyrdom.

The tragedy narrative can easily turn into a vicious cycle of silence, fear, and increased misinformation. The less we face the stigma and our personal concerns, the worse are the outcomes:

- ◆ Most people don't investigate the possibility of dementia until they are in later stages, which is too late to create an optimal relationship for thriving with dementia.
- ◆ Stigma keeps us from sharing our needs, dreams, tips, and resources, as we might do with other challenges, such as cancer.
- ◆ Too few doctors and their patients know how to thrive with dementia.
- ◆ Too little money is allocated to creating and publicizing dementia breakthroughs like those reported in this manual.

Refusing to accept stigma and the tragedy narrative is a gift to ourselves and others.

The earlier we face the possibility of a dementia diagnosis, the more likely it is that (1) we as care partners can build a relationship to support thriving with dementia and (2) discover and treat conditions that may mimic dementia, such as brain trauma, Lyme disease, or dehydration.

Once we get beyond the stigma and tragedy narrative, we can access our natural gifts such as curiosity and imagination. We can then discern what strategies could help our partner (1) reduce the risk of dementia, (2) delay its onset or progression, and/or (3) thrive with dementia for as long as possible.

## 7.3 What's Grief Got to Do with It?



*Lynette Wilson, MSN, RN, Contributor*

We typically think of grief as a response to the death of a person. However, grief is really a natural human response when we lose anything that we love. We experience grief when we go through a divorce, watch a pet die, or give up our social support because of a move to another city. At its core, grief is a process of letting go and learning to accept and live with a loss. Whether we are aware of it or not, grief is a constant companion during the dementia journey.

How intense grief is, what it feels like, and how long it lasts is individual for every person and for every loss. There is no right or wrong way to grieve and no specific timeframe. Grief doesn't go in a straight line, but back and forth, up and down, and sometimes in circles. We don't "get over" grief, but its intensity lessens over time.

So what helps today? Following are some suggestions for learning how to cope with the grief you experience as a care partner.

- ◆ **Acknowledge losses as they occur.** You can do this either in writing or verbally, privately or with someone else. Try writing the loss down on a piece of paper, dating it, and putting it in a box or include the loss in your journal if you are keeping an ongoing record of life during the dementia journey. Although I have always enjoyed writing, I found it impossible to journal during our life with dementia. But I did frequently share losses with our daughters verbally.
- ◆ **Allow yourself to grieve.** Remember there's no right or wrong way to get through this. Allow yourself to feel however you feel. Grief does not mean you are giving up hope; it just means that you are aware of change and what has been lost. Healing happens if you grieve along the way. You may feel sadness, hopelessness, loneliness, and anger. You can also grieve by being proactive — getting practical information on dementia, finding solutions to the problems you face daily, or doing comforting things for yourself and for the person living with dementia. Most people experience grief through some blending of these styles.
- ◆ **Find ways to take control.** Nothing feels worse than being out of control. Gaining knowledge about what to expect or how to respond to changes related to the impacts of dementia is a powerful way to take control in a situation where you can't change the diagnosis or the ultimate outcome. Even when you can't control what is going on around you, you can learn to control your thoughts, actions, and reactions.

- ◆ **Maintain a sense of humor.** I found that there were many truly funny things that happened during our dementia journey. I chased turtles and alligators from the bathroom, listened to explanations for why the horse wanted to go out to play, and had my foot peed on multiple days in a row because getting him seated on the toilet took far too much time. My husband and I frequently laughed together when he said something that made no sense but was clearly funny to him. I cherish those moments when he was very happy.
- ◆ **Find and create moments of joy.** We often focus only on our connection to others through verbal communication. Since language abilities are lost to varying degrees during dementia, focus instead on what is communicated through tone of voice, body language, touch, and other nonverbal ways. Being outside in nature or listening to music that you both enjoy allows you to share connections that do not depend on talking.
- ◆ **Connect with others.** It's easy to lose connections with others when the demands of everyday life are great or when we are simply too sad to try. Spending time with people who are understanding and supportive gives you insight and energy to keep going. This support may come from family, friends, or members of a dementia support group. Be willing to accept help from others and don't be afraid to ask for help if you need it. And finally, seek counseling if you are finding yourself so overwhelmed or hopeless that it is difficult to function.
- ◆ **Practice forgiveness.** This includes forgiving those who disappoint you by not "showing up" in the way you had hoped and forgiving yourself for not being perfect. Confusion and doubt are not signs of failure. Remind yourself frequently that both you and the person with dementia are doing the best you can every minute of every day no matter what doing your best looks like at a given moment.
- ◆ **Take care of yourself.** Eat well, sleep, exercise. The question of how to be a good care partner has many answers but taking care of yourself is always one of them. You are now the most important individual in the life of the person with dementia so finding time for yourself and for participating in some activities that are normal for you is essential.
- ◆ **Find meaning in what you are doing.** Accept that you will never know the answers to all your questions or find the solutions to all your problems but have confidence and faith that things will work out. Give yourself credit for successes and for your ability to cope in an extremely difficult situation. Being able to find meaning was what did the most to get me through 10 years as a dementia care partner. I believe that we always have the option to choose to learn from what we are going through and to turn that learning into positives for ourselves and for others in our lives.

- ◆ **Consider holistic methods of coping.** These methods include guided imagery, meditation, and mindfulness. There are multiple apps available that can be used to practice these skills at home. Massage and acupuncture are often used to help with stress reduction. You can also express your feelings through art, music, and journaling.

One of my favorite quotes related to loss, grief, and coping is something Christopher Robin says to Winnie the Pooh in the book *Pooh's Grand Adventure*. It goes like this:

*If ever there's a tomorrow when we're not together,*

*there's something you must remember ...*

*You're braver than you believe,*

*and stronger than you seem,*

*and smarter than you think.*

What a mantra for care partners as they deal with the grief that is an unavoidable part of the dementia journey!

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*The question of how to be  
a good care partner  
has many answers  
but taking care of yourself  
is always one of them.*

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## 7.4 Reframing Living with Dementia: 5 Ps



*Pat Snyder, Contributor*

My long journey with my late husband, who had Lewy body dementia, and my many interactions with other dementia care partners taught me what a difference our attitudes truly can make in our experience of the condition and our whole family's experience of it. For those of you who are new to living with dementia and those of you who may feel disheartened,

I am hoping this message will give you a new way to reframe how you see yourself as a care partner. Even though you must accept the reality of the diagnosis, that does not mean it totally controls your life going forward. A reframed acceptance means you now take action to learn all you can about how to manage symptoms and how best to live with them.

I found several actions to be truly helpful. I call them *the 5 Ps*:

- ◆ **Be positive**
- ◆ **Be proactive**
- ◆ **Be perceptive**
- ◆ **Be persistent**
- ◆ **Preserve your loved one's personhood**

### Be Positive

You can have a negative attitude, but what's the benefit in that? I am not talking about a denial of reality, but, rather, having a positive attitude. Living with dementia is tough. As care partners, we need the most effective tools we can find. Research has proven that positivity builds resilience in those who practice it. Besides, having a positive attitude is free, and it will benefit your well-being.

Negative energy drains us. Positive energy strengthens us. We need all the resilience and strength we can get for this marathon called care partnering. Now ... how do we do that?

When you feel consumed by a negative feeling, identify and acknowledge it. This is **self-awareness**. Take time to pause and reflect about what is happening to you inside. Then choose to take action that will *neutralize* or *minimize the impact on you*.

For example:

- ◆ **I feel sad** ... so ... I am going to call a friend who will listen and make me laugh ... or I am going to watch an old TV show that made me laugh. You are using the laughter to neutralize the sadness.
- ◆ **I feel angry** ... so ... leave the room and take three slow deep breaths and center yourself.

## Be Proactive

Be proactive instead of reactive. Rather than reacting as things unfold, try to anticipate issues by educating yourself (join a support group or go online) and staying ahead of things in a proactive way. Find out what resources or tools are available where you live and how to access them.

Being proactive means being willing to speak up when you know something is not right. You are your loved one's advocate — their voice. Share what you are learning with others — especially medical professionals who may not be as familiar as you would hope about your loved one's form of dementia.

It is important to do your homework as a care partner. Learn what you need to know, so that you can ask key questions when you are at a doctor's appointment. "Could we try [another med] for that symptom?" or "What could be causing this symptom?"

Establish a team to support you and your loved one (see [Who Should Be on your Healthcare Team?](#), Section 5.2, page 277). Doing so will feel empowering. Find a knowledgeable doctor who listens to your loved one and to you. Who else should be on your team? Caring, supportive friends, family members, neighbors, and colleagues are a good place to start. Many people find going to a therapist very helpful.

Consider a therapist for the whole family. Having a loved one living with dementia emotionally impacts everyone. A therapist can help you and your family navigate coping skills, communication issues, relationship dynamics, forgiveness of past hurts, and grief issues.

## Be Perceptive

Tune in to what is happening around you. Ask others you trust to be objective about your circumstances and what things are priorities to address. It's difficult to be objective when you are in a situation. Trusting others can be hugely helpful in seeing things you might not. Being perceptive helps you to be insightful and sensitive — valuable assets for a care partner.

Be sensitive to your loved one's symptoms. Record changes in physical, psychological, and behavioral symptoms. Report these to the doctor and work together to find solutions. Identify specific triggers that affect disease experience, such as:

- ◆ Multiple people speaking at once
- ◆ Forgetting to explain what you are about to do before you begin
- ◆ Too much change from routine
- ◆ Loud voices or sounds
- ◆ Wrong lighting
- ◆ Rushing
- ◆ Too many choices

## Be Persistent

Persistence is the opposite of being passive. You stick with your plan. You don't give up. You don't take no for an answer when you are advocating for your loved one. It is a daily choice to be positive, proactive, and perceptive. Be persistent about **taking breaks**, too!

Be persistent about managing stress levels, both for yourself and for your loved one. In many instances, changing my expectations resulted in reduced stress. When I felt less stressed, I found I was calmer all around and could better deal and handle daily life. Knowing that positive outcome was a good motivator and reminder whenever I felt stressed.

## Preserve Your Loved One's Personhood

John did not become his dementia condition. His dementia became just one aspect of who he was as a person. What helped me was separating in my mind and heart actions and emotions that were caused by his Lewy body dementia from other actions and emotions. This allowed me to continue to see and enjoy the continued essence of the human being John was. I gave his dementia a name — Lewy. Then when Lewy reared its head, I could blame Lewy instead of John.

I used this technique with our grandchildren. I would say to my grandsons, "That is just mean old Lewy talking to you right now. Your Pops would never speak to you like that. Pops loves you." "Leave the room if Pops looks mad or does something mean. That's just old

Lewy, not your Pops. Wait a bit and go back to Pops later.” It gave them something to blame and preserved the personhood of their grandfather.

So, to recap:

- ◆ Be positive
- ◆ Be proactive
- ◆ Be perceptive
- ◆ Be persistent
- ◆ Preserve your loved one’s personhood

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*One way to be a family caregiver is to take the time to figure out every resource in your community: Does your church have a day program? Can someone cover two hours a day to help you? People think they have to do it all themselves. You need to pull people together. If one has financial skills, ask them to pay all the bills. If you live half an hour away, come twice a week and take them to dinner or cook meals to drop off. When family and friends ask how they can help, have a list of 10 things that need to be done.*

Tia Powell, MD



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## 7.5 Caring for a Parent



*Molly Fisher, LCSW, Contributor*

As the adult child with a parent living with dementia, there can be a lot to consider. If you're feeling overwhelmed, breaking down pieces into manageable chunks is very helpful.

### Where to Start?

Start with an open and honest conversation with your parent(s). It is really important for you to share your thoughts and feelings about what is going on, even if you think that your parent(s) may not listen.

When my father was experiencing memory loss and confusion, you could see he knew what was happening. I encouraged him to see a doctor, to get a better sense of what he was working with. I remember it so clearly — we were sitting in his room. He was sad. He said he could tell something was wrong and knew what they were going to say. I said that knowing could mean that there are things we can do to help maintain the cognition he has and the potential for participating in studies or in trying medication. I let him know there was a lot of my life he still needed to see — to walk me down the aisle, to meet my children.

It's helpful to get the family (whether of origin or of choice) together so everyone has a chance to understand the situation and to discuss it. The person living with dementia should absolutely be included in this conversation, and if possible, lead it. Leading a discussion about something as important as dementia is empowering and enabling for the individual and a good chance for the family to begin practicing, if not already doing, empowerment and enablement. These are two powerful tools to help support the well-being of the person living with dementia.

If direct, in-person communication isn't possible, consider a video discussion. If you and your parent(s) are estranged, consider writing a letter and not sending it. This can be a cathartic, expressive experience. Think of it as writing in a diary or journal. Or use this as an opportunity to reconnect.

## How Much Support Can I/Should I Provide?

Guilt? Shame? Frustrations? Resentments? Many adult children (and spouses/partners) may experience some or all these feelings throughout the course of a dementia-related illness. Take an honest look at your life. What are your commitments, where are you in proximity to your parents, how much time can you give without jeopardizing work, family, and other obligations?

Be open and realistic about what you can do and cannot do. Having a team is very important because no one person can do it all. (See [Who Should Be on your Healthcare Team?](#), Section 5.2, page 277)

If you have had a difficult or estranged relationship, it is okay to not want to give too much of your time, if any. If you don't know what to do or how to handle the situation, speaking with a therapist who has expertise working with families living with dementia can be very helpful.

Try not to listen to unhelpful voices. So what if your friend says they could never imagine placing their parent in assisted living, or judge you for not calling your mom weekly? Relationships are complicated — and not everyone will understand this. Trust your gut. If you know that making this commitment to help care for your parent is going to negatively impact you, that is something to recognize — whether with your partner, therapist, or family. Care partnering is stressful, no matter what the relationship, so if this is creating anxiety, triggering past traumas or somatic experiences, think before you act.

## What If I Don't Live Close?

Long distance care partnering can be a challenge. Try to build a team in the same location as your parent. Bringing in a geriatric care manager (also called aging life care manager) is a good place to start, even if it's just a conversation or initial assessment.

Talk with siblings, if applicable, and set the expectations about what each is willing and able to do. Discuss the pros and cons of a move for your parent(s) to be closer to you, or you closer to them.

Try to be realistic. Is your home age-friendly in its design (e.g. stairs)? Do you have young children whose energy can be disruptive to the person's schedule and need for calm as they progress through their illness? Is your spouse on board, as this can create a strain for you, individually or as a couple?

If you can, commit to a set schedule for visits. This way, other care partners and the person living with dementia know when to expect you. Video calls are a great tool for continued contact when you can't be close.

Explore other ways you can contribute, whether it's sending groceries, researching treatments and care options, creating playlists of favorite music, or providing support to siblings and your well parent via daily or weekly calls. Utilize support groups for long-distance care partners.

## **What If My Siblings and I Don't Agree?**

Siblings can be a situation in and of themselves. It's crazy but true that often the stress and strain of dementia in the family can bring back old sibling rivalries or accentuate the strong roles among siblings. Typically, the daughter (or sometimes the daughter-in-law) is the one who takes charge. Older children or the child who lives closest may be looked at to take the lead. Challenge these assumptions if you don't think they are fair or the best for your parent and their wishes.

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*Ensure that plans are created well before a crisis, including power of attorney and healthcare proxies whom your person chooses.*

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Communication is key. Getting on the same page with your siblings is ideal. In families where this may seem impossible, getting a sense of who wants what is a starting point and understanding that you may simply agree to disagree.

A group text with your siblings is a great way to communicate without having to be on the phone the whole time. Share updates on the person who is living with dementia after a visit or a doctor's appointment. Include your parent if that would be helpful or possible. Or you may find that you want to connect just as siblings.

Ensure that plans are created well before a crisis, including power of attorney and healthcare proxies whom your person chooses. This way, if things get contentious, you have their voice clearly heard through the legal decisions that have been laid out for care.

## **What If I Don't Agree with My Parent's Choices?**

At the end of the day, these are our parents, and we are their children. We don't like when people tell us what to do, and similarly, parents don't always welcome their children's input

— no matter how sound it is. Our parents are different than our children and try to avoid making that comparison.

Imagine if suddenly, you are no longer able to go to the bathroom alone as you have been doing for 60, 70, 80 years. Imagine that you need someone to undress you and wash you. Imagine you must have someone spoon feed you. This is a great loss and a very real example of the changes that your parent at some point may go through. On some level, they know they have been able to do these things before, and indeed they likely did them for you. Having compassion for how it might feel to receive this assistance can help put the support in perspective.

People can be stubborn, including our parents. They have their own feelings of denial, loss, trauma, shame, and guilt. These feelings shape their opinions and decisions. We can only control what we can control and often that doesn't include other adults. There may be a point where all we can do is state our thoughts and suggestions in a calm manner, share our reasoning, and leave it out there for them to receive.

Learn how to set boundaries. If you become consumed trying to change your parent(s), it will negatively impact you at some point. Setting a limit for yourself is practical and useful.

What this can look like:

- ◆ Listen mom, I'm worried about you continuing to lift dad and care for him on your own. I see how it is impacting your health — your back is getting worse, you've lost weight, you aren't sleeping. A good care partner needs to care for themselves. Bringing someone into the home, even for a few hours a week, might be a good idea. I know you keep saying no and having me come help instead. This isn't sustainable. I'm willing to send someone in my place who is better equipped than both of us to help.
- ◆ I'm not sleeping, worrying about you and dad. It's not healthy for me seeing you continuing to make the choices that you make. I can't keep being a part of it in this way. I am going to take a few steps back. I can send XYZ support for you to assist, and I'll plan to visit twice a week instead of daily. I need to find balance, and I hope you will too.
- ◆ Modeling healthy behaviors and establishing boundaries can be helpful to show siblings and parents that taking the time for yourself (for example) can have positive outcomes. Even if it doesn't create a change within the family, it can help you manage what can feel like an out-of-control situation. It is you taking control of what you control — which is you and how you choose to react and engage.

Working with a geriatric care manager, social worker, or therapist can assist you in boundary setting and communicating around these challenging issues.





## ***One Family's Story: My Dad is Still Living on His Terms***

### ***The Carson-Arand Family, Manual Guides***

Dave Arand of Port Angeles, Washington, is the primary care partner for his dad, Ray Arand. Ray is retired from law enforcement and Dave and his wife, Katie, are both police officers. Dave's sister, dementia specialist Jennifer Carson of University of Nevada-Reno, is a long-distance care partner. They share their reflections on what they've learned.

When Ray Arand was diagnosed with dementia, he was very clear about one thing: he wanted to remain at home until the end of his life. His children, Dave and Jennifer, were determined to help him achieve that goal.

"We're a working-class family who couldn't afford memory care even if we liked that model," says Jennifer. "The way we're working together to handle this has been successful."

As Ray's need for in-home help grew, his ability to pay for it shrank. That's when Dave came up with a creative plan. He and his wife and kids already lived in the same neighborhood as his father. Why not live together?

"He was having care partners come to his house several hours a day," Dave says. "It was not quite enough. We realized he's got a four-bedroom house, maybe we should combine households, and have my family move in with him. We bought his house, and he set aside the money to pay for his care." The move itself was challenging, as they combined their belongings. Some of their things are still in storage. Another recent challenge: Dave's work schedule was suddenly changed, making it harder for him to check in on his dad or to be there for dinner. Fortunately, Dave's wife, Katie, and teenage son, Tom, pitch in. Overall, the plan is working well.

Early on, after Ray's wife died and he was dealing not only with his grief but with a serious diabetes-related issue and his dementia, he named Dave as his power of attorney and Jennifer his medical power of attorney. In 2019, he made Dave a co-signer on his bank account and Dave began paying bills and managing the money. "Whenever we needed to make a significant financial decision, we made sure Dad was included," Dave says.

Perhaps even more important than the legal and financial power-sharing is their family culture of decision making. "We have always had family meetings around the kitchen table when we have something important to discuss," says Jennifer.

At one such family meeting, they made a commitment to shared decision making when it came to Ray's dementia. That was important both for Ray to not feel he was being stripped of his autonomy, but also for Dave and Jennifer's well-being. "My dad may feel fine about taking some kind of risk, but that same risk can make us feel quite anxious," says Jennifer. "Because my dad loves us, he has been willing to consider our feelings."

Among the important issues they have negotiated together: Ray's decision to give up driving, allowing Dave to safely store Ray's guns, sale of the house, and hiring paid care partners. "We always made sure that our dad was still the decision maker," says Jennifer. "Because of that, my dad chose wisely."

Ray's role in choosing his paid care partners (from the agency Home Instead) is a good example. He interviews potential care partners and decides who would be best. On one occasion when Ray had an uneasy feeling about someone, Dave asked the agency not to send them again. Not that there aren't challenges. When a favorite care partner had to take a leave of absence, it was hard for the agency to find replacements and Dave scrambled to figure out what to do. Like care partnering across the nation, there is a shortage of workers. "You need to build in redundancies and try to have a back-up plan," says Jennifer. "No plan works out perfectly."

## Other Lessons the Family Has Learned

◆ **Share stories from others living with dementia.** Jennifer suggested Ray and Dave attend an online *Dementia Conversations* session with other care partners and people living with dementia. Jennifer co-hosts the free program every Monday with Chuck McClatchey, who has been living with Alzheimer's disease since 2014. "I thought my dad would appreciate meeting people who are living well with dementia and willing to share their experiences — people who are breaking the stigma of dementia. Prior to his diagnosis, my dad didn't really know anyone with dementia. His concept had been shaped by stories my mom and I would share after coming home from work at a nursing home decades ago.

Ray came to the program once while visiting Jennifer at her home. Then months went by before he expressed an interest in joining the group again. When he did mention it, Dave helped his dad purchase his own tablet. As Ray developed more familiarity and comfort with the other participants, he started coming more often. Now he is a regular, Zooming in nearly every Monday to share his perspective in this supportive community. "It's good to know I'm not alone," Ray explains.

Jennifer adds: “The people who participate in *Dementia Conversations* are not Pollyannas. But they’re taking us beyond tragedy as the only view of dementia. Yeah, it’s hard, and you’ll have obstacles, but you can still experience joy and beauty and happiness.”

- ◆ **Include others on your support team.** Dave and Katie’s household is a welcoming place for extended family, for their teenage son’s friends, and for peers in law enforcement who have known Ray for years. Ray is not isolated. Jennifer has educated extended family, in particular her nephew, Tom, and his close friends, about providing positive dementia support.
- ◆ **Support each other.** Dave and Katie want to take their sons on a European vacation in November. Jennifer will come home to be with Ray so that Dave and his family can go with peace of mind. These types of changes in support are best when planned well in advance.
- ◆ **Create a binder of instructions.** Jennifer created two types of binders: one for direct-care partners (family and professionals) and one for neighbors, extended family, and friends. The one for direct-care partners includes the family’s person-centered philosophy, and specific details about how Ray can have a smooth day in a calm environment.

The other is more general, with a focus on communication and environmental supports, and how to respond if Ray is experiencing distress. In explaining her approach to living with dementia, Jennifer wrote: “People living with dementia are the genuine experts in the experience of dementia. As such, Dad’s perspectives, wishes, and preferences should always be sought and respected in any decisions that affect his life. Just be sure to provide the information in a clear manner. Truly engaging my dad as a legitimate contributor to his own experience opens a world of possibilities.”

- ◆ **Be open and honest with each other.** “One of the biggest things I can think of is the no-[b.s.] rule,” says Dave. “Be honest with each other. When you’re discussing what issues you’re facing, be tactful, but don’t dance around a problem. You have to face it head on and work through the problem together. It makes things easier in the long run.”

Ultimately, says Jennifer, it’s hard work. “But my own relationship with my dad has grown and been strengthened through this experience. We talk about really important things that before we never had cause to talk about. I feel honored that I get to support my dad, and he continues to support the family. It’s changed quite a bit, but there’s more reciprocity than ever before.”



## **One Sister's Experience: 'You've Always Shown Me the Way'**

**Karen Gallant**

*Karen Gallant of Soquel, California, is the younger sister of Coille Hooven, who is living with Alzheimer's disease. Coille is a well-known porcelain artist whose work is exhibited nationally. Karen and Coille's mother also had dementia. After many years of living at home with her husband, Coille moved to a memory care center in Berkeley, and she is now in hospice there. Karen reflects on what the experience has been like for her.*

I welcome the opportunity to talk about this not as a big tragedy but as a thing that is part of life. It's striking — when you say, "My sister has Alzheimer's," everybody's response — 100 percent — is "Oh, I'm so sorry." Early on, I'd say, "It's okay — I still really enjoy being with her." I felt I had to defend myself that it wasn't this awful thing.

Her dementia started at least eight years ago, when she said, "I think I've got what Mom had." I noticed that if I was going to have lunch with her, she'd open the door and be surprised to see me. We both saw something was going on. She went to her neurologist, and he said, "You have an excellent brain." Another year went by, and then they retested her and she was told she had early Alzheimer's. I remember distinctly talking to my sister about it, and she was so irritated at people's reactions. People were thinking she wasn't still *her*. She felt the problem wasn't that she was becoming less functional — it was people's reactions around her.

I'd say to my sister, "If you can't remember things, I'll remind you. Let's find things we enjoy together." She once told me, "It's kind of great I don't have to be responsible for things!" I would think of different things to do. We did art projects, we took walks. I had to stop counting on her to come visit me. She couldn't do that anymore.

With my mom, I didn't have the acceptance. I kept trying to fix things. When my sister was still able to go to a restaurant, I took her out and she ordered waffles with fried chicken. She would only eat with her hands. I was trying to nudge her to use a fork and knife, and she got very mad at me and said she knew how to eat. I realize that I was embarrassed by her. I should have just let her enjoy them and get messy and not worried about it.

The relationship began to change. I couldn't have the talks I used to be able to have with her. But it was clear we loved each other, and I still enjoyed being with her. She and her husband Peter kept doing things. There was a show [of her art] in New York that she really seemed to enjoy.

Peter told me I was part of the care team. I would regularly come up for the weekend so he could have a break, and I really enjoyed those times. Until she declined a little further and at one point, when Peter wasn't there, she got very anxious. She no longer felt safe with me. We tried that a couple of more times, but then he was the only person she would be with. I'd still come up for the day, but he had to be there.

Then I would do things that would irritate her. I had to up my skill level. It became a learning adventure. We were in new territory, and I wanted to figure out the best way to do it. It was kind of challenging. I did begin to feel like I was losing her. Then came the time when she didn't know who I was. Here's the funny thing. I felt more angry than anything. I felt something like, "Oh, she doesn't really care about me. It was always about HER!!" Deep family patterns. I was thinking "Doesn't she even appreciate me?" And then I see how selfish I'm being, not her!

It was confusing for me, because until this day she doesn't seem unhappy. I know who she is, and I still love her. I'm glad for that. It's not a relationship of peers anymore, but it's a relationship of love.

The move [to a memory care home] was very traumatic for the family. The first few days were tough. The lead-up to it was dreaded. It was a very tough decision, and it was a difficult transition for her too. I didn't see her until she'd been there for at least a month. By then the story had changed and it was working real well.

She's done well there. Even though she had 24-7 caregivers when she was at home, she was isolated. Here, it's a party. She gets animated by other people. These are other people who are in the same world she is. She is among her peers. Things are going on, and she's part of it. My sister was always a party person.

When I go see her now, her daughter is so loving. I see this as a wonderful way for Molly to experience a loving relationship with her mother. She's decorated my sister's room really nicely. It's not depressing to be there. They've got dogs at the home. The caregivers are so positive, and there are activities in the common room. My sister is not unhappy. It's the weirdest thing. It's not awful. It's curious. It boggles my mind what is going on in her brain. It's so mysterious.

Molly brought her some of the porcelain teacups that Coille made. My sister smiles and enjoys them so much. She knows who Molly is. When my brother went to visit, she seemed to know that he was somebody special.

The last time I visited, Molly and I talked for a while and we stroked her, and then it was time to go. I said, "Bye Coco, you've been a wonderful big sister, you've always shown me the way." She's showing me now how to do this, if it's my fate too.

It's the end of life. This is what happens to us. Some of us go quickly and some of us go slowly like this. It's facing old age. That's helping me.



## ***A Husband's Reflection***

### ***Rushern Baker, Manual Guide***

*Being honest with people and asking for help*

*Rushern Baker served in Maryland's state legislature and was a two-term County Executive of Prince George's County. His late wife, Christa "Cis" Beverly, had been his political partner before being diagnosed with younger-onset Alzheimer's. After initially trying to keep her diagnosis private, the family went public as a way to reduce stigma and help others. From that point on, he brought Cis with him on the campaign trail he ran for his second term as County Executive. Cis died in 2021.*

I grew more in the last 10 years than I ever had before.

We did everything together. We had a ball for a year. It really was what kept her going. In the morning we'd get up, get dressed, and I'd tell her, "You're going with me." She was never left at home by herself. It was stimulation. The worst thing was to leave her alone.

In the past, she was always charming, beautiful, tough. She was a grown up. No one would ever have called Cis "cute." But she was cute during that campaign. She was a funny, whimsical person then. It was great. It made us closer. Everyone loved her. And it was good for us as a family. We were blessed. Win or lose. When we won, even more so, she got a chance to fully embrace it and know it and understand we did this. She was there.

When people ask me to talk about what happened, it's always like "what a great job you did." Not really, I was not good, but you can learn from my mistakes. The biggest was,



you can't do this by yourself. Every day in the beginning was the best day you were going to have. It would get worse.

Ask for help. Once we went public, the world opened up. Her line [sorority] sisters who were concerned about her kicked into hyper gear. A whole network of people would come get her on Sundays, or if I was out, there was a group of people who were always there.

The local Alzheimer's Association was a blessing that I'd wished I'd tapped into in the very beginning. People said I should go to a support group, and I didn't — all bad mistakes. When I got desperate, I found through the Alzheimer's Association how I could help her brush her teeth. It was a support group right there. I wanted to be part of it.

*Miss Cissy was tough. But she invested so much in me, even through her dementia.*

*She would walk through her house and carry her degrees. And one day she said to me,*

*"You don't have one of these."*

*And I said, "No ma'am, I don't."*

*And she turned to me and said, "Why not?"*

*And I could not answer her. I want to tell Miss Cissy today I do have my degree. I have my bachelor's and I have my master's, and this is because of Miss Cissy saying, "Why not?"*

**Sylvia Wilson, professional care partner, at the memorial service for Christa "Cis" Beverly**

There was one point when she thought everybody was the enemy. She didn't recognize our son. And then she didn't trust people and would lash out. She could tell when people were nervous around her. We went to our son's graduation, and she hit somebody with her umbrella. Then she'd look at me and start laughing.

What I say to folks is be honest with people, ask for help. I wish I could get this across. Because of stigma, everyone thinks their life is over. It isn't over. You need to find new ways to thrive.

If everybody is saying, "I feel so bad for you," it doesn't help me. You want somebody to say, "It's going to be tough, but you're going to have tough times in life no matter what. You know what you're dealing with and believe it or not, people have gotten through it."

The last five years she stopped talking, other than one or two words. Every now and then, she'd look at me and she'd say, "No, that's not right." It would be a moment of clarity.

Once I embraced that life would be different every day that I came home, it was a new normal. I never stopped having conversations about what I was doing during the day or asking for her opinion. A lot of times I could read it in her eyes.

I still took her everywhere. If I went to a ball game, then Cis was coming. I like classical music, and we'd go to concerts at University of Maryland. If you're uncomfortable with her being there, that's your problem.

You can make your life full and their life full and rich. It was that way until the very end. It does not have to be unhappy and unfulfilling, and it can be richer than you ever thought. She saved the best for the last 10 years. I grew more in the last 10 years than I ever had before — it forced me to listen to her. I had to pay attention.

## 7.6 Coping with Expressions of Distress

Caring about someone living with dementia can play havoc on your emotions. You can't visually see the brain changes to have a sense of what is happening or when there is a change. Most forms of dementia are degenerative, meaning that brain changes and impairments are not singular events but rather are ongoing and can occur without warning. These unknowns can cause you (and them) to feel frustrated, angry, upset, fearful, and fatigued among other emotions.

"If I have to do something — pay a bill, get the stuff ready for the taxes, clean the house — I need to be left alone or I can't concentrate, and I just lose patience. I feel bad for him, but I feel bad for me too," says Sheila Felsen, whose husband of 57 years has mixed dementia. She has tried signing him up for classes and support groups, but he tends to dominate the group. "He likes to be the center of attention, and he likes an audience. He's used to being



the person in charge — he had a lot of people working for him. So it's very hard for him. My heart goes out to him."

For most people living with dementia, the disease process eventually prevents them from verbally communicating their wants and needs. They can feel that no one is listening to them and that they can't fix what's bothering them, whether they're bored, or feel too cold or too warm, or simply want to take a walk in the fresh air. They may express their frustrations (often called "behaviors") in ways that are hurtful or scary or alarming to themselves and to those around them. Too often, especially in care settings, the response has been to sedate people to calm them down. Experienced care partners and professional experts say that most of the time, these expressions of distress can be eased by addressing the underlying cause. Rather than load people up with medications and the side effects they bring, care partners can become skilled at anticipating or figuring out what's upsetting and eliminating or solving the problem. (See [The Power Your Attitudes and Actions Can Have](#), Section 7.7, page 366) This is hard work, but it will pay off for both of you.

Anne Ellett, a nurse practitioner who has worked for decades with people living with dementia in a variety of settings, has found that putting herself in the person's shoes is helpful. "When people are no longer able to use words and they get so frustrated and then they slap someone who's trying to help them, could we just consider that's a normal reaction to not being able to control your environment or to feeling threatened because they're not being listened to? The person who is banging on the door to get out — that's pretty normal behavior if any of us were locked in. Or the wandering — they're searching for something. They're looking for something familiar or comforting. I try to approach challenging behavior in that way."

## Supporting Meaningful Engagement

Depending on the form of dementia, individuals can lose the cognitive ability to self-initiate activities and tasks. While it may appear that they are not interested in doing an activity or task, it is highly possible they don't know how to initiate it. Gently asking whether they need a little help getting started with something can be a caring way to support them without diminishing their self-worth.

Neural damage to the brain that impairs the ability to initiate activities can result in the individual becoming inactive and bored. Distressed behavior can signal that they need support to help get involved in an interesting activity or to go out. A physiological response triggers in the brain when a person is meaningfully engaged and emotionally connected. Naturally-produced brain chemicals, known as neurotransmitters, such as endorphins,

oxytocin, and serotonin, are released into the body. These produce good feelings and a sense of well-being.

The opposite can occur when people are not well supported emotionally. When an individual is bored, fearful, lonely, and inactive, the body produces different neurotransmitters, such as cortisol, adrenaline, and norepinephrine. These neurotransmitters serve as important protective measures when, for instance, a hand touches something hot, but they are not beneficial for everyday life. Anyone can learn to successfully support meaningful engagement with a little effort. The more you do it, the better you will get. Staying meaningfully engaged and emotionally connected are essential for well-being.

## Skillful Communication

Individuals living with dementia often have trouble finding words and communicating verbally. There is a difference between expressive speech (expressing oneself) and receptive speech (understanding what others are saying). Expressive speech abilities can become incrementally impaired living with dementia. (See *By Us For Us* guide, [Enhancing Communication](#), Section 2.8, page 138)

Care partners often mistakenly think that if the individual has difficulty expressing themselves, they also don't understand what is said. This may not be true. The person living with dementia may still be able to understand but they need you to slow down your speech so their brain can have time to process what is being said.

Stand in front of the individual at their eye level. Seeing your facial expression and lip movements are helpful visual cues. Tips that can help:

- ◆ Ask how you can best support them when they can't find the right words. Some individuals want additional time to come up with the words, while others prefer you to offer some word suggestions. Some people might be able to show you what they cannot verbally express. Asking how they want to handle this supports their decision-making control which is important for preserving dignity and personhood.
- ◆ Use short, simple sentences. They are easier to process.
- ◆ Be pleasant and relaxed when you speak. Your mood and attitude are contagious.
- ◆ Frame single questions rather than a statement containing several questions.
- ◆ Use effective non-verbal communication.

## Give Yourself a Break

Sheila Felsen struggles with the constant demands she faces. As his condition worsens, her husband wants her by his side all the time. She worries about her own health. She has found that turning to others helps, including:

- ◆ **Paid caregivers** — even 15 hours a week, a few hours a visit, gives her some breathing room to complete tasks or get out of the house for a bit.
- ◆ **Support groups** — she is in a support group on Facebook for care partners of people living with dementia, where she's gotten great advice on practical things like purchasing supplies and problems with medications. "The most helpful was to find that some of the things he does now are normal. My husband will shove anything in his pockets — a gavel, my medicine. I learned this is very normal too."
- ◆ **Being with friends** — "My friends have been wonderful. I started a foody group, and we go out once a month to international restaurants. They always include my husband."

## 7.7 The Power Your Attitude and Actions Can Have



*Pat Snyder, Contributor*

Your attitude and actions can have a powerful effect on family life with a person living with dementia. Before you act, remember to recognize that the person living with dementia is not a problem. The person has a medical condition causing problems.

If the person living with dementia is doing something unexpected, likely they are not doing it on purpose. Their brain is malfunctioning. Just as you would not expect someone with a broken arm to lift a heavy object, you cannot expect someone with cognitive impairment to problem solve and do everything as they did before.

Generally, behavioral expressions are a response to what is happening in their environment or within themselves. This is the way for them to communicate their needs and concerns. If a behavioral expression is problematic, **be a detective**. Examine the events that led up to the problem. What might have triggered this?

When you try various approaches to helping, examine those events to figure out what made it better or what made it worse. This trial-and-error technique will guide you in ways to manage things in the future.

- ◆ **Respond to the situation.** When we are confronted with upsetting behavior from our loved ones, which of these choices puts us more in control of the situation? To respond to it or to react to it? Which one shows that we have done some homework and given some thought to better ways to deal with it? Which one is more proactive and likely to result in a better outcome? Responding puts you in a proactive position rather than a reactive one.

There are some basic techniques that have worked for me most of the time.

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*Generally, behavioral expressions  
are a response to what is happening  
in their environment or within themselves.  
This is the way for them to  
communicate their needs and concerns.*

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- ◆ **Trust your own instincts.** Instincts are those still quiet voices in you that move you to make choices. Others may say what they think you should do, but you know yourself and your loved one better than anyone. That often puts you in a position to instinctively know what to do.
- ◆ **Use the opposite emotion to neutralize a negative emotion.** For example, when your loved one is angry, try to be cool and collected. Ignore their words and respond to the underlying emotion. It truly is best to not react by arguing or becoming overly emotional yourself. When they are negative, you be positive. It is almost impossible to have an argument by yourself.
- ◆ **Sometimes just ignore what is happening and leave the room.** Say, "Oops! I forgot something." Then exit and take some deep breaths to reset.
- ◆ **Learn from what did not work.** Rather than wallowing in guilt, treat these events as opportunities where you learn what NOT to do. Your response or approach influences their reaction and mood. So how can you do it differently next time?
- ◆ **Allow yourself to fail then quickly forgive yourself.** Save your energy for the work of today. Making good memories right now in small moments is much better for you and everyone else in your story.
- ◆ **Everyone needs a place to vent when we get frustrated.** Trusted friends, support group, and memory café members can be good shoulders for you to express your

frustrations on. They understand that sometimes it's helpful for you as a primary care partner to vent. Don't be surprised if you find yourself laughing with them after venting.

- ◆ **Consider the effects of medications.** Sometimes expressions of distress are a result of infections, dehydration, blood pressure or blood sugar levels that are off, pain, or medication side effects or interactions. Consider whether a new medication or increase in a medication may be causing a problem. Many prescribed and over-the-counter medications can have behavioral side effects. Talk with your pharmacist about side effects and potential medication interaction issues. Regularly scheduling visits with your primary care physician and other specialists will keep you in close touch so health issues can be monitored.

## Management Strategies

- ◆ **Use a problem-solving approach to identify the cause of what's going on and choose a strategy.** Define the behavior. What might be causing it? Is there a medical issue? Did something or someone trigger it? Is it disturbing to the person living with dementia? Some behavior does not cause them stress, so no intervention is needed — even if it is disturbing to you.
- ◆ **Stay calm and carry on.** Speak in a calm voice. Use reassuring words that fit the context. Keep your face composed and your body language relaxed. When John approached me one day in the doorway of our bathroom as I was brushing my teeth, held up his hands like claws and grimaced at me showing his teeth ... I looked at him, looked back at the mirror, made some comment about getting ready for bed, finished my teeth, and walked into our bedroom through another door. When I did not react, but stayed calm and relaxed, his agitated behavior evaporated into thin air. How you react can calm agitation.
- ◆ **Speak to those underlying emotions when you respond.** You may have to say you are sorry in many situations. It does not matter what reality is here. Just speak to the underlying feeling rather than reacting to whatever has just been said. Dementia specialist Teepa Snow recommends these ways to say, "I'm sorry."  
"I'm sorry ...  
... I was trying to help.  
... I made you feel (emotion) angry, irritated, frustrated, sad, isolated...  
... This is hard! (for both of us)."
- ◆ **Validation can be useful.** Another technique that can be helpful is validation. This means you meet them where they are emotionally to validate them. You can

do this by repeating what they said or something close to it. Or you can speak directly to the emotion behind it by saying something like “That must feel awful.” You are joining them. Stay calm.

- ◆ **Redirection can help.** When John said he was leaving me to go out West with his young care partner, I repeated his words calmly back to him and that affirmed what he had just said. This allowed me to move the conversation to a safer emotional place. I repeated “going out West” a couple of times. Then I got a faraway look in my eyes and said, “I remember when we took the kids out West and we hiked through the Narrows at Mt Zion Park, saw the Redwoods ...” John got the same look on his face and said, “Yeah!” with contentment as he relaxed in his recliner. I quickly exited the room to “get some ice cream for us.”

You can say things like “I can see that you are upset. We are in this together.” If they want to go home, say “What should we do at home?” Or “tell me about where you grew up.” To redirect, you could say, “Let’s go run some errands. I like it when you come with me.”

- ◆ **Leave the room briefly.** I used this strategy a lot when John’s behavior was causing me to feel stressed. I would make an excuse and leave the room, take some deep breaths, and say a quick “Help me, Lord” prayer, and reenter with a smile and often some treat for John. He almost always had reset by then, and could focus on my upbeat tone and whatever goodie I brought him.
- ◆ **Use gentle touch as a calming technique.** I massaged John’s feet and legs a lot to soothe muscle cramps but also to comfort him. The lavender lotion I use relaxes me while it relaxes him. I placed a small amount on his neck and shoulders, so he can smell it. I stroked his face with affection. I wanted John to feel loved and valued. It seemed to reassure and help him stay calm.
- ◆ **Say “I love you” 10,000 times.** It brings comfort and security. It makes clear how much you value them. It strengthens their emotional memory. The more you say it, the more it grows within you. I believe that ... Love is the most powerful force in the universe. It is patient ... kind ... is not self-seeking ... is not easily angered ... and keeps no record of wrongs. It always protects ... always trusts ... always hopes ... always perseveres.

That is the kind of power I strongly recommend that you tap into with your whole heart in this journey. And when you do, you may be surprised at who you are at the end of it. When you look back you just may find that you have left a legacy of strong love and kindness for your children and grandchildren to embrace as they journey through life. **Love ... is a powerful tool.**

## 7.8 Care Partner Sex and Intimacy



*Emily Franke, MSW, LSW, Contributor*

It is very common for care partners to find that taking on a caregiving role affects their desire for, or expression of, intimacy and sexuality in their relationship.

Try using *the 3 Ts* framework — Talking, Time, Touching. (See [Intimacy and Sexuality](#), Section 3.3, page 203)

- ◆ **Time:** Allowing more time for connection and putting less importance on a particular physical act or outcome (like orgasm)
- ◆ **Touch:** Emphasizing affectionate touch versus instrumental touch (for example: if you help someone bathe, you may turn instrumental touch like washing into affectionate touch like massage)
- ◆ **Talking:** Acknowledging and communicating about sexual and intimacy needs

Throughout any relationship seeking consent for touch, both sexual and nonsexual, is important and likely as nuanced as your relationship. Consider how your partner’s dementia diagnosis may affect their ability to understand and consent. There is no straightforward rule to follow regarding consent. Continue to check in with your partner regarding all types of touch (more talking!).

The effects of dementia can alter a person’s sexual expression and behavior, and these changes may not be something a person can control or fully understand. Seeking support from a counselor, therapist, or support group is a productive way to explore your feelings and get tips for addressing the problems you encounter.

## 7.9 Creative Things to Try



*Pat McHenry Sullivan, Contributor*

John’s total lack of shame around dementia freed me to talk to anyone, anywhere, about our needs and dreams. This led to wonderful opportunities including:

- ◆ Meeting a fellow attendee at a talk on dementia who told me of a research program at University of California, Davis, Alzheimer’s



Disease Center—East Bay in Walnut Creek which gave John a free, thorough assessment and diagnosis of his dementia, then a free 18-month thorough follow-up.

- ◆ The resources provided by the neurologists at UC Davis led us to many groups where people shared methods for dealing with different aspects of dementia.
- ◆ Each bit of research led to others, while friends and families offered their own ideas and support.
- ◆ John and I discussed and chose how to use these resources together. Gradually we discovered that anything that supports a rich life is likely to support dementia and vice versa.

We'll forever be grateful to friends Marilyn Flower and Siddika Angle for inviting John to join them for improv classes at Oakland, California's world-renowned training for seniors in the performing arts, Stagebridge ([stagebridge.org](http://stagebridge.org)). Their enthusiasm for Stagebridge convinced him to try it.

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*Improv has become integral to our lives. It guides us through John's times of confusion and my being overwhelmed as a care partner, household administrator, and a working writer/speaker.*

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He came home standing taller, more confident, and committed to ongoing improv training. That was five years ago. He would still be doing improv at Stagebridge but for the pandemic lockdown. He'd be returning, but we are now moving to Virginia, where we will get superb family support.

Improv has become integral to our lives. It guides us through John's times of confusion and my being overwhelmed as a care partner, household administrator, and a working writer/speaker.

We've even learned how to have fun letting go of frustrations and anger together and individually by fighting in gibberish or singing scat-style like his beloved Louis Armstrong and Ella Fitzgerald.

Imagine: what would our life be like if stigma or the tragedy narrative had kept Siddika and Marilyn from suggesting that improv would be fun for John? What does it cost you when stigma or shame prevent you from sharing your needs and dreams with people? How do you win when you live — even for a short time — beyond shame or stigma?



What illusions or feelings of shame do you have around care partnering? How can you best accept and bless who you are now so that you and your partner can thrive?

With creativity, vision, and planning, almost anything that helps us thrive as humans can help us thrive as humans with dementia.

Until recently, almost all dementia caring activities were based on the medical model. Today, body/mind/spirit and creativity work are rapidly expanding the opportunities for people living with dementia and their care partners.

This word cloud shows just a few of the modes, practices, and attitudes that are contributing to a new dementia world based on making thriving the new norm.



Every practice or group mentioned in this essay used one or more of the approaches above, plus others.

When you look at this model, what surprises you? Which of the words makes you want to learn about the concepts or resources behind them? What would you add if you made your own word cloud of possibilities?

The following are a few examples of our favorite practices based on seeing ourselves and each other more clearly, bringing what we've learned from research into our lives, and becoming creative. Throughout this manual are many other resources you can adapt to your particular thriving dreams.

Every practice, resource, tip, or ally is presented as a starting point for your own exploration and creativity. Feel free to copy what we've done or allow ideas here to be a catalyst for your own creativity.

Above all, let your mind be open to new possibilities. Then as you explore an idea, imagine how it might work for you. Use whatever visioning and planning skills you already have or get the help of others who have those skills. Then discern what's most likely to be right for you. Enjoy!

## Finding Your Best Resources and Allies Starts with Research

Research is curiosity in action. By research, we don't mean using the scientific method, but learning about topics that will help us live more fully. If you don't yet know how to do research, your first project may start by listing basic questions (these can be for you or your partner or both) like:

- ◆ What do I know about dementia?
- ◆ What really matters to me, and how do I want to make the best of the rest of my life?
- ◆ What else do I need to know so I can handle this specific challenge or dream?
- ◆ Who can help me, and how can I contact them?

A good place to start is with your local librarian and social workers. Ask your health plan or local dementia organization to refer you to a social worker. One social worker found us a \$1,000 respite grant to hire an art tutor for John. That freed me up and delighted him for many hours. Here are some of the resources that we found helpful:

- ◆ Websites for Dementia Action Alliance and Dementia Mentors are great sources, including events for your loved one or yourself, and stories, videos, and other resources about how to thrive with dementia. Visit: [daanow.org](http://daanow.org) and [dementiamentors.org](http://dementiamentors.org)
- ◆ The Alzheimer's Foundation of America is an excellent information, resources, and fundraising site for dementias of all kinds. Their 24/7 National Tollfree Helpline, 866-232-8484, is a well-staffed superb source for referrals to elder care law attorneys or social workers who can handle tough challenges. Visit: [alzfdn.org](http://alzfdn.org)
- ◆ Re-Imagining Dementia, A Creative Coalition for Justice is a resource for those who want to transform the tragedy narrative through laughter, play, arts, and social therapy for the benefit of both of you. The site is filled with poetry, articles, photography, and other creative expressions. Visit: [www.reimaginingdementia.com](http://www.reimaginingdementia.com)

In the 2019 Washington Post article *Changing the Tragedy Narrative: Why a Growing Camp is Promoting a More Joyful Approach to Alzheimer's* by Tara Bahrapour, Mary Fridley of the East Side Institute notes that "Dementia is enormously painful, but I truly believe it is an opportunity, if people so choose, to be improvisational, to be silly, to play, to free ourselves from the constraints of truth and knowing and assumptions." We have certainly found that to be true.

Resources for you as a care partner: education, training, help with specific challenges, and self-care.

Pre-pandemic, most assisted living and memory care homes in our area marketed their services by providing free programs, often by leaders in the dementia field. So did many senior centers and Village Movement groups ([vtnetwork.org](http://vtnetwork.org)). Today, even as many groups re-open, many will continue to offer programs via Zoom, so you can access educational resources anywhere you live.

Other suggested training and educational resources:

- ◆ Pat Snyder, a care partner educator based in North Carolina who contributed two of the essays in this Section of the manual, offers a YouTube Channel filled with her insights and those of colleagues and medical experts on Lewy body and other forms of dementia. Visit: [www.youtube.com/channel/UCrjzZYVyeopBjasIMmCLH3g](http://www.youtube.com/channel/UCrjzZYVyeopBjasIMmCLH3g)
- ◆ Teepa Snow's newsletters, Instagram, and videos all promote her Positive Approach to Care as well as paid training for individuals and companies that care for people living with dementia. Check out free webinars and other training possibilities and get on her email newsletter at: [www.teepasnow.com](http://www.teepasnow.com). Look also for the fun Brain Café which you and your partner can enjoy together. Then there's her wonderful You Tube Channel at: [www.youtube.com/channel/UCSXrEX7LkWOmfTaV6u1C7wQ](http://www.youtube.com/channel/UCSXrEX7LkWOmfTaV6u1C7wQ)
- ◆ HFC, formerly Hilary for Charity, was founded in 2012 by actors and filmmakers Seth Rogan and Lauren Miller Rogan. With the help of friends, they offer comedy sessions, with the intent of erasing stigma, bringing younger people into awareness of the disease, and raising funds for research and care partner support. Today they also provide regular free support groups and webinars at: [wearehfc.org](http://wearehfc.org)
- ◆ Family Caregiver Alliance offers both national and regional services, online and in-person. They have a collection of videos of caregiving tips and self-care, plus links to research stories and clinical trials, some of which may offer compensation. Visit: [www.caregiver.org](http://www.caregiver.org)
- ◆ Neighborhood resources, such as local listservs, are good sources of allies, resources, and events. They could help you get a free walker or give one away, build a support team, or find a support group.

## Resources you can use together

- ◆ Art Is ... In, free weekly or bi-weekly art lessons for persons living with dementia and their care partners to use together, with free art supplies, poetry to discuss, and questions. Sponsored by the Center for Comprehensive Care and Research for Memory Disorders at the University of Chicago Medicine in partnership with GoldMind Arts. Visit: [thememorycenter.uchicago.edu/artisin/](http://thememorycenter.uchicago.edu/artisin/)
- ◆ Moving Together Senior Health's research study incorporates the Feldenkrais Method, a type of body work; mindfulness meditation; and music to increase cognitive capabilities. It's part of a larger program at Together Senior Health that offers ongoing movement programs. For information on the research program, visit: [www.togetherseniorhealth.com/current-research-study](http://www.togetherseniorhealth.com/current-research-study)
- ◆ Many activities of DAA and other groups can be done together, especially the ones related to spirituality, arts, and educational programs.

Here are some of the rituals and activities John and I invented or adapted that you may enjoy:

- ◆ Start your day with a song, such as "We All Stand Together," by Paul McCartney and the Frog Chorus. Currently, John sings this as soon as he hears me getting up. Visit: [www.youtube.com/watch?v=gVfaf43W9cM](http://www.youtube.com/watch?v=gVfaf43W9cM)
- ◆ Follow your morning song with your statement of purpose, e.g., "Today I choose to find more joy in surprising places or activities."
- ◆ End your day with at least three expressions of gratitude. This prepares you for relaxed sleep and affirms what's good in your lives. This is the best antidote I know for busting stress, burnout, or exhaustion.
- ◆ Grieve as you go, by naming your small losses, then claiming what they mean to you. This normally leads to creative ideas and new hope.
- ◆ Do any kind of art and movement together. Our latest fun is to put on classical music and act like symphony conductors with exaggerated body and eye movements. Great for transforming stuffiness, frustration, and tiredness.
- ◆ One of you talks gibberish; the other translates.
- ◆ Watch videos of beautiful places on Share Care Videos through Firefox and other TV providers. As we watch, relaxing visual affirmations often flow freely. Birds fly tension away, tropical fish swim away with our worries. Wide vistas expand our vision, waterfalls cleanse our brain.

## The Best Laid Plans of Care Partners Often Go Awry

Critical factors for John's and my ability to thrive much of the time are our years of spiritual practice and my decades of stress release (not just management!) practices, mixed with the ability to laugh at ourselves and with each other. These habits help sustain us in tough times that inevitably make the job of care partnering harder than normal.

That's true, even when Super Bad Chap (John's joke name for dementia so we can get mad at his condition, not each other) seems determined to send us back to Doom, Gloom, and Tragedy Land for his own amusement.

It's true: we can't control our experiences with dementia any more than we can stop or start the ocean tides. But we can trade thoughts of doom, gloom, tragedy, or stigma for empowering insights from our imagination, blessings, curiosity, role models, and other wisdom sources. As we change our thoughts, we can change our actions, which can lead to another day of thriving with dementia. Even when times are unexpectedly difficult.

### 7.10 What's Your Plan B?

Whether or not you or someone you care for and support is living with dementia, it's good to have a Plan B for your future. Most Americans want to stay in their own homes forever, but that is not always possible.

"Whether or not you can remain at home depends on family and financial resources," says dementia specialist Joanne Rader RN. "Some states will pay family members rather than have someone moved to an expensive care facility. It also depends a lot on the care partner. Some can make the shift to full-time care partnering, and some cannot. I think everyone should develop a Plan B because life is unpredictable."

For starters, your home might be more difficult to manage as physical needs change. A flight of stairs may be great for exercise now but may become dangerous as vision and spatial perception shifts. It's a good idea to have an occupational therapist or aging-in-place expert walk through your home with an eye towards safety and comfort. (See [Living Safely in Your Home](#), Sections 3.5, page 217; and [Supportive Home Modifications](#), Section 4.7, page 246.)

In addition to thinking about your home setting, consider if you will be able to provide caring support to your family member 24/7 as the disease progresses. As you consider how you might get help, a first step is to look at your finances. Is there enough to pay for home care, and if so, for how many hours a week/month? What type of care might you need? According to Homecare.org, 10 hours or so a week of companion care averages \$1,100 or so a month, and round-the-clock home health care averages more than \$17,000 a month.

Assume that care needs are likely to increase over time. Visit: [www.homecare.org/the-cost-of-24-7-in-home-care/](http://www.homecare.org/the-cost-of-24-7-in-home-care/)

Most communities have adult day programs that can provide the care partner with respite and the person living with dementia a chance to be around other people. Programs, which average \$70 a day (or less if you qualify), typically include meals, transportation, social activities, and exercise. This can be a good option. Contact your local area agency on aging to learn more about what day programs are available in your area.

At some point, you may feel you can't manage at home, and you may consider a long-term care community. "Making that transition from caring for somebody at home to placing their care with someone else can be so painful," says Kim McRae of the Culture Change Network of Georgia. "People describe it as the most difficult thing in their life. It feels like they're choosing to let that person down, but too many times I've seen care partners continue to care by themselves or with limited help until they're so exhausted that they have health problems."

Before that day comes, Anne Ellett says, you need to ask yourself, "Is this home environment really going to work when this person maybe isn't mobile anymore, maybe can't get to the bathroom by themselves, when the person gets anxious and wants to leave? What is our plan and what needs might there be? I encourage people to go out and visit local residential care options even if they have absolutely no intention of moving someone there. What if there is an emergency or the person has to go to the hospital, and the doctor says they can't go back home? If you don't have prior knowledge of options, then you're going to make that decision blind. If nothing else, you might need some other resources that the places have. Maybe they have a day program. You might find one that might be suitable for occasional respite care."

*Families need not just someone on the other end of the computer. There are studies that show the value of in-person family education groups. Being able to be in community with people who are going through what you are. You can laugh, cry, scream, and learn from each other.*

**Pam Brandon, founder of  
Age-U-Cate Training Institute**





Often care partners put off planning for a potential move, either because of the cost or because they don't want to upset the person living with dementia. Ask people you know or hire a geriatric care manager (also called aging life care specialist) to recommend a few assisted living or other care communities that are well regarded. Contact the communities and ask if you can come for lunch and a tour, ideally with your family member. Get a sense of the environment and how residents there seem. For more information, visit the National Consumer Voice for Quality Long-Term Care. They have great resources for family members.

And remember, once people have settled in, the move may actually be an improvement. Don't see it as a failure on your part. Sometimes the person living with dementia thrives when they are less isolated in their own home. Moving to a community with more activity and connections may be a good alternative.

## SUGGESTED RESOURCES

### Books

Bell, V. and Troxel, D., (2012). *A Dignified Life — The Best Friends Approach to Alzheimer's Care*. Health Professions Press.

Brackey, J. 2016. *Creating Moments of Joy Along the Alzheimer's Journey: A Guide for Families and Caregivers*. (5th edition). Purdue University Press.

Snyder, P. (2012). *Treasures in the Darkness: Extending the Early Stage of Lewy Body Dementia, Alzheimer's, and Parkinson's Disease*.

### Publications

CaringKind, "Finding Comfort: Living with Advanced Dementia in Residential Care," 2022.

Emmons, R., (2013). "How gratitude can help you through hard times," Greater Good, University of California, Berkeley.

### Websites

SPECAL® Method is based on an innovative way of understanding dementia from the point of view of the person with the condition

[contenteddementiastrust.org](http://contenteddementiastrust.org)

The Consumer Voice is an organization representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves

[theconsumervoice.org](http://theconsumervoice.org)

# SECTION 8: Learning About MCI and Dementia

## 8.1 What is Mild Cognitive Impairment?

Mild cognitive impairment (MCI) is a condition that causes some problems with cognitive abilities, such as memory or math. The cognitive symptoms are not sufficient to interfere significantly with daily life. Most people experience a gradual decline in mental abilities as they age. In the case of MCI, the decline in cognitive abilities is greater than that of normal aging. It is common in aging, for example, to pause at times to remember directions or words. It is not common, however, to lose things often, forget to go to events or appointments, or have more trouble coming up with words than other people of the same age.

An estimated 5 to 20 percent of people 65 and older are living with MCI. It is not a form of dementia, although a person living with MCI is more likely to develop dementia. Many people who are diagnosed with MCI use this as an opportunity to improve their lifestyle. There are many things a person can do to help reduce their chances of MCI progressing to dementia (see [Pillars of Well-Being](#), Section 2.2A, page 87).

### Symptoms of MCI

People who have MCI do not experience personality or other behavioral changes that are characteristic of dementia. Signs of MCI can include:

- ◆ Memory — losing things often, forgetting to go to an event or appointment
- ◆ Reasoning, planning, or problem-solving — struggling with thinking things through
- ◆ Attention — being very easily distracted
- ◆ Language — taking much longer coming up with words than other people of the same age
- ◆ Visual depth perception — struggling to interpret an object in three dimensions, judge distances, or navigate stairs



For a person living with MCI, these cognitive changes may cause minor problems or may require help with more demanding daily tasks, such as paying bills, managing medication, and driving. MCI does not cause major problems with everyday living activities, such as shopping, preparing meals, taking care of a pet, and doing laundry. If there is a significant impact on everyday activities, this may suggest something other than MCI is happening.

## Types of MCI

There are two types of MCI based on the cognitive areas affected: amnesic MCI which primarily affects memory; and non-amnesic MCI which affects other cognitive abilities such as language, reasoning, and attention. Research suggests that amnesic MCI is about twice as common as non-amnesic MCI. Symptoms are not severe in either type, but the symptoms can be upsetting and disruptive.

## Diagnosing MCI

MCI is usually diagnosed by similar testing methods used for dementia. The diagnostic process begins with a comprehensive medical history, including what medications are being taken and a discussion about the types of cognitive changes being experienced, and any other relevant information. This is generally followed by a physical examination and blood tests to rule out other causes of cognitive changes such as depression, stress, medication side effects or interactions, or a nutritional deficiency.

If other causes have been ruled out, general tests for cognitive function are then conducted. Not all physicians are knowledgeable about cognitive conditions and may refer you to a neurologist or a neuropsychologist for the cognitive testing.

## Managing MCI

There is no standard treatment or approved medication for MCI, but there are things a person can do to keep healthy and manage changes in cognition. The following are some recommendations:

- ◆ Follow a daily routine
- ◆ Use memory tools such as calendars, to-do lists, and notes to yourself
- ◆ Put commonly used objects in the same place each day

- ◆ Learn a new skill
- ◆ Volunteer in your community, at a school, or at your place of worship
- ◆ Spend time with friends and family
- ◆ Get enough sleep, generally seven to eight hours each night
- ◆ Exercise and eat well
- ◆ Don't drink a lot of alcohol
- ◆ Get help if you feel depressed for weeks at a time

Because MCI may be an early sign of more serious memory problems, it's important to see a doctor or specialist every six to 12 months. A doctor can help track changes in memory and thinking skills over time. It is helpful to keep a record of cognitive changes you experience and when you experience the changes.

People living with MCI might also consider participating in clinical trials or studies. Clinical trials are research studies that help test if a treatment, like a new drug, is safe and effective in people. To find out more about participating in clinical trials for people with cognitive changes, call the Alzheimer's and Related Dementias Education and Referral (ADEAR) Center at 1-800-438-4380.

## **Does MCI Lead to Dementia?**

According to the National Institute on Aging, researchers have found that more people living with MCI than those without it go on to develop a form of dementia. An estimated 10 to 20 percent of people age 65 or older living with MCI develop dementia over a one-year period. However, not everyone who has MCI develops dementia. In many cases, the symptoms of MCI may stay the same or even improve. Research suggests that genetic factors may play a role in who will develop MCI, as they do with dementia. Studies are underway to learn why some people living with MCI progress to dementia and others do not.

## Signs of Healthy Aging vs. Mild Cognitive Impairment vs. Dementia

The chart below highlights how mild cognitive impairment differs from the changes seen in healthy aging and dementia.\*

	Healthy Aging	Mild Cognitive Impairment	Dementia
Sometimes forgetting which words to use	✓		
Losing things from time to time	✓		
Missing a monthly payment occasionally	✓		
Difficulty coming up with words		✓	
Losing things often		✓	✓
Forgetting to go to important events		✓	✓
Trouble having a conversation and/or reading and writing			✓
Asking the same question or repeating the same story over and over			✓
Difficulty with basic daily activities			✓
Problems handling money and paying bills			✓
Becoming lost in familiar places			✓
Hallucinations, delusions, and paranoia			✓

\*This is not a complete list of all symptoms associated with these conditions, but it is designed to show how the symptoms differ.



## 8.2 Dementia

This manual is inclusive for people who are experiencing some cognitive changes, have been diagnosed with mild cognitive impairment, or who have been diagnosed with a form of dementia. Instead of writing cognitive impairment/dementia throughout the manual, we use the term “dementia” for brevity to mean any type of cognitive change.

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*There are some excellent online sources for information about dementia. This section includes, with permission, information about dementia from a variety of trusted sources. These sources are a good place to start if you have questions about your condition and up-to-date research.*

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Dementia is a degeneration of the brain that causes a progressive decline in people’s ability to think, reason, make decisions, communicate, and remember. Their personality, behavior, and mood can also be affected. Everyone’s experience of dementia is unique, and the progression of the condition varies. Some symptoms are more likely to occur with certain types of dementia.

*Used with permission of:*

*CLEVELAND CLINIC FOUNDATION*

### **Does Memory Loss Mean Dementia is Starting?**

One common misbelief about memory loss is that it always means you or a loved one has dementia. There are many causes of memory loss. Memory loss alone doesn’t necessarily confirm a diagnosis of dementia.

It’s also true that some memory changes are normal as people age (some neurons in your brain naturally die as we age). However, this type of memory loss isn’t functionally disabling, meaning it doesn’t interfere with daily life.

Dementia interferes with your ability to function. Dementia isn't forgetting where you left your keys. A person living with dementia can have situations like forgetting what keys are used for. Dementia is not a normal part of aging.

## Who Gets Dementia?

Dementia is considered a late-life disease because it tends to develop mostly in people who are older. About five to eight percent of all people over the age of 65 have some form of dementia, and this number doubles every five years above that age. It's estimated that as many as half of people 85 years of age and older are living with dementia.

The number of people aged 65 and older who have Alzheimer's disease and related dementias by race is:

- ◆ Blacks: 14%
- ◆ Hispanics: 12%
- ◆ Non-Hispanic whites: 10%
- ◆ American Indian and Alaska Natives: 9%
- ◆ Asian and Pacific Islanders: 8%

## How Common is Dementia?

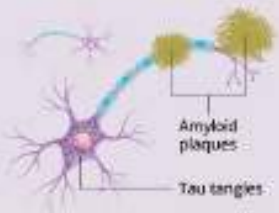



The U.S. Centers for Disease Control and Prevention (CDC) estimate that five million U.S. adults aged 65 or older have Alzheimer's and related dementia. By 2060, the CDC projects that about 14 million people will be living with dementia, which is about 3.3 percent of the population.

# Understanding Different Types of Dementia

As we age, it's normal to lose some neurons in the brain. People living with dementia, however, experience far greater loss. Many neurons stop working, lose connections with other brain cells, and eventually die. At first, symptoms can be mild, but they get worse over time. Read on to learn more about four different types of dementia.



## TYPES OF DEMENTIA

Alzheimer's Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
What Is Happening in the Brain?			
<p>Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain.</p>  <p>Amyloid plaques Tau tangles</p>	<p>Abnormal amounts or forms of tau and TDP-43 proteins accumulate inside neurons in the frontal and temporal lobes.</p>  <p>Frontal lobe Temporal lobe Tau TDP-43</p>	<p>Abnormal deposits of the alpha-synuclein protein, called "Lewy bodies," affect the brain's chemical messengers.</p>  <p>Lewy body</p>	<p>Conditions, such as blood clots, disrupt blood flow in the brain.</p>  <p>Blood clot</p>

*\*These changes are just one piece of a complex puzzle that scientists are studying to understand the underlying causes of these forms of dementia and others.*

Living with dementia can be challenging, but there are ways to manage it. To learn more about these types of dementia and other conditions that can cause dementia, visit [www.nia.nih.gov/health/what-is-dementia](http://www.nia.nih.gov/health/what-is-dementia).





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## **Types of Primary Dementia**

### **ALZHEIMER'S DISEASE**

This is the most common type of dementia. Two abnormal proteins build up in your brain: tau and amyloid proteins. These proteins disrupt communication between nerve cells in your brain. Nerve cells die, starting in one area and spreading as more nerve cells die in other areas. Symptoms include short-term memory loss, confusion, personality and behavior changes. Trouble talking, remembering distant memories and issues with walking happen later in the disease. Alzheimer's disease mainly affects adults who are older — up to 10 percent of those over age 65 and about 50 percent of people older than 85 have the disease. Family history is an important risk factor. Approximately 60 to 80 percent of people living with dementia have Alzheimer's disease.

### **VASCULAR DEMENTIA**

This is the second most common type of dementia. It's caused by conditions such as strokes or atherosclerosis, which block and damage blood vessels in your brain. Symptoms include memory problems, confusion, and trouble concentrating and completing tasks. The decline may appear suddenly (following a major stroke) or in steps (following a series of mini strokes). Risk factors include high blood pressure, diabetes and high cholesterol levels. About 15 to 25 percent of people living with dementia have vascular dementia.

### **LEWY BODY DEMENTIA**

This condition involves the buildup of clumps of proteins — called Lewy bodies — in your brain's nerve cells. Lewy bodies damage nerve cells. Symptoms include movement and balance problems, changes in sleep patterns, memory loss, planning and problem-solving difficulties, and visual hallucinations and delusions. About 5 to 10 percent of dementias are Lewy Body dementia.

### **FRONTOTEMPORAL DEMENTIA (FTD)**

This dementia results from damage to the frontal and temporal lobes of your brain. The damage is caused by the buildup of abnormal proteins in these areas. It causes changes in social behavior, personality, and/or loss of language skills (speaking, understanding or forgetting the meaning of common words) or

motor coordination. FTD is a common cause of early dementia, often occurring in people between the ages of 45 and 64. Between 5 and 6 percent of all dementias are FTD.

## **MIXED DEMENTIA**

This is a combination of two or more types of dementia. The most common combination is Alzheimer's disease with vascular dementia. It's most common in people 80 years of age and over. It's often hard to diagnose because symptoms of one dementia may be more obvious and/or many symptoms of each overlap. The decline is faster in people who are living with mixed dementia compared with those who only have one type. Researchers don't know exactly how many older adults currently diagnosed with a specific type of dementia actually have mixed dementia, but autopsies indicate that the condition may be significantly more common than previously realized.

## **Dementia Due to Other Diseases and Conditions**

### **HUNTINGTON'S DISEASE**

A single defective gene causes this brain disorder. The disease causes a breakdown in your brain's nerve cells, which causes body movement control problems, as well as thinking, decision-making and memory trouble, and personality changes.

### **PARKINSON'S DISEASE**

Parkinson's disease is a brain disorder that causes unintended or uncontrollable movements, such as shaking, stiffness, and difficulty with balance and coordination. Symptoms usually begin gradually and worsen over time. Many people in the later stages of Parkinson's disease develop dementia. Symptoms include trouble with thinking and memory, hallucinations and delusions, depression and trouble with speech.

### **CREUTZFELDT-JAKOB DISEASE**

This rare infective brain disease affects about only one in one million people. An abnormal protein in your brain called prions causes the disease. These prions clump together and cause nerve cell death in your brain. Symptoms include problems with thinking, memory, communication, planning and/or judgment, confusion, behavior changes, agitation and depression.



## **WERNICKE-KORSAKOFF SYNDROME**

This brain disorder is caused by a severe thiamine (vitamin B1) deficiency. This can result in bleeding in key areas related to memory in your brain. It's most commonly caused by alcohol use disorder but can also be due to malnutrition and chronic infection. Symptoms include double vision, loss of muscle coordination, and difficulty processing information, learning new skills and remembering things.

## **TRAUMATIC BRAIN INJURY**

Repeated blows to your head can cause this injury. It's most often seen in football players, boxers, soldiers and people who've had a vehicle accident. Dementia symptoms, which appear years later, include memory loss, behavior or mood changes, slurred speech, and headaches.

## **Dementias Due to Reversible Causes**

Some conditions can cause dementia-like symptoms that can be reversed with treatment.

### **NORMAL PRESSURE HYDROCEPHALUS (NPH)**

This condition happens when cerebrospinal fluid (CSF) builds up in your brain's spaces (ventricles). The excess buildup harms your brain. NPH can be caused by a brain infection, brain injury, brain bleed, or previous brain surgery. Symptoms include poor balance, forgetfulness, trouble paying attention, mood swings, frequent falls, and loss of bladder control. Your healthcare provider can drain excess fluid through the surgical placement of a shunt (tube).

### **VITAMIN DEFICIENCY**

Not getting enough vitamin B1, B6, B12, copper and vitamin E in your diet can cause dementia-like symptoms.

### **INFECTIONS**

Infections that can cause dementia-like symptoms include HIV infection, syphilis and Lyme disease. Symptoms reported with COVID-19 infection include "brain fog" and acute delirium. Because of the inflammation and stroke risk seen with COVID-19 infection, both short- and long-term cognitive effects are being investigated. Urinary tract infections (UTIs) and infections in your lungs in the elderly can also result in dementia-like symptoms. Other central nervous system

infections and brain infections caused by fungi, bacteria, and parasites can also cause cognitive symptoms.

### **METABOLIC AND ENDOCRINE CONDITIONS**

Conditions that can mimic dementia include Addison's disease, Cushing's disease, low blood sugar (hypoglycemia), exposure to heavy metals (like arsenic or mercury), high calcium levels (hypercalcemia, often due to hyperparathyroidism), liver cirrhosis, and thyroid problems.

### **MEDICATION SIDE EFFECTS**

Some medications, in some people, can mimic dementia symptoms. These include sleeping pills, anti-anxiety drugs, antidepressants, anti-seizure drugs, anti-Parkinson drugs, nonbenzodiazepine sedatives, narcotic pain relievers, statins, and others. Ask your healthcare provider to review your medications if you have any dementia-like symptoms.

### **OTHER CAUSES**

Other causes of dementia-like symptoms include brain tumors and subdural hematomas (brain bleeds between your brain's surface and the covering over your brain).

## 8.3 What's the Difference Between Dementia and Alzheimer's Disease?

Dementia is a description of the state of a person's mental function and not a specific disease. Dementia is an "umbrella term" describing cognitive decline that's severe enough to interfere with daily living.

There are many underlying causes of dementia, including Alzheimer's disease and Parkinson's disease. Alzheimer's disease is the most common underlying cause of dementia.



### ***Making the Case for an Early Diagnosis***

***Sherrie All, PhD, Contributor***

*Sherrie is founder and owner of the Centers for Cognitive Wellness*

Many people do not get diagnosed with dementia until they are experiencing moderate symptoms. Delaying diagnosis until this point limits the opportunities for proactive actions that could slow or delay progression of symptoms.

Your primary care physician, occupational or speech therapist, or other healthcare professional should be able to screen your cognition using a standardized cognitive screening tool like the Montreal Cognitive Assessment (MoCA) or St. Louis University Mental Status (SLUMS). **It is not recommended that you look for these tests on the internet or study up because that will only weaken test results.**

Unfortunately, many healthcare practitioners use ineffective cognitive screening tools. If your doctor only asks you six or so questions during your annual physical and gives you a clean bill of cognitive health, ask for a more detailed screening. The Mini-Mental Status Examination (MMSE) is generally outdated and often administered in an unstandardized way, plus it was never designed to be sensitive to mild cognitive impairment, so it is likely to miss early, potentially treatable changes. **If you are only asked to remember a list of three words and not five words, this is a sign of getting an incomplete cognitive screen test.**

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*It is not recommended that you look for these tests on the internet or study up because that will only weaken test results.*

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If you are seeing your healthcare provider specifically because you are experiencing cognitive changes, ask to be given the MoCA or SLUMS cognitive screening test. If your healthcare provider does not use these screening tests, ask to be referred to a specialist who conducts more thorough cognitive screens, such as a neuropsychologist or neurologist.

## **Diagnostic Process**

Your doctor will first rule out conditions that can cause confusion and memory problems that are reversible, such as depression, stress, vitamin B-12 deficiency, medication reactions, or low levels of thyroid. A physical exam, thorough medical history, and blood work are done to rule out conditions that may be affecting your cognition. You will likely be given written tests and asked questions that in the past you would have answered easily but may now find challenging.

Thorough cognitive and neurological testing can take many hours and can be very tiring and humbling. The various testing is used to assess thinking, memory, problem solving, language and math skills, as well as balance, sensory response, and reflexes.

These tests are designed to be very sensitive. You will not get every answer right. While it may feel like you're not doing very well, you may be doing just fine. We have to push you beyond your capacity. If you think you got a question wrong, you may not have. And it's not a big deal if you did get it wrong. Don't ruminate on the last question, let it go. Focus on this next question.

Finding anything early, we have intervention tools and the intervention is meaningful at that point. The longer you are able to be independent and be proactive about your brain health, the better quality of life you'll have. Testing can be uncomfortable but it's really important.

In addition to cognitive tests, your doctor may order:

- ◆ An MRI to look for brain shrinkage or a brain tumor
- ◆ A spinal tap to look for biomarkers of Alzheimer's disease, called amyloid plaques and tau tangles
- ◆ A PET scan to differentiate frontotemporal or Lewy body dementia from Alzheimer's disease
- ◆ A sleep study if Lewy body dementia is suspected

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*If your healthcare provider does not use the MoCA or SLUMS screening tests, ask to be referred to a specialist who conducts more thorough cognitive screens, such as a neuropsychologist or neurologist.*

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Be sure to check whether Medicare or other insurance will pay for these tests before undergoing them.

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DEMENTIA UK — <https://www.dementiauk.org/about-dementia/young-onset-dementia/what-is-young-onset-dementia/>

## 8.4 Young Onset Dementia

Dementia is described as “young onset” when symptoms develop before the age of 65, usually between 30 to 65 years of age. It is also referred to as “early onset” or “working age” dementia, but these terms can cause confusion. “Early onset” can be interpreted as the early stages of dementia and “working age” is now less defined as retirement age is more flexible.

As dementia is frequently, and wrongly, thought of as a condition that is just associated with old age, the early symptoms of young onset dementia are not always recognized and may be attributed to other causes including depression, stress, menopause, physical health problems, and relationship issues. This can lead to a significant delay (on average four years) in getting an accurate diagnosis and access to appropriate support. This can have a negative impact on not just the person living with dementia’s life but also the whole family.

### How Does Young Onset Dementia Develop?

The early symptoms of young onset dementia may not be memory loss. Symptoms can differ from one person to another depending on the type of dementia a person has, and which parts of the brain it affects.

Dementias affecting the frontal and temporal lobes of the brain are more common in younger people so it is more likely that the early symptoms may include changes in:

- ◆ Personality
- ◆ Behavior
- ◆ Language
- ◆ Social functioning
- ◆ Relationships with others

- ◆ Activities of everyday living
- ◆ Motivation
- ◆ Mood (e.g., depression, anxiety)
- ◆ Concentration levels
- ◆ Decision making and problem solving
- ◆ Vision and spatial awareness

In addition, the person may not recognize the changes or may be reluctant to accept there is anything wrong when they are otherwise fit and well, and so put off visiting their doctor.

*Reprinted with permission from:*

*ALZHEIMER'S DISEASE INTERNATIONAL —*

<https://www.alzint.org/about/risk-factors-risk-reduction/>

## **8.5 Risk Factors for Dementia**

There are many factors which have been linked to the development of dementia. Some are risk factors, while others appear to be predictive.

Risk factors are characteristics that appear to have some relationship to the development of a disease. If these risk factors are present, there is an increased chance, but not a certainty, that the disease will develop. For example, not everyone who smokes develops heart disease and not everyone with heart disease has been a smoker. However, smoking is a strong risk factor for heart disease.

Some risk factors can be modified, for example lowering blood pressure reduces the risk of a stroke. Other risk factors cannot be modified, such as age or family history.

The greatest risk factor for dementia is increasing age. Although age increases risk, dementia is not a normal part of aging.

We know there are more than 20 genes which affect a person’s risk of developing dementia. The gene APOE was the first known to increase a person’s risk of developing Alzheimer’s disease, and it is still the strongest risk gene known. There are also genes which directly cause dementia, but these deterministic genes are rare — they are estimated to account for less than one percent of dementia cases and cause young-onset forms in which symptoms usually develop before the age of 60.



Women are more likely to develop Alzheimer’s disease than men, even accounting for the fact that women live longer on average. The reasons for this are unclear.

## Modifiable risk factors

Although we can’t change our genes or stop aging, there are changes that we can make to reduce our risk of dementia, either lifestyle changes as individuals or wider changes across society. A growing body of research evidence exists for 12 potentially modifiable risk factors. We might prevent or delay up to 40 percent of cases of dementia, if we were able to modify all of the risk factors.

Although behavior change is difficult and some associations might not be causal, individuals have a huge potential to reduce their dementia risk. Many of the risk factors



are also shared with other non-communicable diseases such as heart disease, cancer, diabetes, and chronic respiratory diseases.

Keeping active, eating well, and engaging in social activities all promote good brain health and may reduce your risk of developing dementia. Keeping your heart healthy, including by avoiding smoking and excessive alcohol consumption, can lower your risk of dementia and other diseases too.

The following is a list of risk factors for dementia along with suggestions of how to counteract them and reduce risk.

### **PHYSICAL INACTIVITY**

Regular physical activity is one of the best ways to reduce your risk of dementia. It's good for your heart, circulation, weight, and mental wellbeing. It is recommended that adults aim for either 150 minutes of moderate aerobic activity or 75 minutes of vigorous aerobic activity each week.

### **SMOKING**

Smoking greatly increases your risk of developing dementia. You're also increasing your risk of other conditions, including type 2 diabetes, stroke, and lung and other cancers. It's never too late to quit — stopping smoking later in life also reduces the risk of dementia.

### **EXCESSIVE ALCOHOL CONSUMPTION**

Alcohol misuse and drinking more than 21 drinks with alcohol in a week increase the risk of dementia. The harmful use of alcohol is a causal factor in more than 200 disease and injury conditions. There is a causal relationship between harmful use of alcohol and a range of mental and behavioral disorders, other non-communicable diseases as well as injuries.

### **AIR POLLUTION**

A growing amount of research evidence shows that air pollution increases the risk of dementia. Policymakers should expedite improvements in air quality, particularly in areas with high air pollution.

### **HEAD INJURY**

Head injuries are most commonly caused by car, motorcycle, and bicycle accidents; military exposures; boxing, football, hockey and other sports; firearms and violent assaults; and falls. Policymakers should use public health and other policy measures to reduce head injuries.

## **INFREQUENT SOCIAL CONTACT**

It is well established that social connectedness reduces the risk of dementia. Social contact enhances cognitive reserve or encourages beneficial behaviors. There is not much evidence for any specific activity protecting against dementia. Joining a club or community group are good ways to stay socially active.

## **LESS EDUCATION**

A low level of education in early life affects cognitive reserve and is one of the most significant risk factors for dementia. Policymakers should prioritize childhood education for all.

## **OBESITY**

Particularly in mid-life, obesity is associated with an increased risk of dementia. Obesity is also associated with other non-communicable diseases and can generally be addressed through lifestyle changes such as diet and exercise.

## **HYPERTENSION**

Hypertension (high blood pressure) in mid-life increases a person's risk of dementia, as well as causing other health problems. Medication for hypertension is the only known effective preventive medication for dementia.

## **DIABETES**

Type 2 diabetes is a clear risk factor for development of future dementia. Whether any particular medication helps with this is unclear, but treatment of diabetes is important for other health reasons.

## **DEPRESSION**

Depression is associated with dementia incidence. Depression is part of the prodrome of dementia (a symptom that occurs before the symptoms that are used for diagnosis). It is not clear to what extent dementia may be caused by depression or the reverse. In any case, it is important to manage and treat depression because it is associated with increased disability, physical illnesses, and worse outcomes for people living with dementia.

## **HEARING IMPAIRMENT**

People with hearing loss have a significantly increased risk of dementia. Using hearing aids seems to reduce the risk. As hearing loss is one of the risk factors which affects the most people, addressing it could result in a large impact on the number of people developing dementia.

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MAYO CLINIC — <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-20350447>

## 8.6 Alzheimer's Disease

### Overview

Alzheimer's disease is a progressive neurologic disorder that causes the brain to shrink (atrophy) and brain cells to die. Alzheimer's disease is the most common cause of dementia — a continuous decline in thinking, behavioral and social skills that affects a person's ability to function independently. Approximately 5.8 million people in the United States age 65 and older are living with Alzheimer's disease. Of those, 80 percent are 75 years old and older. Out of the approximately 50 million people worldwide living with dementia, between 60 and 70 percent are estimated to be diagnosed with Alzheimer's disease. The early signs of the disease include forgetting recent events or conversations. As the disease progresses, a person living with Alzheimer's disease will develop severe memory impairment and lose the ability to carry out everyday tasks. Medications may temporarily improve or slow progression of symptoms. These treatments can sometimes help people living with Alzheimer's disease maximize function and maintain independence for a period of time. Different programs and services can help support people living with Alzheimer's disease and their caregivers. There is no treatment that cures Alzheimer's disease or alters the disease process in the brain. In advanced stages of the disease, complications from severe loss of brain function — such as dehydration, malnutrition, or infection — result in death.

### Symptoms

Memory loss is the key symptom of Alzheimer's disease. Early signs include difficulty remembering recent events or conversations. As the disease progresses, memory impairments worsen and other symptoms develop. At first, a person living with Alzheimer's disease may be aware of having difficulty remembering things and organizing thoughts. A family member or friend may be more likely to notice how symptoms worsen.

Brain changes associated with Alzheimer's disease lead to growing trouble with:

### **Memory**

Everyone has occasional memory lapses, but the memory loss associated with Alzheimer's disease persists and worsens, affecting the ability to function at work or at home.

People living with Alzheimer's may:

- ◆ Repeat statements and questions over and over
- ◆ Forget conversations, appointments or events, and not remember them later
- ◆ Routinely misplace possessions, often putting them in illogical locations
- ◆ Get lost in familiar places
- ◆ Forget the names of family members and everyday objects
- ◆ Have trouble finding the right words to identify objects, express thoughts, or take part in conversations

### **Thinking and reasoning**

Alzheimer's disease causes difficulty concentrating and thinking, especially with concentrating

and thinking, especially math related tasks. Multitasking is especially difficult, and it may be challenging to manage finances, balance checkbooks, and pay bills on time. Eventually, a person living with Alzheimer's may be unable to recognize and deal with numbers.

### **Making judgments and decisions**

Alzheimer's causes a decline in the ability to make reasonable decisions and judgments in everyday situations. For example, a person may make poor or uncharacteristic choices in social interactions or wear clothes that are inappropriate for the weather. It may be more difficult to respond effectively to everyday problems, such as food burning on the stove or unexpected driving situations.

### **Planning and performing familiar tasks**

Once-routine activities that require sequential steps, such as planning and cooking a meal or playing a favorite game, become a struggle as the disease progresses. People living with advanced Alzheimer's often forget how to perform basic tasks such as dressing and bathing.

## Changes in personality and behavior

Brain changes that occur in Alzheimer's disease can affect moods and behaviors. Problems may include the following:

- ◆ Depression
- ◆ Apathy
- ◆ Social withdrawal
- ◆ Mood swings
- ◆ Distrust in others
- ◆ Irritability and aggressiveness
- ◆ Changes in sleeping habits
- ◆ Wandering
- ◆ Loss of inhibitions
- ◆ Delusions, such as believing something has been stolen

## Preserved skills

Many important skills are preserved for longer periods even while symptoms worsen. Preserved skills may include reading or listening to books, telling stories and reminiscing, singing, listening to music, dancing, drawing, or doing crafts. These skills may be preserved longer because they are controlled by parts of the brain affected later in the course of the disease.

## Genetics of Alzheimer's Disease

Many people worry about developing Alzheimer's disease, especially if a family member has had it. Having a family history of the disease does not mean for sure that you'll have it, too. But it may mean you are more likely to develop it.

People's genes, which are inherited from their biological parents, can affect how likely they are to develop Alzheimer's disease. Genetic risk factors are changes or differences in genes that can influence the chance of getting a disease. These risk factors are the reason some diseases run in families.

There are two types of Alzheimer's — early-onset and late-onset. Both types have a genetic component.

### Late-Onset Alzheimer's Disease

Most people living with Alzheimer's have late-onset Alzheimer's disease, in which symptoms become apparent in their mid-60s. Researchers have not found a specific gene that directly causes the late-onset form of the disease. However, one genetic risk factor — having one form, or allele, of the apolipoprotein E (APOE) gene on chromosome 19 — does increase a person's risk. APOE4 is called a risk-factor gene because it increases a person's risk of developing the disease. However, inheriting an APOE4 allele does not mean that a person will definitely develop Alzheimer's. Some people with an APOE4 allele never get the disease, and others who develop Alzheimer's do not have any APOE4 alleles.

### Early-Onset Alzheimer's Disease

Early-onset Alzheimer's disease occurs between a person's 30s to mid-60s and represents less than 10 percent of all people living with Alzheimer's. Some cases are caused by an inherited change in one of three genes. For other cases, research shows that other genetic components are involved. Researchers are working to identify additional genetic risk variants for early-onset Alzheimer's disease.

## Some Differences Between Late-Onset and Early-Onset Alzheimer's Disease

Late-Onset Alzheimer's	Early-Onset Alzheimer's
Signs first appear in a person's mid-60s	Signs first appear between a person's 30s and mid-60s
Most common type	Very rare
May involve a gene called APOE ε4	Usually caused by gene changes passed down from parent to child

### Progression of Alzheimer's Disease

#### Mild Alzheimer's disease

As Alzheimer's symptoms progress, people experience greater memory loss and other cognitive difficulties. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, taking longer to complete normal daily tasks, and personality and behavior changes. People are often diagnosed in this stage.

#### Moderate Alzheimer's disease

In this stage, damage occurs in areas of the brain that control language, reasoning, conscious thought, and sensory processing, such as the ability to correctly detect sounds and smells. Memory loss and confusion grow worse, and people begin to have problems recognizing family and friends. They may be unable to learn new things, carry out multistep tasks such as getting dressed, or cope with new situations. In addition, people at this stage may have hallucinations, delusions, paranoia, and may behave impulsively.

#### Severe Alzheimer's disease

Ultimately, plaques and tangles spread throughout the brain, and brain tissue shrinks significantly. People with severe Alzheimer's cannot communicate and are completely

dependent on others for their care. Near the end of life, the person may be in bed most or all of the time as the body shuts down.

[nia.nih.gov/health/alzheimers-disease-fact-sheet](https://nia.nih.gov/health/alzheimers-disease-fact-sheet)

### **How is Alzheimer's disease diagnosed?**

There is currently no single test to identify Alzheimer's disease. The diagnosis is made only after careful clinical consultation.

The clinical diagnosis might include:

- ◆ A detailed medical history
- ◆ A thorough physical and neurological examination
- ◆ A test of intellectual function
- ◆ Psychiatric assessment
- ◆ Neuropsychological tests
- ◆ Blood and urine tests
- ◆ Lumbar puncture for cerebral spinal fluid tests
- ◆ Medical imaging (MRI, PET)

These tests will help to rule out other conditions with similar symptoms such as nutritional deficiencies or depression. After eliminating other causes, a clinical diagnosis of Alzheimer's disease can be made with about 80 to 90 percent accuracy if the symptoms and signs are appropriate. The diagnosis can only be confirmed after death by examination of the brain tissue.

It is important to have an early and accurate diagnosis to determine whether a treatable condition other than Alzheimer's disease is causing the symptoms. If Alzheimer's disease is diagnosed, medical treatment and other assistance can be discussed.



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[https://alzheimer.ca/sites/default/files/documents/other-dementias\\_vascular-dementia.pdf](https://alzheimer.ca/sites/default/files/documents/other-dementias_vascular-dementia.pdf)

## 8.7 Vascular Dementia

Vascular dementia is a type of dementia caused by damage to the brain from lack of blood flow or from bleeding in the brain. For our brain to function properly, it needs a constant supply of blood through a network of blood vessels called the brain vascular system. When the blood vessels are blocked, or when they bleed, oxygen and nutrients are prevented from reaching cells in the brain. As a result, the affected cells can die.

When brain cells die from lack of blood flow or from bleeding, then stroke symptoms can result. Vascular dementia can be a consequence of stroke. Stroke symptoms may include paralysis and loss of speech. The location and size of cell death determines how the thinking and physical functioning of the individual will be affected. Conditions such as cerebral small vessel disease that narrow or cause long-term damage to the blood vessels in the brain can also lead to vascular dementia. Someone with vascular dementia may notice changes in their ability to make decisions, plan, or organize as their first symptoms. Other changes may include difficulties with movement, such as slow gait and poor balance. Symptoms tend to appear slowly, and specific impairments may occur in steps, where the person's abilities can deteriorate, stabilize for a time, and then decline again.

### Types of Vascular Dementia

Different kinds of brain blood vessel and cardiac conditions can lead to strokes and other kinds of vascular brain damage. This brain damage may also result in vascular dementia. To find out the cause of the blood vessel problem in the brain, doctors will ask questions and do tests for conditions like atherosclerosis (cholesterol build up), arteriosclerosis (hardening of the small arteries of the brain, commonly caused by high blood pressure), and others.

Two types of vascular dementia include subcortical dementia and cerebral amyloid angiopathy.

## **SUBCORTICAL DEMENTIA**

Subcortical dementia is caused by small vessel disease, a condition in which the small vessels in the brain become stiff and twisted, resulting in reduced blood flow to the brain. Small vessel disease often damages the nerve fibers that carry signals around the brain, known as white matter. Small vessel disease tends to damage deeper areas of the brain.

## **CEREBRAL AMYLOID ANGIOPATHY**

Often occurring with Alzheimer's disease, cerebral amyloid angiopathy occurs when there is an accumulation of amyloid in the brain blood vessels. Amyloid is the same protein that can accumulate outside of cells in Alzheimer's disease, forming plaques that disrupt brain function. When amyloid accumulates inside the blood vessels, strokes or bleeding may happen which can result in symptoms of dementia.

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*FAMILY CAREGIVER ALLIANCE — <https://www.caregiver.org/resource/vascular-dementia/>*

## **Testing and Diagnosis**

Concerns about vascular dementia should be raised with a physician. Early diagnosis is important, as it provides access to treatment, advice regarding planning for the future, and possible recommendations for lifestyle changes that may slow down the progression of the underlying disease. Recommended lifestyle changes may include following a healthier diet, getting physically active, quitting smoking, and quitting or decreasing alcohol consumption. Depression frequently coexists with vascular dementia and can contribute to, or worsen, vascular-based cognitive symptoms. Medical conditions that may present symptoms similar to depression (fatigue, irritability, insomnia, decreased appetite, anxiety) caused by vascular disease should first be ruled out. A thorough medical examination for vascular dementia can include a variety of different tests and studies. A physician will conduct a full medical history and likely order blood tests to rule out reversible causes of cognitive decline, such as low Vitamin B12 or hypothyroidism. Often individuals are referred to a neurologist for more specialized examination of motor functioning, as well as reflexes, sensation, and gait (manner of walking). A brain scan

(e.g., CT, MRI, MRA) is often ordered in the examination stage to identify the presence of strokes or disease in the blood vessels.

Some individuals may also be referred for a carotid ultrasound if there is concern about blockages in these specific arteries. Referral to a specialist for evaluation of thinking skills, such as memory and processing speed, is typical and an important component of the evaluation. The specialist consulted may be a psychiatrist or neuropsychologist. Evaluating independent function is important to determine if the cognitive difficulties are impacting day-to-day activities enough to indicate a diagnosis of dementia. Patients who have cognitive decline but intact daily functioning might instead be given a diagnosis of Mild Cognitive Impairment (MCI).

If the medical examination indicates the person has dementia or MCI due to vascular disease of the brain, the diagnosis will be made and discussion about the next steps will be provided.

Vascular dementia can be difficult to differentiate from other forms of dementia because there is frequently an overlap in symptoms. Also, many individuals with dementia have both vascular disease and another brain disease such as Alzheimer's or Lewy Body Dementia, and therefore have a "mixed dementia."

*Reprinted with permission from:*

*Lewy Body Dementia Association —*

<https://www.lbda.org/facing-lewy-body-dementia-together-an-introduction-to-lbd/>

## **8.8 Lewy Body Dementia**

### **Understanding Lewy Body Dementias**

Lewy body dementias (LBD) affect an estimated 1.4 million individuals and their families in the United States. At the Lewy Body Dementia Association (LBDA), we understand that though many families are affected by this disease, few individuals and medical professionals are aware of the symptoms, diagnostic criteria, or even that LBD exists.

Lewy body dementia (LBD) is the third most common form of dementia. The most common form of dementia is Alzheimer's disease followed by vascular dementia. LBD is associated with the presence of Lewy bodies (abnormal deposits of a protein called alpha-synuclein) in the brain.

LBD can have three common presentations. Regardless of the initial symptom, over time all three presentations of LBD will develop very similar cognitive, physical, sleep, and behavioral features.

1. Some individuals will start out with a movement disorder leading to the diagnosis of Parkinson's disease and later develop dementia. This is diagnosed as Parkinson's disease dementia (PDD).
2. Another group of individuals will start out with a cognitive/memory disorder that may be mistaken for Alzheimer's disease, but over time two or more distinctive features become apparent leading to the diagnosis of "dementia with Lewy bodies" (DLB).
3. Lastly, a small group will first present with neuropsychiatric symptoms, which can include hallucinations, behavioral problems, and difficulty with complex mental activities, also leading to an initial diagnosis of dementia with Lewy bodies.

## Symptoms of LBD

- ◆ **Parkinson's-like symptoms** (or Parkinsonism) include rigidity or stiffness, shuffling gait, tremor and slowness of movement. Sometimes a Parkinson's medication called levodopa is prescribed for these symptoms.
- ◆ **Hallucinations** are seeing or hearing things that are not present. Visual hallucinations occur in up to 80 percent of people living with LBD, often early on. Nonvisual hallucinations, such as hearing sounds, smelling things that are not present, or feelings of being touched are less common than visual ones but may also occur.
- ◆ **REM Sleep Behavior Disorder** involves acting out dreams, sometimes violently. This symptom appears in some people years before any changes in cognition. Some sleep partners have reported being physically injured when the disorder was left untreated. REM Sleep Behavior Disorder can be responsive to treatment by melatonin and/or clonazepam.
- ◆ **Impaired thinking**, such as loss of executive function (planning, processing information), memory, or the ability to understand visual information. Fluctuations in cognition, attention or alertness.

- ◆ **Severe sensitivity to neuroleptics** is common in people living with LBD. Neuroleptics, also known as antipsychotics, are medications used to treat hallucinations and serious mental disorders. Up to 50 percent of people living with LBD treated with any antipsychotic medication may experience severe neuroleptic sensitivity, including worsening cognition, heavy sedation, increased or possibly irreversible parkinsonism, or symptoms resembling neuroleptic malignant syndrome (NMS), which can be fatal. NMS causes severe fever, muscle rigidity and breakdown that can lead to kidney failure.

While traditional antipsychotic medications, e.g., haloperidol and thioridazine HCL, are commonly prescribed for individuals living with Alzheimer's, these medications can affect the brain of an individual living with LBD differently, sometimes causing severe side effects. **For this reason, traditional antipsychotic medications like haloperidol should be avoided.** Some newer "atypical" antipsychotic medications like risperidone may also be problematic for someone living with LBD.

- ◆ **Significant changes in the autonomic nervous system**, including temperature regulation, blood pressure, and digestion. Dizziness, fainting, sensitivity to heat and cold, sexual dysfunction, early urinary incontinence, or constipation are common LBD symptoms
- ◆ **Repeated falls** attributed to dizziness, fainting, or the effects of parkinsonism on posture and balance
- ◆ **Other mood disorders and psychiatric symptoms** such as depression, delusions (false beliefs), and anxiety

### **Certain medications may worsen your condition**

Speak with your doctor about possible side effects. The following drugs may cause sedation, motor impairment, or confusion:

- ◆ Benzodiazepines, tranquilizers like diazepam and lorazepam
- ◆ Anticholinergics (antispasmodics), such as oxybutynin (Ditropan, Oxytral) and glycopyrrolate (Cuvposa, Glycate)
- ◆ Some surgical anesthetics
- ◆ Tricyclic antidepressants
- ◆ Certain over-the-counter medications, including diphenhydramine (Benadryl) and dimenhydrinate (Dramamine)

Some medications, like anticholinergics, amantadine (Gocovri), and dopamine agonists (Mirapex, Requip, Neupro), which help relieve parkinsonian symptoms, might increase confusion, delusions, or hallucinations.

**NOTE:** Be sure to meet with your anesthesiologist in advance of any surgery to discuss medication sensitivities and risks unique to LBD. People living with LBD often respond to certain anesthetics and surgery with acute states of confusion or delirium and may have a sudden significant drop in functional abilities, which may or may not be permanent. Possible alternatives to general anesthesia include a spinal or regional block. These methods are less likely to result in postoperative confusion. If you are told to stop taking all medications prior to surgery, consult with your doctor to develop a plan as some medications cannot be stopped immediately.

### **Not all treatments include taking medications**

- ◆ Physical therapy includes cardiovascular, strengthening, flexibility exercises, gait training, and general physical fitness programs.
- ◆ Speech therapy may improve low voice volume, poor enunciation, muscular strength, and swallowing difficulties.
- ◆ Occupational therapy helps maintain skills, and promotes safety, functional ability, and independence.
- ◆ Music and aromatherapy may reduce anxiety and improve mood.
- ◆ Individual and family psychotherapy may be useful for learning strategies to manage emotional and behavioral symptoms, and to help make plans that address individual and family concerns about the future.
- ◆ Support groups may be helpful for caregivers and persons living with LBD to identify practical solutions to day-to-day frustrations and to obtain emotional support from others.

### **What is the long-term prognosis for someone with Lewy body dementia?**

The prognosis is different for each person and may be affected by your general health or the existence of unrelated illnesses. Because LBD progresses at varying rates for each individual, it is not possible to determine how long someone may live with the disease.

The average duration of individuals living with LBD is typically five to eight years after the onset of obvious LBD symptoms but may range from two to 20 years. It is important to remember that this is a disorder that progresses gradually over years, not days or months.

While some people may find a diagnosis of LBD distressing, studies indicate that most individuals find some relief in knowing what is happening to them. An accurate diagnosis also leads to an optimum treatment plan.

### **What information will the doctor need to make an accurate diagnosis and provide the best treatment?**

Most people know to tell their doctors about any memory or other cognitive problems they are experiencing. However, since the symptoms of LBD and other types of dementia go far beyond cognitive issues, be sure to tell your doctor about any memory, cognitive, emotional, behavioral, movement, cardiac, digestive, or sleep problems you are having. Bring someone close to you with you, such as a spouse or an adult child, to discuss any changes they have observed. Also, tell your doctor about all of your current medications, including prescriptions, over-the-counter drugs, vitamins, and herbal supplements, since certain medications can worsen your symptoms.

The doctor may perform physical and neurological exams, run blood tests to rule out other diseases, do a brief mental status test, and order one or more types of brain scans that provide images of your brain or brain functioning. Ask your doctor for a referral for a complete neuropsychological examination. This is an assessment of thinking abilities, including memory, attention, word-finding, and visual-spatial skills. Neuropsychological exams are much more extensive and sensitive than routine office tests of mental status and can help differentiate among LBD, Alzheimer's disease, the usually mild changes associated with normal aging, and other neurological conditions.

### **LBD is a family disease, affecting both the patient and primary caregiver**

Unfortunately, LBD is not an easy disease with which to live. It affects both the person living with LBD and their family and friend network. Here are some considerations thinking ahead:

- ◆ Share your diagnosis with those closest to you, so you can stand together to face LBD.
- ◆ Become a knowledgeable partner with your doctor. Learn everything you can about LBD symptoms, treatment options, and caregiving. To learn more, visit the Lewy Body Dementia Association's website at: [www.lbda.org](http://www.lbda.org)
- ◆ Subscribe to a medical alert bracelet service to provide important medical information to emergency care providers.
- ◆ Identify local resources that provide information or assistance before you need it, including your local Area Agency on Aging office.

- ◆ Consult with an attorney who specializes in “elder law” about your legal and financial situation during the early stage of LBD.
- ◆ Fill out and carry the LBD Medical Alert Wallet Card, and present it any time you are hospitalized, require emergency medical care, or meet with your doctors.  
Find at: [lbd.org/wp-content/uploads/2020/09/Medical-Alert-Wallet-Card-PDF-Front-and-Back.pdf](https://lbd.org/wp-content/uploads/2020/09/Medical-Alert-Wallet-Card-PDF-Front-and-Back.pdf)



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### Cognitive Symptoms of Lewy Body Dementia

LBD causes changes in thinking abilities. These changes may include:

- ◆ Unpredictable changes in concentration, attention, alertness, and wakefulness from day to day and sometimes throughout the day. Ideas may be disorganized, unclear, or illogical. These kinds of changes are common in LBD and may help distinguish it from Alzheimer’s disease.
- ◆ Severe loss of thinking abilities that interfere with daily activities. Unlike in Alzheimer’s dementia, memory problems may not be evident at first but often arise as LBD progresses. Other changes related to thinking may include poor judgment, confusion about time and place, and difficulty with language and numbers.



## Movement Problems and Lewy Body Dementia

Some people living with LBD may not experience significant movement problems for several years. Others may have them early on. At first, movement symptoms, such as a change in handwriting, may be very mild and easily overlooked. Movement problems may include:

- ◆ Muscle rigidity or stiffness
- ◆ Shuffling walk, slow movement, or frozen stance
- ◆ Tremor or shaking, most commonly at rest
- ◆ Balance problems and repeated falls
- ◆ Stooped posture
- ◆ Loss of coordination
- ◆ Smaller handwriting than was usual for the person
- ◆ Reduced facial expression
- ◆ Difficulty swallowing
- ◆ A weak voice

## Lewy Body Dementia and Sleep

Sleep disorders are common in people living with LBD and are often undiagnosed. A sleep specialist can help diagnose and treat sleep disorders. Sleep-related disorders seen in people living with LBD may include:

- ◆ REM sleep behavior disorder
- ◆ Excessive daytime sleepiness (sleeping two or more hours during the day)
- ◆ Insomnia
- ◆ Restless leg syndrome

## Behavioral and Mood Symptoms of Lewy Body Dementia

Changes in behavior and mood are possible in LBD and may worsen as the person's thinking abilities decline. These changes may include:

- ◆ Depression
- ◆ Apathy, or a lack of interest in normal daily activities or events and less social interaction
- ◆ Anxiety and related behaviors, such as asking the same questions over and over, or being angry or fearful when a loved one is not present
- ◆ Agitation, or restlessness, and related behaviors, such as pacing, hand wringing, an inability to get settled, constant repeating of words or phrases, or irritability
- ◆ Delusions, or strongly held false beliefs or opinions not based on evidence (for example, a person may think his or her spouse is having an affair or that relatives long dead are still living)
- ◆ Paranoia, or an extreme, irrational distrust of others, such as suspicion that people are taking or hiding things

## Other Symptoms of Lewy Body Dementia

People living with LBD can also experience significant changes in the part of the nervous system that regulates automatic functions such as those of the heart, glands, and muscles. The person may have:

- ◆ Changes in body temperature
- ◆ Problems with blood pressure
- ◆ Dizziness
- ◆ Fainting
- ◆ Frequent falls
- ◆ Sensitivity to heat and cold
- ◆ Sexual dysfunction
- ◆ Urinary incontinence
- ◆ Constipation
- ◆ A poor sense of smell

## You Are Not Alone!

You don't have to face Lewy body dementia alone. The Lewy Body Dementia Association is here to educate, assist, and support you and your family as you begin your journey with this unique form of dementia. Since 2003, LBDA has grown to national recognition as a leader in LBD issues. You will find more in-depth information on our website:

[lbda.org](http://lbda.org)

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MAYO CLINIC — <https://www.mayoclinic.org/diseases-conditions/frontotemporal-dementia/symptoms-causes/syc-20354737>

### 8.9 Frontotemporal Dementia

Frontotemporal dementia (FTD) is an umbrella term for a group of brain disorders that primarily affect the frontal and temporal lobes of the brain. These areas of the brain are generally associated with personality, behavior, and language. In frontotemporal dementia, portions of these lobes shrink (atrophy). Signs and symptoms vary, depending on which part of the brain is affected. Some people with frontotemporal dementia have dramatic changes in their personalities and become socially inappropriate, impulsive or emotionally indifferent, while others lose the ability to use language properly.

Frontotemporal dementia can be misdiagnosed as a psychiatric problem or as Alzheimer's disease. FTD tends to occur at a younger age than does Alzheimer's disease. FTD often begins between the ages of 40 and 65 but occurs later in life as well. FTD is the cause of approximately 10 to 20 percent of dementia.

## What are the Types and Symptoms of FTD?

In the early stages, it can be hard to know which type of FTD a person is living with because symptoms and the order in which they appear can vary from one person to another. Also, the same symptoms can appear across different disorders and vary from one stage of the disease to the next as different parts of the brain are affected.

Symptoms of FTD are often misunderstood. Family members and friends may think that a person is misbehaving, leading to anger and conflict. It is important to understand that people with these disorders cannot control their behaviors and other symptoms and lack any awareness of their illness.

There are three types of frontotemporal disorders (FTD): behavioral variant frontotemporal dementia (bvFTD), primary progressive aphasia (PPA), and movement disorders.

### Behavioral variant frontotemporal dementia

The most common FTD, bvFTD, involves changes in personality, behavior, and judgment. People living with this disorder may have problems with cognition, but their memory may stay relatively intact. Symptoms can include:

- ◆ Problems planning and sequencing (thinking through which steps come first, second, and so on)
- ◆ Difficulty prioritizing tasks or activities
- ◆ Repeating the same activity or saying the same word over and over
- ◆ Acting impulsively or saying or doing inappropriate things without considering how others perceive the behavior
- ◆ Becoming disinterested in family or activities they used to care about

Over time, language and/or movement problems may occur, and the person living with bvFTD will need more care and supervision.

## **Primary progressive aphasia**

PPA involves changes in the ability to communicate — to use language to speak, read, write, and understand what others are saying. This includes difficulty using or understanding words (aphasia) and difficulty speaking properly (e.g., slurred speech). People with PPA may have one or both of these symptoms. They may become mute or unable to speak. Many people living with PPA develop symptoms of dementia. Problems with memory, reasoning, and judgment are not apparent at first but can develop over time. As the condition progresses some people with PPA may experience significant behavioral changes, similar to those seen in bvFTD.

There are three types of PPA, categorized by the kind of language problems that appear first.

### **SEMANTIC PPA**

A person slowly loses the ability to understand single words and sometimes to recognize the faces of familiar people and common objects.

### **AGRAMMATIC PPA**

A person has more and more trouble speaking and may omit words that link nouns and verbs (such as to, from, the). Eventually, the person may no longer be able to speak at all. The person may eventually develop movement symptoms similar to those seen in corticobasal syndrome.

### **LOGOPENIC PPA**

A person has trouble finding the right words during a conversation but can understand words and sentences. The person does not have problems with grammar.

Researchers do not fully understand the biological basis of the different types of PPA. They hope one day to link specific language problems with the changes in the brain that cause them.

## **Movement disorders**

Two rare neurological movement disorders associated with FTD, corticobasal syndrome and progressive supranuclear palsy, occur when the parts of the brain that control movement are affected. The disorders may affect thinking and language abilities, too.

- ◆ Corticobasal syndrome can be caused by corticobasal degeneration — a gradual atrophy (shrinkage) and loss of nerve cells in specific parts of the brain. This degeneration causes progressive loss of the ability to control movement, typically

beginning around age 60. The most prominent symptom may be apraxia, the inability to use the hands or arms to perform a movement despite normal strength. Examples of apraxia include difficulty closing buttons or operating small appliances. Other symptoms can include muscle rigidity and difficulty swallowing. Symptoms may appear first on one side of the body, but eventually both sides are affected. Occasionally, a person living with corticobasal syndrome first has language problems or trouble orienting objects in space and later develops movement symptoms. Not everyone who is living with corticobasal syndrome has problems with memory, cognition, language, or behavior.

- ◆ Progressive supranuclear palsy causes problems with balance and walking. People living with the disorder typically move slowly, experience unexplained falls, lose facial expression, and have body stiffness, especially in the neck and upper body — symptoms similar to those of Parkinson’s disease. A hallmark sign of this disorder is trouble with eye movements, particularly looking down. These symptoms may give the face a fixed stare. Problems with behavior, memory, problem solving, and judgment can also develop.

Other movement-related types of FTD include frontotemporal dementia with parkinsonism and frontotemporal dementia with amyotrophic lateral sclerosis (FTD-ALS).

- ◆ Frontotemporal dementia with parkinsonism can be an inherited disease caused by a genetic tau mutation. Symptoms include movement problems similar to those of Parkinson’s disease, such as slowed movement, stiffness, and balance problems, and changes in behavior or language.
- ◆ FTD-ALS, also called FTD with motor neuron disease, is a combination of bvFTD and ALS, the latter commonly known as Lou Gehrig’s disease. In addition to the behavioral and/or language changes seen in bvFTD, people living with FTD-ALS experience the progressive muscle weakness seen in ALS, fine jerks, and wiggling in muscles. Symptoms of either disease may appear first, with other symptoms developing over time. Mutations in certain genes have been found in some people living with FTD-ALS, though most cases are not hereditary.

*The following material is reprinted with permission from:*

*THE ASSOCIATION FOR FRONTOTEMPORAL DEGENERATION (AFTD), [theaftd.org](http://theaftd.org) —*

*<https://www.theaftd.org/living-with-ftd/managing-ftd/>*

## **Managing FTD**

As public awareness and diagnostic tools improve, more people are diagnosed with an FTD disorder in the early stage when symptoms are mild. It is important to stay healthy and active to reduce the impact of symptoms as long as possible.

While no lifestyle change will stop the progression or reverse the disease, steps can be taken to manage symptoms to the best of your ability. For example, research shows that proper nutrition, regular exercise, and stress management can help to protect brain functioning, among other benefits (including reducing the risk of heart disease).

### **Following a daily routine**

Many people living with FTD, as well as their care partners, benefit from following a regular daily routine. Predictable patterns and activities — meals, household tasks, physical activity, hobbies, social interaction, spiritual development, a regular sleep schedule — provide an important framework for both the person with FTD and the caregiver.

While routines are important, FTD is unpredictable, so it is important for care partners and persons living with FTD to remain flexible. While you may not be able to do things as quickly or easily as before, activities can be adapted and still provide enjoyment.

### **Engaging in activities**

It is also important for people living with FTD to stay engaged in enjoyable and stimulating activities of their choosing. If competitive poker or bridge was a favorite social activity, playing a more casual or simpler version with fewer rules, if needed, can engage the person, connect with that part of their past, and provide a meaningful way to interact with others. These activities should bring enjoyment to the person living with FTD. If one becomes too difficult or stressful as abilities change, it is time to reevaluate and adjust. An activity can be as simple as listening to music or watching the birds outside, as long as it brings enjoyment. FTD impairs an individual's ability to think clearly and act rationally. A person living with FTD may act compulsively, aggressively, or otherwise out

of character. These are symptoms of the disease. People diagnosed cannot control these types of behaviors, and they often struggle to correct them, even when a loved one points them out.

### **Driving and FTD**

Determining whether a person diagnosed with FTD can and should still drive becomes increasingly urgent. In early FTD, persons diagnosed may still be able to drive, but at some point, driving will become impossible. Because no two cases of FTD are alike, there is no exact timetable dictating when driving should stop.

### **Managing symptoms**

Since people living with FTD often cannot be expected to change their behavior, care partners and caregivers must adjust their own expectations when it comes to managing these symptoms. Confronting a person diagnosed and trying to correct their actions after the fact is usually less successful than trying to prevent these behaviors before they happen, and reducing the risks involved if they do happen.



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[https://alzheimer.ca/sites/default/files/documents/other-dementias\\_vascular-dementia.pdf](https://alzheimer.ca/sites/default/files/documents/other-dementias_vascular-dementia.pdf)

## 8.10 Other Dementias

### Mixed Dementia

Because different types of dementia can have different causes, it's possible for a person to have more than one type of dementia. When this occurs, that person is diagnosed with mixed dementia. A person living with mixed dementia will show symptoms of at least two different types of dementia. Usually, mixed dementia consists of the two most common types: Alzheimer's disease and vascular dementia. Because many symptoms overlap between different types of dementia, it can be hard to figure out if someone has mixed dementia. However, it's important that we are aware whether someone has mixed dementia because the combination of two or more dementias will likely have a greater impact on their brain than experiencing one disease alone. This can affect how a person's symptoms progress.

#### **How many people are living with mixed dementia?**

Researchers don't know exactly how many people currently diagnosed with a specific type of dementia actually have mixed dementia. However, autopsy studies indicate that mixed dementia may be much more common than previously realized.

Some experts recommend considering mixed dementia whenever a person has both evidence of cardiovascular disease and dementia symptoms that get worse slowly over time. Evidence like this may indicate the presence of both Alzheimer's disease and vascular dementia.

Currently, there aren't any pharmaceutical drugs available that are specifically targeted to treating mixed dementia. In situations where the physician considers Alzheimer's disease to be among the conditions contributing to a person's dementia symptoms, they may prescribe the medications intended for Alzheimer's disease treatment.

## **Outcomes**

Many researchers believe that by increasing our understanding of mixed dementia, coupled with recognizing that vascular changes are the most common coexisting brain change, we may reduce the number of people who develop dementia. Controlling our risk factors for diseases of the heart and blood vessels (like blood pressure, cholesterol levels, body weight, and diabetes) may also protect the brain from vascular changes.

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## SUGGESTED RESOURCES

### Websites

<b>Alzheimer's Disease International</b>	
Helpful resources, including how to find a clinical trial	<a href="http://alzheimers.gov">alzheimers.gov</a>
Risk Factors for Dementia	<a href="http://www.alzint.org/about/risk-factors-risk-reduction/">www.alzint.org/about/risk-factors-risk-reduction/</a>
Mixed Dementia	<a href="http://alzheimer.ca/en/Home/About-dementia/Dementias/Mixed-dementia">alzheimer.ca/en/Home/About-dementia/Dementias/Mixed-dementia</a>
<b>Alzheimer's Society of Canada</b>	
Vascular Dementia	<a href="http://alzheimer.ca/sites/default/files/documents/other-dementias_vascular-dementia.pdf">alzheimer.ca/sites/default/files/documents/other-dementias_vascular-dementia.pdf</a>
<b>Association for Frontotemporal Degeneration</b>	
A nonprofit organization that provides information, education and support to those affected by frontotemporal dementia and their care partners	<a href="http://www.theaftd.org/">www.theaftd.org/</a>
<b>Cleveland Clinic Foundation</b>	
Dementia	<a href="http://my.clevelandclinic.org/health/diseases/9170-dementia">my.clevelandclinic.org/health/diseases/9170-dementia</a>
Frontotemporal Dementia	<a href="http://my.clevelandclinic.org/health/diseases/21075-frontotemporal-dementia">my.clevelandclinic.org/health/diseases/21075-frontotemporal-dementia</a>
Lewy Body Dementia	<a href="http://my.clevelandclinic.org/health/diseases/17815-lewy-body-dementia">my.clevelandclinic.org/health/diseases/17815-lewy-body-dementia</a>
<b>Dementia UK</b>	
What is Young Onset Dementia?	<a href="http://www.dementiauk.org/about-dementia/young-onset-dementia/what-is-young-onset-dementia/">www.dementiauk.org/about-dementia/young-onset-dementia/what-is-young-onset-dementia/</a>

## Family Caregiver Alliance

Caregiver's Guide to Understanding Dementia Behaviors

[www.caregiver.org/resource/caregivers-guide-understanding-dementia-behaviors/](http://www.caregiver.org/resource/caregivers-guide-understanding-dementia-behaviors/)

Dementia, Caregiving, and Controlling Frustration

[www.caregiver.org/resource/dementia-caregiving-and-controlling-frustration/](http://www.caregiver.org/resource/dementia-caregiving-and-controlling-frustration/)

Dementia: Is This Dementia and What Does It Mean?

[www.caregiver.org/resource/is-this-dementia-what-does-it-mean/](http://www.caregiver.org/resource/is-this-dementia-what-does-it-mean/)

Vascular Dementia

[www.caregiver.org/resource/vascular-dementia/](http://www.caregiver.org/resource/vascular-dementia/)

## Lewy Body Dementia Association

Supports those affected by Lewy body dementia by raising awareness and promoting scientific advances

[www.lbda.org/](http://www.lbda.org/)

## Mayo Clinic

Alzheimer's Disease

[www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-0zz350447#:~:text=Overview,person's%20ability%20to%20function%20independently.](http://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-0zz350447#:~:text=Overview,person's%20ability%20to%20function%20independently.)

Dementia

[www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013](http://www.mayoclinic.org/diseases-conditions/dementia/symptoms-causes/syc-20352013)

Frontotemporal dementia

[www.mayoclinic.org/diseases-conditions/frontotemporal-dementia/symptoms-causes/syc-20354737](http://www.mayoclinic.org/diseases-conditions/frontotemporal-dementia/symptoms-causes/syc-20354737)

## National Institute on Aging

Alzheimer's Disease Fact Sheet

[www.nia.nih.gov/health/alzheimers-disease-fact-sheet](http://www.nia.nih.gov/health/alzheimers-disease-fact-sheet)

Next Steps After an Alzheimer's Diagnosis

[www.nia.nih.gov/sites/default/files/2020-09/next-steps-after-alzheimers-diagnosis.pdf](http://www.nia.nih.gov/sites/default/files/2020-09/next-steps-after-alzheimers-diagnosis.pdf)

What Are Frontotemporal Disorders? Causes, Symptoms, and Treatment

[www.nia.nih.gov/health/what-are-frontotemporal-disorders](http://www.nia.nih.gov/health/what-are-frontotemporal-disorders)

What Causes Alzheimer's Disease?

[www.nia.nih.gov/health/what-causes-alzheimers-disease](http://www.nia.nih.gov/health/what-causes-alzheimers-disease)

What Is Lewy Body Dementia? Causes, Symptoms, and Treatments

[www.nia.nih.gov/health/what-lewy-body-dementia-causes-symptoms-and-treatments#:~:text=Lewy%20body%20dementia%20\(LBD\)%20is,movement%2C%20behavior%2C%20and%20mood.](http://www.nia.nih.gov/health/what-lewy-body-dementia-causes-symptoms-and-treatments#:~:text=Lewy%20body%20dementia%20(LBD)%20is,movement%2C%20behavior%2C%20and%20mood.)

Understanding Different Types of Dementia

[www.nia.nih.gov/sites/default/files/understanding-types-dementia\\_0.pdf](http://www.nia.nih.gov/sites/default/files/understanding-types-dementia_0.pdf)

**Schlegel – University of Waterloo, Research Institute of Aging**

Young Onset Dementia — An inspirational guide for people living with dementia

[the-ria.ca/wp-content/uploads/2018/11/BUFU\\_Young-Onset-Dementia\\_eversion\\_A.pdf](http://the-ria.ca/wp-content/uploads/2018/11/BUFU_Young-Onset-Dementia_eversion_A.pdf)

**The Young Dementia Network, hosted by Dementia UK**

A community of people living with young onset dementia, their family and friends, as well as professionals who work in the field of health and social care and voluntary sector.

[www.youngdementianetwork.org/](http://www.youngdementianetwork.org/)

## ADDITIONAL RESOURCES

Alzheimer's Association, *Legal and Financial Worksheet* — A useful financial and legal worksheet to help you organize important papers and information. If you fill out any information in the worksheet, be sure to store it in a secure place so only people you trust have access to the information.

[www.alz.org/media/documents/worksheet-financial-legal.pdf](http://www.alz.org/media/documents/worksheet-financial-legal.pdf)

Alzheimer Society of Canada, *All About Me* — This booklet helps record information that describes your background and history, likes and dislikes, and what's important to you. The completed information can be given to people who are supporting and caring for you if you are not able to articulate this information yourself. Knowing the person is fundamental to person-centered and directed support.

[alzheimer.ca/sites/default/files/documents/All-about-me-Alzheimer-Society.pdf](http://alzheimer.ca/sites/default/files/documents/All-about-me-Alzheimer-Society.pdf)

Alzheimer Society of Canada, *Long-Term Care Home Checklist* — This checklist can be used as you and your care partner(s) consider and conduct site visits to select a residential care community.

[alzheimer.ca/sites/default/files/documents/Long-term-care-home-checklist-Alzheimer-Society\\_0.pdf](http://alzheimer.ca/sites/default/files/documents/Long-term-care-home-checklist-Alzheimer-Society_0.pdf)

Alzheimer Society of Canada, *Preparing for Your Doctor's Visit* — This document will guide you and your care partner(s) to gather information about the changes you have been experiencing and have you consider things you want to discuss during your doctor's visit.

[alzheimer.ca/sites/default/files/documents/tipsheet\\_preparingforyourdoctor\\_e.pdf](http://alzheimer.ca/sites/default/files/documents/tipsheet_preparingforyourdoctor_e.pdf)

Alzheimer Society of Canada, *Signs and Symptoms of Young Onset Dementia, A Personal Checklist* — This is a checklist intended to help people be aware of the signs and symptoms of young onset dementia. It is a tool that you could use to start a conversation with your doctor if you are concerned about symptoms you are experiencing.

[alzheimer.ca/sites/default/files/documents/young-onset-dementia-personal-symptom-checklist.pdf](http://alzheimer.ca/sites/default/files/documents/young-onset-dementia-personal-symptom-checklist.pdf)

Alzheimer's Society UK, *Living with Dementia My Life, My Goals* — A practical guide full of hope to help you set and reach your goals. This guide has been created with people living with dementia to help you think about and decide what is important to you.

[www.alzheimers.org.uk/sites/default/files/2021-09/my-life-my-goals-workbook.pdf](http://www.alzheimers.org.uk/sites/default/files/2021-09/my-life-my-goals-workbook.pdf)

Alzheimer's Society UK, *Making your home dementia friendly* — This booklet provides information and things to consider to make your home dementia friendly.

[www.alzheimers.org.uk/sites/default/files/migrate/downloads/making\\_your\\_home\\_dementia\\_friendly.pdf](http://www.alzheimers.org.uk/sites/default/files/migrate/downloads/making_your_home_dementia_friendly.pdf)

Alzheimer's Society UK, *My Checklist for Possible Dementia Symptoms* — This checklist is helpful for people who suspect they or someone they care about have symptoms of dementia.

[www.alzheimers.org.uk/sites/default/files/2022-05/Symptoms\\_Checklist.pdf](http://www.alzheimers.org.uk/sites/default/files/2022-05/Symptoms_Checklist.pdf)

Dementia Action Alliance, *Important Questions to Ask your Doctor About a Dementia Diagnosis* — This is a list of questions that people living with dementia developed and found useful when being diagnosed with dementia.

[daanow.org/papers-webinars/](http://daanow.org/papers-webinars/)

Dementia Action Alliance, *What Matters to Me* — This storybook formatted resource was developed by people living with dementia and care partners as an easy-to-use tool to fill out about what matters to them. *What Matters to Me* can be provided to care partners of an individual living with advanced symptoms of dementia so they can get to know the person and what is important to them.

[daanow.org/wp-content/uploads/2022/09/What-Matters-to-Me.pdf](http://daanow.org/wp-content/uploads/2022/09/What-Matters-to-Me.pdf)

Dementia Action Alliance, *Words Matter* — This document was developed by people living with dementia and care partners to heighten awareness and understanding about the impact words can have on the well-being and lived experience of people living with dementia.

<https://daanow.org/words-matter/>

*Dementia Friendly America Toolkit* — The DFA toolkit guides communities through a step-by-step process to help communities implement dementia friendly practices.

[www.dfamerica.org/toolkit-getting-started](http://www.dfamerica.org/toolkit-getting-started)

*Dementia Toolkit, Guide to the Living with Dementia Toolkit* — This toolkit was developed as part of the UK's IDEAL research program that has been finding since 2014 what helps people living well with dementia. It was prepared by people living with dementia, care partners and researchers.

[livingwithdementiatoolkit.org.uk/wp-content/uploads/2022/04/Dementia-Toolkit-English-Guide\\_April-2022.pdf](http://livingwithdementiatoolkit.org.uk/wp-content/uploads/2022/04/Dementia-Toolkit-English-Guide_April-2022.pdf)

*Dementia Understand Together, At Home Activities: A selection of meaningful activities for people living with dementia and care partners* — This booklet, developed by the Alzheimer's Society of Ireland/Dementia Together, provides meaningful activities that can be done together at home.

[www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/at-home-activities-for-people-with-dementia-families-and-carers.pdf](http://www.hse.ie/eng/services/news/newsfeatures/covid19-updates/partner-resources/at-home-activities-for-people-with-dementia-families-and-carers.pdf)

*Jewish Family & Children's Services Memory Café Toolkit and Virtual/Hybrid Supplement* — This resource provides step-by-step instructions to help you launch and sustain a memory café and includes templates you can download and adapt to fit your own program. The Toolkit was developed as a public service by Jewish Family & Children's Services Alzheimer's/Related Disorders Family Support with support from the Massachusetts Association of Councils on Aging (MCOA).

[www.jfcsboston.org/Our-Services/Older-Adults/Alzheimers-Related-Disorders-Family-Support/Memory-Caf%C3%A9-Toolkit](http://www.jfcsboston.org/Our-Services/Older-Adults/Alzheimers-Related-Disorders-Family-Support/Memory-Caf%C3%A9-Toolkit)

Lewy Body Dementia Association, *Comprehensive LBD Symptom Checklist* — LBDA has created a helpful checklist that will assist people diagnosed with LBD or care partners with collecting new or concerning LBD symptoms they should discuss with their physician.

[www.lbda.org/wp-content/uploads/2020/09/comprehensive\\_lbd\\_symptom\\_checklist\\_2019.pdf](http://www.lbda.org/wp-content/uploads/2020/09/comprehensive_lbd_symptom_checklist_2019.pdf)

National Institute on Aging, *Getting Your Affairs in Order: Advance Care Planning* — A helpful checklist for advance care planning developed by the National Institute on Aging.

[www.nia.nih.gov/sites/default/files/2022-04/advance-care-planning-infographic.pdf](http://www.nia.nih.gov/sites/default/files/2022-04/advance-care-planning-infographic.pdf)



National Institute on Aging, *Legal and Financial Planning for People with Alzheimer's Disease Fact Sheet* — This fact sheet from the National Institute on Aging provides helpful considerations for legal and financial planning.

[www.cooleydickinson.org/wp-content/uploads/2019/09/Legal-and-Financial-Planning-for-People-with-Alzheimers-Disease.pdf](http://www.cooleydickinson.org/wp-content/uploads/2019/09/Legal-and-Financial-Planning-for-People-with-Alzheimers-Disease.pdf)

The Conversation Project, *Your Conversation Starter Kit* — This starter kit helps individuals have honest and open conversations about what matters most to them at the end of life.

[theconversationproject.org/wp-content/uploads/2015/09/TCP\\_StarterKit\\_Final.pdf](http://theconversationproject.org/wp-content/uploads/2015/09/TCP_StarterKit_Final.pdf)

The Conversation Project, *Your Conversation Starter Guide For Caregivers of People Living with Alzheimer's or Other Forms of Dementia* — The guide helps care partners understand what matters to someone living with dementia and how to help them have a say in their healthcare.

[theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf](http://theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf)

The Conversation Project, *Your Guide to Choosing a Health Care Proxy* — This guide will help you think about and determine who would be a good healthcare advocate for you.

[theconversationproject.org/wp-content/uploads/2020/12/ChooseAProxyGuide.pdf](http://theconversationproject.org/wp-content/uploads/2020/12/ChooseAProxyGuide.pdf)

The Conversation Project, *Your Guide for Talking with a Health Care Team* — This guide will help you talk to your health team to create a care plan that is right for you and your needs.

[theconversationproject.org/wp-content/uploads/2020/12/HealthCareTeamGuide.pdf](http://theconversationproject.org/wp-content/uploads/2020/12/HealthCareTeamGuide.pdf)

The Hartford Center for Mature Market Excellence, *At the Crossroads Family Conversations About Alzheimer's Disease, Dementia & Driving* — This guidebook is a helpful resource should the need arise to discuss driving safety with a person living with dementia.

[s0.hfdstatic.com/sites/the\\_hartford/files/cmme-crossroads.pdf](http://s0.hfdstatic.com/sites/the_hartford/files/cmme-crossroads.pdf)

World Health Organization, *Risk Reduction of Cognitive Decline And Dementia* — This paper, developed by the World Health Organization, presents dementia risk reduction guidelines with a focus on proactive management of modifiable risk factors.

<https://apps.who.int/iris/bitstream/handle/10665/312180/9789241550543-eng.pdf>





# ABOUT THE DEMENTIA ACTION ALLIANCE

*We are a non-profit national advocacy and educational organization of people living with dementia, care partners, dementia specialists and other advocates. DAA is recognized by the IRS as a charitable 501 (c)(3) organization.*

## Goals

- Educating about the negative effects of stigma and misperceptions.
- Empowering and encouraging a proactive attitude for living with a chronic condition.
- Championing strategies and accommodations for changing cognitive abilities.
- Promoting person- and relationship-centered support practices.
- Creating pathways to connect and engage with others living with dementia.
- Identifying beneficial technologies.

## Our Vision

We are creating a better society in which to live with dementia with accommodations for changing abilities and without stigma and misperceptions through advocacy, education, empowerment and support.



**"We don't want to just survive.  
We want to live and thrive."**



**Dementia Action Alliance**

ENHANCING LIVES

CONNECTING PEOPLE

INCREASING UNDERSTANDING

*I believe that one of the biggest and most ignored human rights for people living with dementia is the right to have hope, to be able to live positively, meaningfully, and as fully as possible.*

**Allen Power, MD, Contributor**



*I use the analogy of a Christmas tree to describe that my dementia symptoms affect some aspects of my abilities, but many other important abilities remain. "A Christmas tree may have many lights and ornaments. Imagine that some of the lights don't work and a few of the ornaments have been removed. The Christmas tree is still beautiful and serves a purpose."*

**Laurie Scherrer, Manual Guide**



*Dementia doesn't strip a person of their essential humanity. There's so much to who we are as human beings than our cognitive function. And if people can embrace all those other aspects of what makes us human, they can more readily live well with dementia.*

**Jennifer Carson, PhD, Contributor**

