Caregiving For a Loved One With Alzheimer's
Resource Guide for Families
For more than six years, we have worked to bring readers up-to-date, substantive and practical information about Alzheimer’s disease and other dementias.

We’ve selected a few of our best articles, resources and tips for this packet, which are suitable for printing should you desire.

Thank you.

- Next Avenue Editorial Team

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How to Prepare to Care for Someone With Dementia

Viewing it as a collaboration between you and your loved one is crucial

By Bruce Johansen October 10, 2017

It's not uncommon to feel ill-equipped to serve as primary care partner for your loved one with dementia. In hindsight, you may think, "I've made lots of mistakes," "I wish I'd done more research," "If only I'd paid more attention to little signs," "I should have had an action plan," "I really didn't know what was coming," "Now I have a lot of guilt."

Although there were early warning signs — Dad was struggling to remember words or Mom was constantly repeating herself — those were chalked up to "old age." Then things boiled over. A wife left a burner on, this time resulting in a fire. A mother stepped on the accelerator instead of the brake, causing an accident. A husband began lashing out, accusing his spouse of having an affair. A father wandered away from home, getting seriously lost.

"Don't wait for a crisis," advises Sandy Markwood, CEO of the National Association of Area Agencies on Aging (n4a). Markwood, whose mother lived with dementia, stresses there are medications and interventions that may help, along with a growing number of resources to prepare and support care partners.

Seeking and Understanding a Dementia Diagnosis

An essential first step is to receive a dementia diagnosis and understand what it means. Neither may be so simple, warns Karen Love, executive director of the Dementia Action Alliance (DAA). Because there is no cure for it, medical professionals tend to view dementia as a "death sentence," says Love, whose father lived with Alzheimer's. As a result, they resist offering a diagnosis, passing patients on from one specialist to the next.

Unfortunately, seeing specialists can be cost prohibitive, says Yolima Chambers, health and wellness department administrator at Minneapolis' Centro Tyrone Guzman, a Latino community center. "For those who don't have health insurance, we refer them to community clinics, but primary doctors don't diagnose, they can't diagnose. It has to be a neurologist or another specialist," notes Chambers.
Due to the expense, a diagnosis necessary for treatment may be delayed, placing the person and family in greater danger. But even when there is a diagnosis, understanding what it means is a common challenge. "What should happen," says Love, "is you walk into the doctor's office, they tell you what you have, what it means and how to feed your soul." However, medical professionals are not always skilled at explaining the diagnosis or what comes next.

Because a person can't count on doctors to be capable communicators, it's crucial to know what other resources are available. Several can be found online at Dementia Action Alliance's Resources Center. People of color and immigrants face additional cultural and language barriers, as well as higher rates of dementia. Latinos are 1.5 times as likely as whites to experience dementia, and African Americans twice as likely. As a result, ACT on Alzheimer's community partners in Minnesota are designing innovative programs targeting specific populations. For example, the Alzheimer's Latino Collaborative at Centro wrote and staged a play, based on three families' experiences, followed by panel discussions.

**A Care Partner Mindset**

"Words matter," says Love, so viewing oneself as a "care partner," not "caregiver," is crucial. The person with dementia is "impaired," she says, "and may come and go," but is still there. You don't want to rob him or her of dignity and independence; denying respect has detrimental effects on the brain, something Love first observed in high school while working in a nursing home. Residents with dementia were routinely dismissed as "senile," she noticed, inanimate objects with whom staff did not engage, leading them to shut down further.

Unfortunately, stigmas remain, says Love, perpetuated by popular culture, advertising, news reporting and the medical community. Once a dementia diagnosis is made, care partners need to make decisions and design an action plan together. Markwood’s advice: "Resist the urge to take over everything." Doing so can take incentive and joy away from the person living with dementia. Among conversations Markwood recommends having following the diagnosis are:

- Managing finances
- Access to checkbooks and credit cards
- Legal planning
- Driving

Another subject, and one that may be the toughest, says Sandra Reyes, Wise Elders coordinator at Centro Tyrone Guzman, is the advance care directive.

This is a conversation Reyes had with her mother after she was diagnosed with Alzheimer's.
Learn Simple Interaction Techniques
It’s incumbent upon care partners to learn as much as they can about the disease, how it progresses and new ways to interact. Understanding neuroplasticity (the ability of the brain to respond to change in response to illness or injury) and how it can spur creativity, learning and communication is key. “Discover what connections points there are,” says Love, who enjoys recounting stories of the profound impact simple gestures can have. Among the simple things a care partner can do:

- Eliminate background noise whenever possible
- Maintain eye contact
- Speak in a slow, calm manner
- Play soft music
- Look at photo albums together
- Recognize the power of touch

Blogs, where others share their personal experiences and what they’ve learned, can be extremely helpful, too, especially for those having just received a diagnosis. Our True Colors: A Family's Journey with Dementia is the collaboration of a mother and daughter recounting what they've learned about various forms of dementia through caring for their husband and father. And remember that listening to, and learning from, those living with dementia is fundamental, since they’re the experts about the experience.

Social Ties Are Important
One of the biggest challenges is maintaining social connections.

“One thing we hear all the time,” reports Markwood, “is that people stop visiting [loved ones with dementia] because they don’t know about the disease and don’t know what to do.” Enlist the support of family, friends and neighbors, she says. “Be upfront about the diagnosis and tell people how they can help,” advises Markwood. Most important, don’t let fears about how you and your loved one might, or might not, be accepted lead to “cloistering.” Fear often keeps partners from stepping out into the community, going to religious services, the grocery store, medical appointments, the barber shop or beauty salon, in turn depriving them of key sources of support.

Consider Support Groups
Seeking out others on a similar journey leads many spouses and family members to find support groups in their area. “You can read all you want,” says Markwood, “but listening to other people and learning from them what's been helpful is invaluable. Going through the emotional pain with others is important.”

Because the middle of the night may be the only time care partners have to themselves, online support groups can be an attractive alternative. “Just be careful and filter, like anything else online,” says Markwood. Finally, the Family Caregiver Alliance offers this reminder: “Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important — and one of the most often forgotten — things you can do...” Its website provides a host of self-care tips.

“Listening to and learning from those living with dementia is fundamental, since they’re the experts.”
How People With Dementia Can Live at Home Longer

The MIND program makes a difference, saving money for families and Medicaid

By Beth Baker       June 30, 2017

Gladys Gerben was always a loner, a trait that grew more pronounced after she was diagnosed with Alzheimer’s disease about four years ago. She was adamant that she would never leave her home of 30 years, in Edgemere, Md. Her son and daughter-in-law, who live minutes away, gradually took over more and more of her responsibilities: first the checkbook, then the car, until finally Sherry Gerben gave up substitute teaching to care for her mother-in-law, visiting her 10 to 15 times a day.

“I was raised that you take care of family,” says Sherry, who also cared for both her parents, who died of cancer.

In February 2016, the Gerbens got a boost from a program in Maryland called Maximizing Independence (MIND) at Home. Designed in 2006 by dementia specialists at Johns Hopkins University and offered to families as part of Johns Hopkins research that is still ongoing, it assigned the family a “memory care coordinator” named Britta Kilbourn. She assessed their needs, gave them educational materials and connected them to resources and benefits, such as a part-time aide to help with the difficult task of bathing.

“[MIND was] a wealth of information,” says Sherry. “I told my husband, if it hadn’t been for [them], I couldn’t have done this. They were really my lifeline.”

Savings for Families and for Medicaid

The Gerbens are among 15 million unpaid caregivers who take care of the nation’s 5.4 million people with Alzheimer’s and other dementias, 80 percent of whom live at home or with family. Like many programs, MIND at Home seeks to extend the time that people with dementia can remain in their homes and communities. The goals: to maintain a higher quality of life for them and to save Medicaid dollars, since Medicaid foots the bill for nearly two-thirds of nursing home residents, the majority of whom have cognitive loss. The Republicans’ proposed health care legislation, if passed, would cut around $800 billion from Medicaid over the next 10 years.
A 2014 study found that people who participated in MIND at Home for 18 months had “a significant delay” in leaving their homes — which could include transitioning to a nursing home or an assisted living facility or dying — when compared to a control group. During a follow-up period more than two years later, the benefits continued: MIND participants were still living at home 948 days, on average, from the time of their enrollment in the study, compared to 660 days at home for the control group.

The difference —288 days, or about nine-and-a-half months — represents huge cost savings for families and for Medicaid, given the cost of care in long-term care facilities. In 2016, the national median monthly price of assisted living was $3,628. For a shared nursing home room, the monthly median was $6,844.

Those in the MIND program also had a significant improvement in self-rated quality of life. Caregivers benefited, too, from support and time savings.

**Person-Centered Care for Dementia Sees Needs Holistically**

Quincy Samus, an assistant professor at Johns Hopkins who leads the MIND at Home research team, is conducting two more studies of the program.

““If it hadn’t been for [MIND], I couldn’t have done this. They were really my lifeline.”

— Sherry Gerben, caretaker

One, through a $6.4 million innovation grant from the Centers for Medicare and Medicaid Services, focuses on low-income older adults and their caregivers. The other, funded with $3.4 million from the National Institute on Aging, looks at participants of all income levels. Both studies will gain insight into the program's costs and long-term sustainability. Combined, they involve 647 people with dementia and an equal number of family members in central Maryland.

“The idea is we go into the person’s home with a multidisciplinary team that’s focused on best practices for dementia care,” explains Samus. Each participant and family member has a full assessment of needs to ensure that they have the proper diagnosis and that problems related to medication and behavior are addressed. The program checks each home for safety hazards, and an occupational therapist suggests meaningful activities for the person with dementia.

“We also look at how well their medical problems are being treated,” says Samus. “If they’re having high blood pressure or diabetes, these can exacerbate symptoms of dementia and all can contribute to unwanted or premature nursing home placement and a poor quality of life, not only for the person with dementia but their caregivers.” Memory care coordinators develop an action plan for each family and check in at least every 30 days. “Things change over time, so we identify new needs that are emergent,” says Samus. As important, says Sherry Gerben, is the emotional support. “You develop a connection with [the care coordinator], you know their heart’s in the right place,” she says. “Sometimes Britta would call and just the fact I could talk to her was helpful. And then she’d always say, ‘And what are you doing for you? If you go down, you’re not going to help Mom. You have to take care of you.’”
Annual Price Tag for MIND’s Coordinated Care: $2,000 to $2,500

“Ideally the MIND at Home program would be something that their primary care physician would write a prescription for at the time of diagnosis [of dementia],” Samus says, describing the future of the program as she hopes it will evolve. Participants would stay in the program as long as they remained at home, with costs covered by public and private insurers. Study results are not complete, but Samus estimates that MIND at Home program costs are $2,000 to $2,500 annually per participant.

Care coordination is a growing trend in health care, as providers, insurers and the government seek to reduce hospital and nursing home admissions and other costly medical care. One thing that makes MIND at Home unique, says Samus, is that the care coordinators are not clinically trained. The program is thus more affordable — salaries are $43,000 compared to $90,000 or more for a registered nurse.

“The care coordinators come from all different backgrounds,” Samus says. “The most important thing is that they enjoy working with older people, that they can relate and communicate well, that they’re creative and have a stick-to-it-iveness so they can solve problems by starting where people are. Dementia care is not rocket science, but it takes a deep understanding of dementia and how it’s experienced by people who have it, as well as family caregivers.”

Care coordinators undergo 40 hours of training and attend monthly team meetings where they collaborate on how to tackle challenges that arise for families. Samus adds that focusing on people in their homes, rather than in a clinic, is key. “We strongly believe the home should be the nexus for dementia care,” she says. Only then can the team get an accurate and full picture of the challenges families face.

To Caregivers: ‘You Are Doing a Really Good Job With This’

Kilbourn, the Gerbens’ care coordinator, says she grew up helping her grandmother, who had Alzheimer’s.

“I was always comfortable around people with memory problems,” she says. She finds that two common needs of MIND participants are fall prevention and caregiver education. “A lot of times the caregiver doesn’t know what to expect and the doctors don’t tell them,” she says. “People think the person with memory problems is going to get better, or they don’t understand the progression of the disease.”

Supporting the caregivers is critical to the program’s success, Kilbourn says. “[Caregivers] are doing as much as they can, but they don’t feel like they are,” she says. “They don’t get the appreciation sometimes. It’s important for us to say, ‘You are doing a really good job with this.’”

On June 11 this year, Gladys Gerben, 88, died of pneumonia. She remained at home until the last month of her life. Sherry Gerben was grateful to see Kilbourn at the funeral. After giving the eulogy, she called Kilbourn forward. She told the gathered family, “The rest of you didn’t meet her. But she was my rock.”
Marriage problems take many couples by surprise. But Deborah Dolan was caught particularly unaware when her husband Todd began to distance himself from her. “We were truly happy. We were on the same page,” she said. “He was such a gentle, kind, funny man. No one laughed more than we did.”

They were both divorced and in their mid-40s when they met; Todd Dolan was delighted to become stepfather to Deborah Dolan’s three adolescent children. “He said he was a man looking for a family, and he found a family looking for a man,” recalled Deborah Dolan.

When Things Started Changing
But in 2006, 13 years after they wed, Dolan felt her husband — then 59 — was losing interest in her. He ended his habit of bringing her flowers. He didn’t invite her to his company Christmas party. Moody and distracted, he stopped playing his guitar.

“Todd had been sober for years, but I wondered if he was secretly drinking or having an affair,” said Dolan, who lives in West Des Moines, Iowa. “When I confronted him, he shrugged.”

Despite his indifference, Dolan was unwilling to give up on her marriage or her husband, who had spent much of his career in automobile sales and dealership management. Her search for what was wrong took years of sleuthing and sent her down repeated dead ends, with multiple misdiagnoses.
Although Dolan was a geriatric care manager with a master’s in gerontology, she did not detect a form of dementia that was changing her own spouse in front of her eyes.

“I was active with the Alzheimer’s Association facilitating support groups. I moderated panels at state conventions,” she said. “I was not seeing those symptoms in Todd.”

Seeking a Diagnosis
In 2008, she put her professional advocacy skills to work, accompanying her husband to a series of doctor appointments. He was first diagnosed with hyperthyroidism and then depression.

It took three more years for his disease to be confirmed.

Todd Dolan was ultimately found to suffer from frontotemporal dementia or degeneration (FTD), a form of dementia centered in the brain’s frontal lobe.

Unlike Alzheimer’s disease, which attacks the brain’s memory centers, FTD causes atrophy in the part of the brain that controls judgment, behavior and executive function.

People with FTD are often described as apathetic, lacking in empathy and exhibiting an impaired social filter.

“They lose their insight, so they could be like a 3-year-old, blurt out, ‘Your dress is ugly.’ They lose impulse control, so they might just take a candy bar at a store,” said Susan Dickinson, CEO of AFTD, the Association for Frontotemporal Degeneration. “They lose their understanding of what is acceptable. You’ll see people who spend the kids’ college fund on a sports car or fall for a scam.”

Younger Patients Affected by FTD
Dickinson notes that FTD is particularly devastating because it strikes at a young age. FTD is the most common form of dementia in people under 60; they’re often still working and can make illogical decisions about relationships and finances that can destroy their family’s security and disrupt their connection to those dearest to them.

“Most family doctors are still not picking up on it. These people are most often treated for a psychiatric disorder. If someone makes an inappropriate [sexual] advance or shoplifts, you don’t think to take them to a neurologist,” Dickinson said. “On average, it takes three and a half years from when symptoms are noticed until the patient is diagnosed. This gap is tragic.”

A Financial and Emotional Toll
The economic burden of the disease takes a steep toll on the health care system as well as on individuals.

According to a study published in the scientific journal Neurology last fall, the average annual cost associated with FTD is nearly $120,000, close to twice the cost of care for Alzheimer’s patients. Researchers concluded the disparity is attributed to the younger age of onset, which results in “major losses of household income” as those diagnosed — and eventually, their family caregivers — stop working.
Searching for Treatments or a Cure
Like Alzheimer’s disease, there is no cure for FTD, and no FDA-approved treatment to reverse or even slow the disease’s progression. But Rosenbloom is optimistic about clinical trials now underway at a number of collaborating hospitals and universities.

In the meantime, AFTD, based in suburban Philadelphia, has helped establish more than 80 support groups (you can find a link to them on the AFTD site). In the past nine years, AFTD has expanded from its part-time staff of three to an organization with 15 full-time employees.

A Growing Recognition
Awareness about FTD is beginning to build beyond medical professionals who treat patients and families living with it.

In December 2017, a daughter told the story of her father’s FTD in a TED Talk. Last November, the family of U.S. Rep. Maurice Henchley, who represented New York in Congress for 20 years, revealed FTD as his cause of death. And in October, the David Geffen Fund was established at AFTD. But delayed pinpointing of the disease remains a stubborn obstacle.

Deborah Dolan diagnosed her husband before his doctor did. Her dogged research led her to believe that Todd had FTD, but she was unable to persuade his physician of her conclusion. She paid for a PET scan out-of-pocket to confirm her suspicion.

“We still needed his income and his insurance, and the poor man was struggling but had to keep working,” she said. “When he had the official diagnosis, he could qualify for Social Security disability.”

Dolan managed her husband’s condition at home for a time, but ultimately placed him in a care facility for his own safety.

“The day I had to leave him broke my heart, but he accepted it. He understood something was changing the way he was thinking and feeling,” she said.
Managing Finances for a Loved One With Dementia

The challenges can be steep, which is why advance planning is vital

By Chris Farrell

October 31, 2017

A classic early warning sign of cognitive decline and possibly dementia is losing the ability to manage your personal finances. And that can lead to a host of challenges if you are the daughter, son, wife, husband or partner of a loved one in this situation.

As Mona Rawlings, of Mendota Heights, Minn., can tell you, however, advance planning can go a long way to heading off thorny issues that come up when you’re handling finances for someone with dementia.

Her 71-year-old mother, Mary Ellen Seth, was diagnosed with dementia (specifically, frontotemporal dementia with primary progressive aphasia) three years ago. At the time, Seth was an accounting instructor at a community college.

“We were sucker-punched,” says Rawlings, 49. “I never thought three years ago we would be in this situation.”

Fortunately, Seth had given her daughter power of attorney, allowing Rawlings the ability to make financial decisions for her mom. Seth also had purchased long-term-care insurance, established a trust for her home and other assets and had written a health directive, specifying the kinds of medical actions she’d like taken if she couldn’t make those decisions herself.

The long-term care policy largely pays for Seth’s care in the memory care unit she moved into earlier this year. And her savings pays the $13,000 monthly tab for additional care 12 hours a day, seven days a week, as well as the rent for a modified minivan for the outings she loves.

Seth’s adult children control their mother’s finances, but, “my brother and I believe it isn’t our money. It’s hers and its meant for her care,” says Rawlings. “We need to make sure she is loved and cared for.” In many cases, though, managing finances for a loved one with dementia can be tougher.

The Stress of Managing Parents’ Money

Three years ago, Anne Stemper’s mother Joanne, now 79, was diagnosed with Alzheimer’s. She and her husband, 83, live in the home they’ve owned for some 50 years in Roseville, Minn., about 20 minutes from Anne.
Joanne had always managed the couple's money, including their retirement savings. Now, Anne pays their bills and handles their retirement funds. She concedes that doing so is pretty stressful.

Fortunately, the transition was eased somewhat by her familiarity with her parents' finances. “I feel so grateful my parents talked about finances years ago. My mom prepared me,” she says. “Unfortunately, our society doesn’t put enough emphasis on this.”

She’s right.

**The Odds You Can’t Ignore**

No family really wants to sit around the dinner table talking about the risk of dementia. But with increases in average life expectancy, the odds are too high to ignore.

The Aging, Demographics, and Memory Study backed by the National Institute on Aging figures that 14 percent of Americans age 71 and older have some form of dementia and The Chicago Health and Aging Project estimates that nearly one-third of people 85 and older have Alzheimer’s. These sobering percentages are likely to worsen with the longevity revolution. Problem is, not enough families are open about the topic of managing money and deteriorating faculties with age.

Just one in four families surveyed discussed how their parents will be financially provided for, or cared for, as they get older, according to the 2014 report *Family & Retirement: The Elephant in the Room* by Merrill Lynch in partnership with the consulting firm Age Wave. Honing in on people 50 and over, the survey noted that about half of those surveyed didn't have a will and only four in 10 had written a health care directive.

**Estate Planning: More Than Bequests and Taxes**

Estate planning is no longer just about bequests and taxes. It also means arranging your finances so if cognitive decline sets in, your caregiver — a spouse or partner, family member, relative or longtime friend — can step in and manage your money and help you maintain your quality of life.

Harvard University economist David Laibson has called this estate planning imperative the $18 trillion dollar question: the net worth of adults 65 and older. To be sure, there's nothing easy about taking care of a family member with dementia. Society places enormous demands on caregivers, let alone offering support to minimize the emotional and financial stress.

**From Feeding to Car Care**

Just ask Linda Mattson of Maple Grove, Minn. Her husband has early-onset Alzheimer’s. Although that diagnosis is unusual, her consuming caregiving experience is typical for caregivers of loved ones with dementia.

“Just one in four families discussed how their parents will be financially provided for, or cared for, as they get older.”

— *Family & Retirement: The Elephant in the Room*

2014 report by Merrill Lynch and Age Wave
As the disease has progressed, I've had to assume every duty associated with my husband's care. This includes everything from information and feeding to record keeping and medication management. Lawn care, home care, car care," Mattson says. "I'm in charge of all of the legal, financial and emotional impacts of the disease."

Sometimes, an adult child also has to prevent a parent with cognitive decline from becoming a victim of elder financial abuse.

Kirsten Mair says her mother, who died last year at 74 after many years of decline, "was always susceptible to get-rich-quick schemes." But as her mom's judgment became more impaired, adds Mair, "she could fill a grocery bag full of scam mail each week if she hadn't been so busy trying to find just the right ones to invest in."

**Know the Basics**
Information on the financial basics of establishing a legal and financial strategy is readily available for families. Among the main building blocks are power of attorney; creating a living will (an advance directive on medical wishes) and determining a health care proxy (a person designated to make medical decisions if incapacitated).

For people with substantial assets, a revocable living trust may make sense.

**Talking and Agreeing**
At least as critical to a successful financial plan when mental deterioration sets in: the rest of the family needs to agree on the big decisions. That wasn't the case with Candace Barrick. Her father died in July 2011 with mild dementia and her mother died in April 2012 with Alzheimer's.

Before the deaths, Barrick and her three siblings disagreed about their parents' living situation and medical treatment. Her advice for other families? Parents need to talk to their grown children regularly about their wishes as they age.

Barrick admires the system that a couple from her church devised. They write a letter to their children around Christmas every year with their current plans for the years ahead and their end-of-life decisions. "One of the most important things for people to do is talk to all their children at the same time," says Barrick. Many families also find it useful to tap into the expertise of professionals.

Says Joseph Gaugler, long-term care professor in nursing at the University of Minnesota: "Often it helps to include a third party who can weigh in," explaining that "with memory loss, it's okay to give up doing the finances."
Most people think of dementia as affecting memory and cognition, and it certainly does. But some of the most distressing symptoms of Alzheimer’s or other dementias are behavioral and psychological.

“What takes a lot of families by surprise are the things like agitation, problems sleeping, getting up and wandering; sometimes people even become violent,” said Dr. Keith Fargo, director of scientific programs and outreach for the Alzheimer’s Association.

Some people exhibiting these kinds of behaviors have been treated with anti-psychotic drugs, which has sparked widespread criticism. And the Food and Drug Administration (FDA) has mandated a black box warning on such drugs with older adults with dementia; they are associated with an increased risk of death.

But there’s an alternative.

“A lot of these [behaviors] can be managed with interventions that are really behavioral in nature, that do not require medication,” Fargo said. Those interventions include reminiscence therapy, music and art therapy, aromatherapy and pet therapy.

**New Recommendations for Dementia Care**

The use of person-centered, non-drug treatments for people with dementia is one of 56 new dementia care practice recommendations issued in late January by the Alzheimer’s Association.

They are “aimed at helping nursing homes, assisted-living facilities and other long-term care and community care providers deliver optimal quality, person-centered care for those living with Alzheimer’s and other dementias,” according to a statement by the Gerontological Society of America (GSA).

The recommendations can be found online and will be published as a supplement to The Gerontologist, the GSA’s peer-reviewed journal.

**Responding to Their Environment**

Sheryl Zimmerman, a professor and gerontologist at the University of North Carolina at Chapel Hill, was one of three authors of The Gerontologist’s article on non-drug practices for people with dementia.
She said the behavioral and psychological symptoms that often accompany dementia aren’t just a product of the dementia-affected brain. “Some of those behaviors are due to the interplay of the person with the environment,” Zimmerman noted.

For example: things may be happening too quickly, which can be frightening. There may be a high level of noise or too much stimulation.

Negative reactions may be exacerbated by the typical losses of aging: “An individual who has trouble seeing, for example, may be easily startled and distressed by noises that are not clearly identifiable, leading to anxiety or agitation,” the study said.

But employing non-drug therapies can help the person with dementia have a better quality of life and allow caregivers to do their job. “And it avoids the potential likelihood of giving the person (with dementia) a medication that would sedate them,” Zimmerman said.

**Evidence for Non-Drug Therapies**

Zimmerman and her colleagues examined 197 articles describing scientific evidence on non-drug practices to treat behavioral and psychological symptoms of dementia.

They fell into these categories: sensory practices (aromatherapy, massage, multi-sensory stimulation and bright light therapy), psychosocial practices (validation therapy, reminiscence therapy, music therapy, pet therapy and meaningful activities), and what are known as “structured care protocols” (particular procedures for bathing and mouth care).

Some of what they found:

**Aromatherapy**

A number of studies have looked at the use of aromatherapy for agitation and aggression in people with dementia.

Overall conclusion: Mixed results. The positive outcomes with some patients may have been because they enjoyed the interpersonal and physical benefits of having cream rubbed into their hands, the study said. More large-scale trials are needed.

**Massage**

“Through tactile connection, a person living with dementia may feel comforted and cared about, especially in residential care environments where touch tends to be instrumental and task specific,” the study said. Massage may also be successful in combating the social isolation that can contribute to negative behaviors. And it may spur the body’s production of oxytocin, which can infuse a sense of reassurance and calm.
Overall conclusion: A "small evidence base" shows positive results in the immediate or short term. However, some people dislike massage; that may increase agitation for them. As with any therapy, success depends on whether it’s right for the person being treated.

**Bright Light Therapy**
Normal aging can prompt sleep disturbances. Dementia can further disrupt a person’s circadian rhythm resulting in agitation and “sundowning,” an increase in confusion, irritability and moodiness as the day wanes. Bright light therapy consists of using a special light fixture, light box or visor, or exposure to natural bright light.

Overall conclusion: Mixed results. It may have some benefit, but further research is required. Some studies found it may actually make agitation worse.

**Pet Therapy**
Pets, particularly dogs, have been used for people with dementia for decades. "Physiologically, quiet interaction with an animal can help lower blood pressure and increase production of neurochemicals associated with relaxation and bonding," which may in turn reduce the behavioral and psychological symptoms of dementia, the study said. In small studies, pet therapy has succeeded in reducing disruptive behavior and increasing interactions with others.

Overall conclusion: There is a "small and preliminary" evidence base for pet therapy, even when the pet is a robotic cat or dog. Understandably, pet therapy would not work well for people who are allergic or who have had bad experiences with animals in the past.

**Bathing**
Bath or shower time can be particularly upsetting for a person with dementia. It is “the personal care task associated with the highest frequency of behavioral expressions of distress for persons living with dementia,” the study said. Its intimate nature may cause embarrassment, especially if the person being bathed does not recognize the caregiver and does not understand what is going on.

Overall conclusion: Studies have shown positive results through relatively simple changes such as sponge baths in bed and creating a "spa-like" environment with music or calming sounds. More high-quality studies are needed for the best evidence, the report said.
Do you go to bed every night exhausted, and wake up with a sense of dread? Do you feel like your patience, strength and finances are stretched to the breaking point? It’s not uncommon for caregivers — particularly those looking after a loved one with Alzheimer’s or other dementia — to experience high levels of stress.

“People with Alzheimer’s are not always easy to care for,” said Ruth Drew, director of family and information services for the Alzheimer’s Association. “It becomes constant, (and) the intensity of the care is ratcheting up and up and up over time.”

If you’re an Alzheimer’s caregiver, it’s important to recognize the signs of stress. That way, you can get help before the stress becomes potentially damaging to your health — and consequently that of your loved one. Check to see if you have one or more of the following signs of stress, from Drew and the Alzheimer’s Association:

1. **Exhaustion:** Constantly feeling tired, even after you have slept; being unable or nearly unable to complete basic daily tasks
2. **Change in sleeping and eating patterns:** Sleeping or eating significantly more or significantly less than you normally would
3. **Anger or irritation:** Feeling like you have a short fuse; losing your temper at your loved one or others and being easily annoyed or frustrated
4. **Anxiety:** Worrying about your ability to care for the person and a deep concern for what is going to happen in the future
5. **Depression:** Feeling sad, empty, hopeless and crying at the drop of a hat; depression affects your ability to cope with even everyday challenges
6. **Lack of concentration:** A sense that things are overwhelming and you can’t focus on what needs to be done every day; you may find yourself forgetting appointments, for instance
7. **Social withdrawal:** No longer getting together with other family or friends you previously enjoyed because it no longer interests you
8. **Denial:** Unwillingness or inability to accept that your loved one has Alzheimer’s, or that there is no cure; you’re the only one in your family to think the person is OK
9. **Health problems:** It is all too common for caregivers to experience health problems. If you can’t remember the last time you felt good, it’s time to see a health professional.
If you have experienced any of these signs, don't despair, Drew said. "Nobody should do this by themselves, and no one has to," she noted. "We encourage people to talk to each other. When you talk to others who are also going through this, the walls stop closing in."

And if you think you don't have time for yourself? That's not good.

Drew said she has spoken with Alzheimer's caregivers who never took a break. "At some point, they broke down," she said. "They stopped being able to do the caregiving."

**Getting Help**

Here are several resources for help in finding support groups, information about Alzheimer's and financial planning:

- Alzheimer's 24-hour hotline. Here, social workers and other trained staff with the Alzheimer's Association answer phone calls from anyone wanting answers to questions about caregiving. The number to call is 800-272-3900.

- The Alzheimer's Association website. It has information on symptoms of Alzheimer's and other dementias; diagnosis, stages, treatment and services.

- National Association of Area Agencies on Aging.

- Message boards. A way to connect online with other caregivers or people with Alzheimer's. The Alzheimer's Association has one.

- Alzheimer's Foundation of America. This group has information about the disease and tools for caregivers. Its toll-free helpline is 866-232-8484.

- Alzheimers.net. This site lists Alzheimer's research centers and organizations.

- UsAgainstAlzheimer's. It's a group that pushes for more government and industry funding for research for a cure.

"When you talk to others who are also going through this, the walls stop closing in."

– Ruth Drew, Alzheimer's Association
Are You Being Helpful or Ageist for People With Dementia?

Offers of support may be perceived as bias

By Denise Logeland March 12, 2018

A few years ago, Angela Lunde, a leader in patient and caregiver education for the Mayo Clinic Alzheimer’s Disease Research Center in Rochester, Minn., sat at a table between two people who live on opposite sides of a dilemma.

On one side of Lunde was a man with early- to mid-stage Alzheimer’s disease. “He said, ‘What I really want from my community is I want somebody to feel comfortable coming up to me when I’m out and about and asking me if I need help’ if he looked confused,” Lunde recalled.

On her other side sat a college-age woman who responded to him: “But I sometimes am not sure I’m supposed to do that, because I may be implying [that you can’t figure things out] and it may offend you.”

That disconnect is common between people living with a cognitive impairment and those who encounter them at work or in the community. It’s important to overcome this, Lunde said. For people with impairment, social isolation and its negative health effects is a risk.

“Their ability to have good interactions is really the difference between somebody living with dementia who still feels they can go out and be part of their community and somebody who has a bad experience in a restaurant and begins to exclude themselves,” she said.

Dementia or Mild Cognitive Impairment?

Dementia is part of a hurtful stereotype of older adults. So it’s no wonder people fear giving insult by offering unneeded, unwanted help to someone who’s just fine, thank you.

About 10 to 12 percent of people 65 and older have dementia, said Dr. Ronald Petersen, director of the Mayo Clinic Alzheimer’s Disease Research Center. Dementia is not synonymous with Alzheimer’s disease, as many people believe. Instead it’s a set of symptoms that center on impaired memory and thinking, for which Alzheimer’s is one possible cause. The rate of occurrence goes up with age.
“At 65, it’s maybe only 2 percent [of people] or less,” Petersen explained. “At 85, it’s maybe 35 to 40 percent.” Even at that, it’s risky to assume anything about a person’s cognition based on age, he acknowledged. A dozen 85-year-olds can be at a dozen different points on a spectrum of physical and cognitive abilities.

Dementia or Mild Cognitive Impairment?

Petersen is part of a research group at the Mayo Clinic that added another layer of nuance to what’s known about dementia. Roughly 20 years ago, conducting a large population study of older adults, they realized they were seeing three groups of people. Some had no cognitive impairment. Some struggled with dementia.

“But there was a swath in the middle of people who were just a little bit different,” Petersen said. “They weren’t remembering as well as they used to, but otherwise they were just fine,” still able to carry out all their day-to-day functioning. The Mayo researchers helped define a new diagnosis, mild cognitive impairment (MCI), which often, but not always, progresses into dementia.

“The MCI person’s degree of cognitive impairment is inconvenient... It makes them less efficient, but they can [function independently],” Petersen said. “Whereas the person with dementia can’t do it, they need somebody else to help them.”

In the Community: ‘Just See a Person as a Person’

Even in families, it can be hard to know when to step in and help someone with dementia. When people ask Petersen whether it’s better to intervene or let a family member with dementia maintain a sense of independence by getting past a hurdle alone, he suggests letting the person “try to the point of frustration,” then stepping in with warmth and maybe a bit of humor and commiseration — saying something like “I forget how to do that half the time myself.”

“That’s what the dementia-friendly community concept is,” Petersen said. “To get organizations... to just be aware that some people may need a little support in doing this, that or the other, without singling them out, without making them feel different from everybody else.”

Lunde said she’s learned to err on the side of risk and offer help whenever someone looks perplexed in the grocery aisle or at a crosswalk or near the restrooms at a restaurant. Most people are appreciative, in her experience. And she doesn’t need to know whether they have dementia: “I just know that signage in general can be confusing. It is for all of us.”

The body language and nonverbal cues of confusion are also basically the same for all of us, Lunde said. “So I think the approach to take is to observe and to offer help without even beginning to think... I wonder if this person is confused because they’re older.”

It’s when we see age that we censor our own good intentions, she suggested. “Just see a person as a person.”

“Be aware that some people may need a little support in doing this, that or the other, without singling them out, without making them feel different from everybody else.”
Michele Foss refers to it as The Great Bacon Incident.

She had gotten a call at her Baltimore home from her mother; both of Foss's parents still lived in her hometown of Eagan, Minn., just outside of St. Paul.

Her father, Darrell Foss, was frying bacon for the two of them. When he was finished, he drained the grease. But instead of pouring it into an old glass jar as he typically would, he drained it onto the kitchen counter.

"Then when my mom asked him about it, he said, 'That's what we do,'" Foss said. "So that was really the trigger of [deciding] hey, we need to talk about this."

That was in 2015. There had been other indications that her father, now 75, was having cognitive problems, Foss said. Some years earlier, the expert handyman and retired CPA began having trouble figuring his way through fix-it projects.

After the family talked about the need to get him tested, he was diagnosed with mild cognitive impairment, which increases his risk of developing Alzheimer's disease or another type of dementia.
But making the decision to broach the subject can help everyone — the parent and other loved ones — because it can lead to a diagnosis, Drew said.

“When you know what you’re dealing with upfront, then you can plan,” she said. “The person [with dementia] can have a voice in what happens next.”

For example, your parent might say: ’If at some point down the road I am not able to take care of myself, here is what I would want.’ Drew said. “That planning is able to give some comfort and also reduce fear of the unknown,” she added. The alternative — waiting until there is a crisis — makes choices very limited, Drew noted.

More Reasons to Talk
An early diagnosis can lead to better medical treatment, the Alzheimer’s Association says. Even though there is no cure for Alzheimer’s and no drugs to slow the disease, some medications may help with symptoms. And lifestyle changes, like better diet and more exercise, can potentially help preserve brain function. Your parent may also elect to participate in clinical trials for Alzheimer’s.

Another important reason to get your parent tested if you suspect dementia: You might be wrong.

Other illnesses and conditions can cause dementia-like symptoms that are potentially treatable. They include: Lyme disease; metabolic or endocrine problems; certain medications, including anticholinergics like Benadryl; autoimmune disorders such as Hashimoto’s thyroiditis and late-stage syphilis.

“You always want to find out what you’re dealing with... rather than just assume, well, this person is of a certain age and so they probably have Alzheimer’s,” Drew said.
New Survey Describes Reluctance

The Alzheimer’s Association released results of a new two-question survey May 31, in advance of Alzheimer’s & Brain Awareness Month in June, on difficulties family members have in talking about the disease. The responses are concerning.

Almost 30 percent of the approximately 1,000 adult respondents said they would not talk to a relative about troubling signs of dementia, despite their worries.

A majority said they would be concerned about “offending” a family member (76 percent) or “ruining [their] relationship” with that person (69 percent). And 38 percent said they would wait to talk to their loved one until symptoms worsened.

The online survey was taken last month.

Pam Montana, 63, said in a statement that getting diagnosed early was vital for her.

“It is important for me to face this disease and share my story while I’m able,” said Montana, of Danville, Calif., who speaks publicly as an Alzheimer’s Association early stage adviser. “That leads to an enormous sense of accomplishment, even with this extremely difficult diagnosis. I want to tell these stories and let others know they are not alone.”

She also wants to demonstrate that having Alzheimer’s does not mean an immediate end to life.

How to Have the Conversation

The Alzheimer’s Association offers six tips for talking with a loved one. They include:

• Have the talk as early in the disease stage as possible

• Think about who is best to approach your loved one

• Practice how you will start the conversation

• Offer support and companionship

• Anticipate that your loved one may deny the problem

• Know that the conversation may not go the way you expect

“It’s a very, very hard conversation to have,” Michele Foss said. “You have to come in with a plan. Because if you just say ‘you have cognitive issues’ and don’t have any plans forward, you don’t take action on it.

“To have a diagnosis means you can make an action plan and to move forward — and the earlier the better,” she said.
View our entire Alzheimer's guide for more articles, resources and tips:
nextavenue.org/special-report/alzheimers-dementia-resources-stories