



The Essential  
Guide for Caregivers

# Dealing with Dementia

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**About this guide.** A dementia diagnosis can feel overwhelming. In addition to the immediate medical issues that arise, there is the uncertainty of what the future may hold. How will the disease progress? What will happen to my loved one along the way? How can my family be ready? How will this change my relationship with my parent or spouse?

A dementia diagnosis can also make it feel as if things are out of your control. These feelings are perfectly natural. You're preparing for how a loved one's life may change, and yours as well. It's a tall order.

One way to cope is to arm yourself with knowledge, because what you learn is something you can control. Reading this guide is a good first step. It will help you understand dementia, some of your options for care, and ways to cope. We hope you find it helpful and reassuring.





To learn more about memory care and memory care communities, please visit our website at [www.fivestarseniorliving.com](http://www.fivestarseniorliving.com). To find a memory care community near you, call us at (617) 796-8387. We look forward to hearing from you.

# We're Here to Help





# The Important Role of Caregiver

Serving as caregiver for someone with dementia is both stressful and rewarding. Your loved one's health and happiness are always on your mind and in your heart. Although caregiving can consume time and resources, it can also create a special bond.

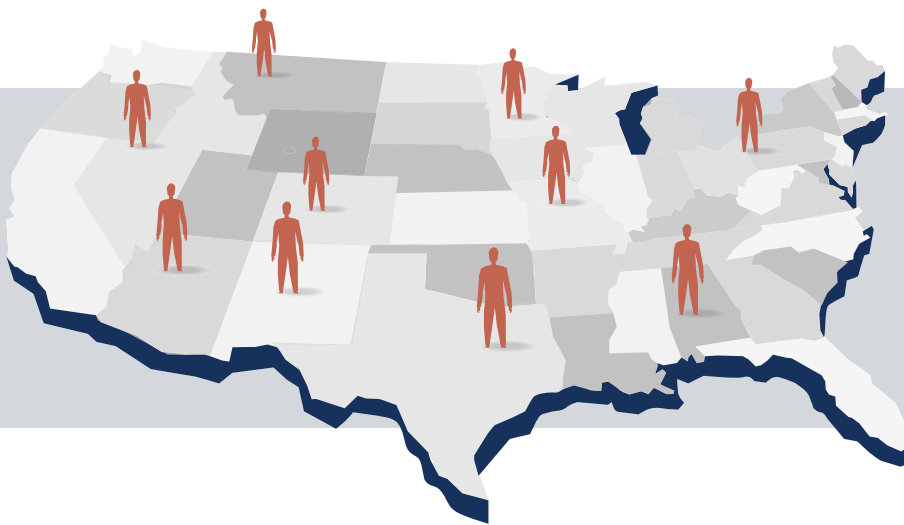
Caring for someone with dementia can be challenging. Your loved one may experience personality changes, which are often more troubling to family than the associated physical and cognitive declines. Changes can happen in unpredictable ways, too, which can be frustrating and even disruptive.

## **You are not alone**

Whether you've recently assumed the role of caregiver or worn the badge for many years, we want you to know that you are never alone. We are here. We have special expertise and experience in memory care and we invite you to rely on us as a resource. Please consider Five Star Senior Living as part of your support network. We would be honored to serve as a trusted advisor.

# What is Dementia?

Dementia is a general term for the impaired ability to remember, think or make decisions that interferes with doing everyday activities. People with dementia experience not just memory loss, but personality and behavior changes as well as the inability to perform daily activities. In the United States, dementia affects more than 5 million people and their loved ones.



More than  
**5 million**  
people in the US  
have dementia<sup>1</sup>

There are several types of dementia. The most common is Alzheimer's disease, followed by vascular dementia, which is linked to stroke and other issues that affect blood flow to the brain. Other types include Lewy body dementia, fronto-temporal dementia and mixed dementia. Dementia also can occur in advanced forms of other diseases, such as Parkinson's.

All types of dementia are considered progressive, meaning they advance in stages over time and result in a general decline in health or function. Dementia can vary widely, however. Some people remain physically and socially active for years after a dementia diagnosis. For others, changes can occur faster. Planning ahead after a loved one is diagnosed can help ensure the right support is in place for each step on the journey, whenever it may occur.

<sup>1</sup> Centers for Disease Control and Prevention. What is dementia? <https://www.cdc.gov/aging/dementia/index.html>. Accessed January 18, 2022.



# Types of Dementia

There are many types of dementia. Familiarizing yourself with the different types can help you know what to expect for your loved one's diagnosis and gain a better understanding of dementia in general.



## >> **Alzheimer's Disease**

Alzheimer's disease is the most common type of dementia, accounting for an estimated 60% to 80% of all dementia cases.<sup>2</sup> Alzheimer's is a slowly progressive brain disease that often begins long before symptoms are detected. Early signs can include depression, apathy and trouble remembering recent events, such as a conversation that just occurred. As the disease progresses, it causes nerve cell damage in the brain, leading to impaired communication, poor judgment, disorientation, confusion, behavior changes and difficulty speaking, as well as trouble remembering more distant events.

## >> **Vascular Dementia**

Vascular dementia is the second most common form of dementia, accounting for 10% of all cases.<sup>3</sup> Vascular dementia is linked to strokes or other issues with blood flow to the brain. People with vascular dementia suffer from impaired judgment and the inability to plan or organize. Symptoms can worsen suddenly if the individual experiences more strokes or mini strokes.

## >> **Lewy Body Dementia**

People with Lewy body dementia disease experience memory loss and thinking problems similar to Alzheimer's. In addition, they may have movement or balance problems like stiffness and trembling. Many people also experience changes in alertness or have trouble sleeping at night. Some may experience visual hallucinations, seeing people or objects that aren't really there.

## >> **Fronto-temporal Dementia**

Fronto-temporal dementia refers to several types of dementia that affect the front and side parts of the brain. The resulting loss of function in these brain regions can cause deterioration in behavior and personality and difficulties speaking or understanding language. Most cases of the most common forms of fronto-temporal dementia occur in people ages 45 to 65.<sup>4</sup>

## >> **Mixed Dementia**

Having more than one type of dementia is referred to as mixed dementia. With mixed dementia, the abnormalities linked to more than one type of dementia are present, for example, Alzheimer's and vascular dementia. It can be hard to tell if someone has mixed dementia because symptoms of one type may be prominent or overlap with another type. Disease progression may be faster than with one type of dementia also.

<sup>2</sup> Alzheimer's Association. What is Alzheimer's disease? <https://www.alz.org/alzheimers-dementia/what-is-alzheimers>. Accessed January 18, 2022.

<sup>3</sup> Centers for Disease Control and Prevention. What is dementia? <https://www.cdc.gov/aging/dementia/index.html>. Accessed January 18, 2022.

<sup>4</sup> Alzheimer's Association. Frontotemporal dementia. <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/frontotemporal-dementia>. Accessed January 18, 2022.

# Dementia-linked Disorders

In addition to the major types, dementia can occur as part of other conditions as well.

## >> **Parkinson's Disease Dementia**

This type of dementia is marked by a decline in thinking and reasoning that develops in many people living with Parkinson's at least a year after diagnosis. The part of the brain affected plays a key role in movement, leading to tremors and shakiness, stiffness, a lack of facial expression and other symptoms. Memory, attention and judgment are affected as the disease progresses.

## >> **Huntington's Disease**

Huntington's, which is hereditary, is a progressive neurodegenerative disease. For those affected, dementia can occur at any stage of the disease. Symptoms include loss of memory, irritability, depression and other mood changes. Loss of muscle coordination and behavioral changes are symptoms as well.

## >> **Traumatic Brain Injury (TBI)**

TBI most often occurs as a result of repeated head trauma, such as experienced by contact sport athletes or soldiers. It can take years following TBI for dementia symptoms to develop. Depending on the part of the brain injured, they can include depression and problems with memory, speech and self-control.

## >> **Creutzfeldt-Jakob Disease**

This rare brain disorder occurs in one out of 1 million people worldwide. It is caused by infectious proteins called prions that destroy brain cells. The disease worsens unusually fast, leading to rapid decline in thinking, reasoning and coordination as well as difficulty walking and mood changes.

<sup>5</sup> Alzheimer's Association. Creutzfeldt-Jakob Disease. <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/creutzfeldt-jakob-disease>. Accessed January 18, 2022.



# Is it Dementia or Simply Aging?

Dementia's symptoms can grow gradually over time. However, not all symptoms or signs point to dementia. As we grow older, even the healthiest among us will exhibit a cognitive disruption or lapse in memory or judgment. Use the chart below to better understand the difference between common age-related behavior changes and more severe changes that may indicate dementia.

## Typical vs. Dementia: Comparing Behaviors

### TYPICAL BEHAVIOR CHANGES

- >> Temporarily forgetting names or upcoming events.
- >> Vision or hearing changes.
- >> Temporarily unable to recall a certain word or phrase. ("It's on the tip of my tongue!")
- >> Suffering from absent-mindedness, such as misplacing car keys or glasses.
- >> Finding it difficult to use devices like microwaves or computers.
- >> Facing misattribution issues, such as recalling an event but not the time or place of the event.
- >> Making errors with checkbooks, bill payment, etc.
- >> Every now and then finding family and friends or other social obligations tiresome or overwhelming.
- >> Becoming irritated when set routines are disrupted.
- >> Erring or making a bad decision.

### MORE SEVERE BEHAVIOR CHANGES

- >> Ongoing memory loss that disrupts his or her everyday life.
- >> Difficulty understanding visual or auditory input and spatial relationships.
- >> New, consistent problems with words in both speech and in writing.
- >> Misplacing things without the ability to retrace his or her steps to find them.
- >> Unable to complete commonplace tasks at home or at work.
- >> Confusing or misremembering the current day of the week or his or her location.
- >> Difficulty in planning or solving problems.
- >> Gradually withdrawing from work or social activities.
- >> Changes in mood and personality such as getting easily upset or being fearful or suspicious.
- >> Changes or a decrease in judgment that causes negative outcomes.



# Five Conditions Masquerading as Dementia

Because Alzheimer's and other dementias have serious implications, it's natural to worry when a loved one seems to have dementia-like ailments or behavior tics. However, dementia is not always the cause of forgetfulness, irritation, or changes in mood. Here are five common conditions that can be mistaken for dementia.



## >> Urinary Tract Infections

While symptoms of a urinary tract infection (UTI) can include painful urination, for older adults UTIs can also cause confusion, agitation or withdrawal. Falls are often associated with urinary tract infections, too.

If you believe your loved one has a UTI, please contact your physician for help.

## >> Polypharmacy

Older adults are often prescribed multiple medications from several providers in addition to taking over-the-counter remedies. So much medicating can sometimes make a person feel worse rather than better, causing memory problems and other side effects similar to dementia.

Two ways to prevent this are to make sure a loved one's primary care doctor has a complete list of all medications and dosages and to use the same pharmacy for all medications. A single pharmacy is better able to spot potentially harmful drug-drug interactions.

## >> Depression

Although not a normal part of aging, depression is common in older adults. Some of the more frequent symptoms of depression mirror those of dementia, including mood and behavior changes, memory lapses and difficulty with reasoning.

If you believe your loved one suffers from depression, consult with their physician, who may refer you to a geriatric psychiatrist, neurologist or geriatrician.

## >> Thyroid Disease

Thyroid disorders are common in older adults and more common in women than men. Dementia-like symptoms can include sluggishness, feeling depressed, forgetfulness or anxiety. Many people with thyroid disease don't know they have it. However, thyroid disease left undetected and untreated can increase the risk of serious conditions, including heart disease and osteoporosis, so a diagnosis can be critical.

If you're at all concerned, a primary care physician or endocrinologist can help determine whether thyroid disease is present and recommend proper treatment.

## >> Hearing Loss

Hearing loss in older adults is very common. The medical term for gradual, age-related hearing loss is *presbycusis*. It can cause older adults to experience attention deficit, misunderstand verbal communication and withdraw from social situations—all associated with dementia. Disorders of the ear are frequently associated with balance issues that can lead to falls as well. So there are many important reasons to know whether presbycusis is behind changes in a loved one's behavior.

A primary care physician, otolaryngologist (ear, nose, and throat specialist) or audiologist can help if you notice any signs of hearing loss.



# Getting Medical Help

If you think your loved one may suffer from dementia, consider scheduling an appointment with their primary care physician (PCP). This doctor should have a thorough medical history of your parent or spouse or other loved one and be able to provide insight into any mental or physical changes that are occurring.

Your PCP may consult with or refer you to one or more physicians who have specialized understanding and training concerning dementia. Here's a brief description of each.

## >> **Neurologist**

A neurologist specializes in the treatment of nervous system disorders. A neurologist may evaluate mental and physical history as well as lab tests, mental status, cranial nerves, motor system, sensory system, deep tendon reflexes, coordination and gait.

## >> **Geriatric Psychiatrist**

Specializing in the mental and emotional needs of older adults, a geriatric psychiatrist will perform evaluations around memory, mood, sleep, depression and thinking.

## >> **Geriatrician**

A geriatrician specializes in the treatment of the health issues of older adults. Geriatricians are board certified in either internal medicine or family practice and have completed a fellowship in geriatrics. They are experts in the biological, psychological, cognitive, and sociological aspects of aging.



## Legal Matters: Planning Ahead

When a loved one is diagnosed with dementia, the prospect can feel overwhelming and stressful. Much will change in both your lives, and it's more important than ever to consider the future, including legal ramifications. If you haven't already, seek legal counsel to help you prepare for any eventuality. Documentation you should look into includes:

1. Medical Directive or Living Will so that your loved one's wishes are known in the event that they can't speak for themselves.
2. Durable power of attorney for healthcare, which should include a HIPAA\* release. This gives you the ability to make healthcare decisions for your loved one.
3. Durable power of attorney for finances so that you will have the ability to take care of money matters.
4. A will, a legal document that outlines the distribution of property upon death and the person(s) who will manage this process.

*\*Health Insurance Portability and Accountability Act.*



# Coping: What You Can Do Now

As noted in the introduction to this guide, arming yourself with knowledge is one way to cope with life after a dementia diagnosis. Here are some other tips for taking care of yourself and ease into your role as caregiver.



**>> Learn the stages.** Speak with the doctor or care team to understand your loved one's current stage of dementia and what lies ahead. For example, they may be in a mild stage now, misplacing objects or having trouble remembering recent events, but it's helpful to know that moderate dementia includes poor judgment, higher need for assistance with everyday tasks, increased agitation and feelings of restlessness.

Knowing what's to come gives you time to prepare and explore potential options, such as memory care, that can be implemented as the dementia progresses.

**>> Start a logbook.** Write down as much as you can, daily. Take notes during doctor visits, jot down symptoms along with dates and times, and record what your parent or spouse might express about future caregiving needs or living situation.

A logbook can help you spot trends, such as side effects that may be related to medication use or signs of dementia progression. It can also help you prepare for the prospect of moving to a memory care community by noting emotional attachments to items—a favorite chair or quilt, for example—that could be brought to the new community. Having familiar things in new surroundings can help your parent or spouse feel comforted and calm.

**>> Share your feelings and fears.** You may be feeling a whirl of emotions, from cautiously optimistic to absolutely terrified. All normal. The Alzheimer's Association recommends working through your feelings by writing them down in a journal, talking to friends and other family members, and tapping into online communities of other adult children who are in the same situation. Consider speaking with a therapist or counselor.

In general, it's healthier to speak openly and honestly about your feelings—even uncomfortable ones—than to wear a brave face and keep them bottled up inside.

**>> Know your memory care options.** Even the most organized and loving people can feel overwhelmed when caring for a parent or spouse with dementia, especially when moderate-stage tasks transition to severe-stage needs. A person who once needed help with remembering tasks and keeping finances in order may now require assistance with eating, walking and going to the bathroom.

Memory care specialists can help. Whether employed as visiting caregivers or in a senior living community, they are highly experienced with the progression of dementia and its ripple effect on families.

Even if your parent or spouse is in a mild stage and has just been diagnosed, consider looking into what options are available in your area, including moving to a memory care community. Visit potential communities to learn what they offer.



## One Day at a Time

No matter what the future holds, know that you can find help at every step. There are ample resources to support you, from your medical care team to online communities to the compassionate staff at a memory care community. Take a deep breath, practice self-care and know your options. Dementia is a journey. You don't have to go it alone

# Taking Care of *You*

Family caregivers sometimes find their own health suffering from juggling the day-to-day responsibilities of looking after a loved one with dementia. From headaches and trouble sleeping to digestive issues and even high blood pressure, caregivers are at increased risk of stress-related symptoms. Fortunately, these can be prevented or minimized with a little self-care. Here are some ways to be good to yourself:

>> **Get organized.** Worried about missing a deadline or an appointment? Setting up a filing system and a calendar with reminders could be time well spent. A physical calendar plus 3-ring binders with copies of your loved one's medical records may be the easiest option, but if you're comfortable with technology, try a health information app, like Healthspek or CareZone.

>> **Accept help.** Like many family caregivers, you may regard looking after your loved one as your duty or a labor of love, or you only trust yourself when it comes to their care. Try to accept or even ask for help from someone you trust or seek recommendations for qualified home health services.

>> **Eat healthy.** It's easy to rely on convenience foods and drive-through fast food when you're pressed for time. Unfortunately, these meals typically contain unhealthy fats and high amounts of sodium. If you aren't able to prepare healthy meals, consider meal delivery services such as Freshly or Silver Cuisine.

>> **Exercise regularly.** Exercise might seem like something a busy caregiver doesn't have time to do. But even 30 minutes a day most days of the week offers many health benefits, including better sleep, a stronger immune system and reduced stress. You'll also help build your muscle strength, which can reduce your chances of a caregiving-related injury.

>> **Laugh often.** It's also important to take time to enjoy yourself. Laughing with loved ones helps lower the risk for depression, an issue Alzheimer's caregivers often struggle with. Watch a funny movie or comedy special, hang out with the grandkids or make a point to spend time with friends who tickle your funny bone.

>> **Consider respite care.** Respite care gives your loved one a safe, temporary place to stay while you enjoy a vacation or some down time. Respite guests can stay at an assisted living community for a few days or even a few weeks. Both you and your loved one can enjoy peace of mind knowing a team of experienced caregivers is always close at hand.



## About Five Star Senior Living

Five Star is a provider of services that enrich and inspire the lives of older adults. We offer independent living, assisted living, memory care and respite stays across the United States. Our rehab and fitness partner, Ageility, provides rehabilitation and wellness services for our residents onsite.

We're committed to helping people maximize their independence and live life to the fullest. To learn more about Five Star and to find a community near you, visit us at [fivestarseniorliving.com](http://fivestarseniorliving.com)

For more about memory care and memory care communities, including advice for families and great tips for caregivers, visit our [Five Star blog](#).

