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# 7 Things I Wish I Knew About Dementia Care

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Written by: [Kate Van Dis](#)

Medical Reviewer: [Natali N. Edmonds, PsyD ABPP](#)

Reviewed by: [Kathleen Cameron, BSPHarm, MPH](#)

## Key Takeaways

- How and where dementia care is delivered will vary based on the type and severity of dementia, the unique preferences of the person living with dementia, and the caregiver's needs.
- All types of dementia are progressive, but dementia progresses differently for everyone.
- Caregivers can support their own health and well-being by using respite care, reaching out to friends and family, and joining support groups.

Every person living with dementia is unique, and so are their caregivers. Still, common threads in dementia care experiences can provide valuable insights for those still on their caregiving journey.

In this article, we share guidance and support for those providing dementia care from people who've been there.

## Why trust us

Our [Local Care Reviews Team](#) works hard to provide clear, transparent information to older adults and their caregivers seeking senior living and home care. To provide you with the best possible information, we have spent more than 1,000 hours:

- Consulting with our advisory board, which consists of a [certified care manager](#), a [board-certified geropsychologist](#), and a [geriatric nurse practitioner](#)
- Analyzing and synthesizing state-specific data from government health regulatory agencies
- Surveying 1,000 older adults and their caregivers about their search for senior living and home care options
- Conducting a focus group with caregivers helping older adults find local care

the [Administration for Community Living](#), and [Genworth](#).

## Understanding dementia and Alzheimer's disease

The Alzheimer's Association [defines dementia](#) as “an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.”

Dementia can occur in many different forms, and memory loss is only one potential symptom of the various diseases under the umbrella of dementia. Other symptoms may include difficulty with problem-solving or being confused about time and place. According to the National Institute on Aging, Alzheimer's disease is the [most commonly diagnosed type of dementia](#). [2] Other types include [Lewy body dementia](#) ⓘ and [vascular dementia](#) ⓘ . Someone living with mixed dementia has a combination of two or more types.

All forms of dementia are progressive, meaning the disease will get worse over time. People living with dementia need more and more support as the disease progresses. It's important to note dementia is a disease and not a normal part of the aging process.

## Understanding dementia care

- Providing care for someone in your home
- Providing and arranging care for someone living in their own home
- Managing care for someone living in a memory care community

In some cases, caregiving means providing hands-on assistance with activities of daily living (ADLs) <sup>ⓘ</sup>, such as bathing and dressing. Caregiving also includes managing someone's finances, coordinating their health care, or helping them find quality residential care.

## Dementia care tips: 7 things caregivers wish they'd known

We talked with several caregivers about their experiences providing dementia care for family members at home, in a memory care community, or both. We also spoke with [Elizabeth Hart](#), OTR/L, an occupational therapist at a continuing care retirement community in Chapel Hill, North Carolina, and a certified Positive Approach to Care (PAC) coach. Hart works with residents at every stage of dementia. She also educates family, friends, and staff about how to effectively communicate and care for someone living with dementia.

Here are the seven most important things about dementia care you should know:

### 1. Dementia is unique, and so are people living with dementia

Foundation at the NYU Grossman School of Medicine. [3]

While defining stages may be useful in identifying some common patterns in the disease, not all people living with dementia have Alzheimer's disease. Additionally, even among those living with Alzheimer's, these stages are general guidelines, not absolutes. Dementia progresses differently from person to person, and pronounced symptoms for some may not be an issue for others.

Because dementia and the people living with it are unique, dementia care should be personalized. What works well for one person may not work for another. "One powerful thing you can do is when people still have the capacity, you can get their preferences, you can ask them what they want, what's important to them, what they don't want," Hart suggested.

Knowing the unique preferences of someone living with dementia is key to finding a connection and providing care. David Moore of Chapel Hill, North Carolina, found music was the key to making his mother "feel like herself." When visiting her at the nursing home where she lived before her passing in December 2023, he brought a phone and a speaker to play her favorite songs. "Somehow, she remembered all the words to the old songs she loved, and we could sing along with her," he said.

Andrea Dixon of Durham, North Carolina, said, "One-on-one or small group time is better for my mom. A big dinner tends to overwhelm her—she feels confused and left out. A smaller, shorter snack with just a few of us is more manageable and enjoyable for her."

Sanford, North Carolina, called her mother's diagnosis validating. "Once we had a diagnosis," she said, "the family could talk about it more clearly without as much of a blow-up." One caregiver described a feeling of relief when they finally got a diagnosis; another said she felt her mother-in-law was in denial about her dementia until she was diagnosed.

According to Hart, the earlier you know what you're dealing with, the better off you'll be in dementia care. She suggests having a frank but gentle conversation with your loved one. Start by describing what you're noticing. Then, express your concern and offer to help. Accompanying them to a doctor's appointment could help both of you.

"There are a lot of things that aren't dementia that can masquerade as dementia," Hart said. "And if it is dementia, knowing from the get-go that this is a neuro-degenerative disease we're dealing with—I think it's empowering." Because there's no cure, primary care physicians might be reluctant to talk about dementia. "They feel like people are going to react badly or spiral into depression," Hart said. "But there's also a strong body of research that most people want to know."

A dementia diagnosis often comes with feelings of grief or loss, and it's important to acknowledge those feelings in yourself and the person receiving the diagnosis. While a diagnosis might seem scary, it also allows people to educate themselves and find support.

Another important reason for getting a dementia diagnosis early is the possibility of being treated with [medicines for early-stage Alzheimer's disease](#), such as Leqembi. Recent developments in treating Alzheimer's and other forms of dementia may slow the disease's progression.

### 3. Know your care partners

As Hart said, it takes a team to care for someone with dementia. She used the term “care partner” to describe the members of a care team, whether a family member, a friend, or a paid caregiver. Knowing your care partners is important to providing comprehensive care for someone living with dementia.

The caregivers we spoke to listed spouses, siblings, cousins, non-licensed companions, certified nursing assistants (CNAs), registered nurses (RNs), and other health care providers as their care partners. If you're providing dementia care to someone living at home, this list could also include neighbors and faith leaders. Care partners might include activity directors and administrators in a memory care community.

Moore, whose mother had Alzheimer's disease, emphasized the importance of staying in regular communication with his mother's care partners. He suggested getting to know the nurses and the CNAs. “Help them out,” he said. “Bake them cookies, learn their names. Let them know they are appreciated and valued.”

## 4. View challenging behaviors through the lens of the disease

Dementia isn't just forgetting things. Like any disease, dementia has a wide range of symptoms, and some can be unpleasant or difficult for inexperienced caregivers to understand. Some frequently occurring symptoms of dementia include:

- **Aggression:** More than half of those diagnosed with dementia [exhibit aggressive behaviors](#), a symptom that can make caregiving especially difficult. [4]
- **Sleep disturbances:** [Sleep disturbances](#) affect between 25%–50% of people living with dementia and tend to worsen as the disease progresses. [5]
- **Sexual disinhibition:** As many as 17% of people living with dementia experience [sexual disinhibition](#). [6] Hypersexuality and related personality changes equally affect men and women living with dementia.
- **Other challenging behaviors:** Wandering, repetitive behaviors, hoarding, delusions, and paranoia are among commonly occurring behaviors affecting those living with dementia.

Not all people with dementia will experience these symptoms, and some will only experience them in advanced stages of the disease. When these symptoms do occur, it's helpful to have a framework for understanding them.



In other words, instead of assuming the person with dementia is just being difficult, assume they're trying to express a physical or emotional need that is not being met. For example, when [someone wanders](#) or displays a lack of physical inhibition, they might be seeking sensory stimulation they're not getting in their current environment.

"We can burn ourselves out just trying to manage behaviors," Hart said. "But if we don't get to the underlying cause of why the behaviors are happening, that's an express road to burnout."

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“People with dementia say and do things that catch us by surprise and aren't what we expect, aren't necessarily what we want. We have to be able to dive underneath and think about the needs underlying this behavior.” —Elizabeth Hart, OTR/L

## 5. Don't navigate the search for dementia care on your own

Once the person you care for has received a dementia diagnosis, it's time to start thinking about care options. For many of the caregivers we spoke to, this was more challenging than they anticipated. Here are some strategies caregivers use in their search for dementia care:

assisted living is typically best suited for people needing help with so-called instrumental activities of daily living (IADLs), like housekeeping, laundry, and medication reminders. Nursing homes help with all basic activities of daily living (BADLs), like bathing, toileting, and getting in and out of bed.

- **Get a clear financial picture.** The cost of in-home care or a memory care community is sometimes far more than families can afford. If your loved one needs to apply for [Medicaid](#) to afford care, it's better to know sooner than later, as the application process can be lengthy. Also, as some of the caregivers we spoke to discovered, Medicaid has a lookback period ⓘ, which can delay eligibility. The lookback varies by state, but it's typically 60 months or five years.
- **If you can, hire help.** Alicia Butler of Durham, North Carolina, hired an elder law attorney to navigate her mother's Medicaid application. The attorney referred Butler to an elder law project manager. The project manager helped her navigate the Medicaid application process at a fraction of the lawyer's fee. Certified care managers can also help you through the process of applying for Medicaid and finding quality care in your community, no matter how you pay for it. You can begin your search for a certified care manager through the [Aging Life Care Association's directory](#).

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“The number one most useful thing I did was hire an elder care attorney. I wish I had done that a lot earlier.” —Alicia Butler, Dementia Caregiver

engaged in caregiving. Jen Lucas of Virginia thought Medicaid’s Program of All-Inclusive Care for the Elderly (PACE) would help her find in-home care for her husband after he was diagnosed with early-onset Alzheimer’s disease at age 51. But PACE only serves Medicaid-eligible people 55 and older.

“I needed to be rescued from constant caregiving before he was 55,” she said. Eventually, she was able to find support through Lorenzo’s House, a nonprofit helping to provide care and resources for families navigating younger-onset dementia.

Memory clinics or neurocognitive clinics often provide resources for dementia caregivers, including support groups based on your specific dementia diagnosis. Dixon found a “Daughters Caring for Aging Parents” support group through Duke University. But in the midst of caregiving, she found it too hard to attend in person. During the pandemic, she began to attend virtually. Once the transportation and time barrier was removed, she found it a fantastic resource.

For dementia caregivers providing care in their own or a loved one’s home, the caregivers we spoke to named respite care and adult day services as essential services. [Respite care](#) provides residential, short-term care for primary caregivers, allowing them time to rest, travel, or attend to their own care needs. Adult day services provide engaging daytime activities for people with cognitive or physical impairments.

Aging and disability resource centers are available across the U.S. to help people find and navigate care. Get connected through the [Eldercare Locator](#).

care at home or helped to manage care for someone in a residential care community.

Sometimes, taking care of yourself means making tough decisions about where and how dementia care will occur. We all want the people we care for to receive excellent care in a safe, comfortable environment. Yet not everyone has the resources or ability to provide in-home dementia care.

Butler, working full time with young children at home, remembered people urging her to reconsider taking her mom into her home. “But how receptive was I?” she said. “My mom was sick. I had to take care of her.”

Ultimately, Butler felt the stress of caregiving contributed to the end of her marriage. “I was single with the kids. No child support. I was drowning,” she said. Butler eventually decided to move her mom to an assisted living community and then to a skilled nursing facility. “I wish I had taken care of myself,” she said.

The essential thing for caregivers is “support, support, support,” Hart said. Whether it’s using respite care, finding a support group, or asking friends and family to set up a meal train, ask for help when you need it, and accept it when it comes. Hart works hard to “convince care partners that it is a loving thing to do, to take care of yourself, so you can be a loving, supportive partner to your loved one.”

It might be easier for some caregivers to accept help if you envision providing insight and support to other caregivers in the future. This was true for Trish Halsey of Chapel Hill, North Carolina. Trish was a caretaker for both of her parents simultaneously. “Being able to accept help from friends and family and people you

## Dementia care resources recommended by dementia caregivers

[Dementia caregivers know best](#) which resources are most helpful. With their guidance, we've compiled a list of dementia care resources to help caregivers at various stages in the process.

**Table 1 Dementia caregivers recommend these resources**

Resource	Description	Contact
Adult day services	Community-based daytime care and activities for people with physical and cognitive impairment	Find adult day services near you with <u><a href="#">Eldercare Locator</a></u>
Certified Care Managers	Family advocates able to help find care, apply for services, develop care plans, and more	<u><a href="#">Verify a CCM near you</a></u> or find the name of a CCM in your state
Dementia Careblazers	Free dementia care training videos for family caregivers	Visit <u><a href="#">Careblazers TV</a></u> on YouTube

Elder law attorney or  
elder law project  
manager

you can work with to prepare power of attorney  
documentation, help with Medicaid spend  
down, and more

near you through the  
[National Elder Law  
Foundation](#)

## Bottom line

Providing dementia care can be lonely and overwhelming, but early diagnosis, educating yourself about the nature of the disease, and communicating with care partners can help.

Most importantly, find ways to take care of yourself. Take breaks from caregiving and find emotional support through friends and family, online or in-person support groups, and/or therapy.

“You have to have someone you trust to pass the baton to so you can tap out on a regular basis to do things not only that you have to do, but that you enjoy doing,” Hart said. “You know what they say—you can’t pour from an empty cup.”

## Frequently asked questions about dementia care

**At what point should dementia patients go into care?**



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**How do you cope with a loved one with dementia?** ▼

Have questions about this review? Email us at [reviewsteam@ncoa.org](mailto:reviewsteam@ncoa.org)

## Sources

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5. Mayo Clinic. Alzheimer's: Managing Sleep Problems. Found on the internet at <https://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/alzheimers/art-20047832>

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**Kate Van Dis**  
Author

Kate Van Dis is a health writer in Chapel Hill, North Carolina. She has written for various audiences on health & wellness, education, and aging. Her current focus is on assisted living, home care, and other extra-care housing options for older adults.



**Natali N. Edmonds**  
Medical Reviewer

Natali Edmonds is a board-certified geropsychologist. She specializes in helping families manage the challenges of caring for a loved one with dementia, so families can have more peace, joy, and connection in what is often a scary journey. She created Dementia Careblazers, an online resource for dementia caregivers. She believes that if we want to build a dementia-friendly world, we must first build a caregiver-friendly world.



Kathleen Cameron, BSP Pharm, MPH, has more than 25 years of experience in the health care field as a pharmacist, researcher, and program director focusing on falls prevention, geriatric pharmacotherapy, mental health, long-term services and supports, and caregiving. Cameron is Senior Director of the NCOA Center for Healthy Aging, where she provides subject matter expertise on health care programmatic and policy related issues and oversees the Modernizing Senior Center Resource Center.

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