Understanding Dementia for Caregivers: Types, Signs, and Treatments

The idea of losing one's memory—or watching a loved one or patient go through this for the first time—is likely frightening to most people.

While most types of dementia—though not all—are incurable, there are ways to recognize the signs early, stave off or slow progression, and care for yourself and those with dementia as the diseases which cause it progress.

This resource is here to help you navigate this topic. It defines dementia, including clarifying what dementia is and is not; explains the different types of dementia; provides information about what to do if dementia is suspected; offers advice about what to do while living with dementia; and offers a list of resources for further assistance.

What is Dementia?

Dementia is an umbrella term for memory loss, challenges with thinking and problem-solving, and impairments affecting everyday life. While dementia is frequently thought of as synonymous with Alzheimer's, they are distinct: Alzheimer's is actually the most common type of dementia, but there are a variety of conditions falling into the dementia category.

While dementia risk increases with age, these conditions aren't a normal part of the aging process and shouldn't be taken lightly.

Are Senility and Dementia the Same?

Yes and no. "Senile" is no longer generally considered an acceptable term, as it has been so widely misused—particularly in insulting ways. When referring to memory loss and other mental changes that aren't part of dementia, "cognitive changes" is better to use than "senility."

You can still find "senile" in medical diagnoses—though these diagnostic terms themselves are also now widely considered outdated.

All that said, dementia is defined as a clear set of disorders, while senility is a blanket term including both dementia and the "normal" cognitive and physical declines that come with aging. Other symptoms of senility are physical decline in addition to cognitive decline, including stiff joints, trouble moving around, brittle bones, and hearing or vision loss.

Though senility, as used in medical settings, is generally "normal," the symptoms should be taken seriously, and interventions should be made.

How Can You Tell Signs of Dementia vs. Signs of Aging?

While every condition under the dementia umbrella has its own signs and symptoms, one main difference between a true health condition and a general sign of aging is that a condition causes a consistent, significant disruption to everyday life, while aging is more manageable. When it comes to mental health and decline, these are some of the things to be aware of as people age:

Normal Aging vs. Possible Signs of Dementia
Normal aging: A slowdown in processing new information, but the new information is processed **Possibly dementia:** Frequently forgetting recent events or repeatedly asking the same question
Normal aging: Everyday tasks remain doable, barring physical limitations like arthritis **Possibly dementia:** Everyday tasks like cleaning and eating become increasingly challenging, including forgetting how frequently-used items, like silverware, work

Normal aging: Occasionally misplacing items, forgetting what you're doing, or getting lost
Possibly dementia: Frequently losing things, forgetting what you're doing, or getting lost—even in oft-visited places

Normal aging: Multitasking can become challenging, but the older adult is still generally able to make good decisions and problem-solve
Possibly dementia: Making poor judgments and greatly struggling to solve problems

Normal aging: Minor difficulty remembering names or words
Possibly dementia: Extreme inability to remember names or words

Sources: CDC, Cleveland Clinic

How Many People Have Dementia?

Nearly six million people in the United States and 50 million worldwide live with some form of dementia. Alzheimer's represents 60-80% of dementia cases in the United States. Studies estimate Alzheimer's cases will increase to 14 million in the United States by 2060.

Can Young People Get Dementia?

While most people with dementia are over the age of 65, there are many younger people with some form of dementia. In the United States, between 200,000 and 240,000 people under age 65 suffer from early-onset or what the medical community calls "young-onset" dementia. Young-onset dementia is defined as a diagnosis between ages 30 and 64.

While both early-onset and late-onset dementia are often attributed to genetic factors, there is a clearer link between genetics and young-onset dementia—particularly Alzheimer's. Researchers have found that for people between ages 30 and 64 diagnosed with Alzheimer's, the link can be traced back to three single-gene mutations causing abnormal proteins to be produced. These findings show if a person's mother or father carries one of those three genes, then they have a 50% chance of carrying the genetic mutation.

"Childhood dementia" also exists under the blanket term "Batten disease." It's extremely rare, affecting between two and four out of every 100,000 U.S. children (0.00002% to 0.00004% of the population). Depending on the type, it can begin before age one or as late as age 30, with most types appearing between ages five and seven.

Types of Dementia and What to Expect

There are various types of dementia, and while some of the signs overlap, each one has distinct symptoms, common ages of onset, and treatment methods. Below, you can find information on the different diseases.

Alzheimer's Disease

Alzheimer's is the most common form of dementia, making up 60-80% of dementia cases in the United States. Younger people (between ages 30-60) have also been known to develop early-onset Alzheimer's. There are large racial disparities among people who suffer from dementia as well. Studies from the Centers for Disease Control and Prevention (CDC) found among people over age 65, Black Americans had the highest prevalence at 13.8%, and Hispanics had the second highest at 12.2%.

Alzheimer's Association has resources for patients and caregivers.

Early warning signs include:
- ✔ memory lapses or memory loss
- ✔ inability to track conversations

- loss in the sense of time

Common age of onset is **65+**
Life expectancy after diagnosis is **3-11 years**

Source: Mayo Clinic

Early signs of Alzheimer's onset might be subtle, but they should cause alarm when occurring regularly. Those symptoms include memory lapses or memory loss, an inability to track conversations, or a loss in the sense of time.

As the disease progresses, symptoms become more apparent or pronounced, such as personality changes or getting lost frequently.

In later stages of the disease, people with Alzheimer's could have trouble performing day to day tasks, lose the ability to communicate, and severe physical decline. In these later stages, patients likely need round-the-clock care with a long-term treatment team either at a care facility or hiring healthcare professionals for home-based care.

Regardless of the degeneration stage, it's important to keep your loved one active and engaged, adapting activities to their abilities and interests.

Creutzfeldt-Jakob Disease

Creutzfeldt-Jakob Disease (CJD) is a rare but rapidly progressing degenerative brain disorder that seems to be attributed to abnormally shaped proteins called a prion. Around 85% of CJD cases don't have an explanation for transmission. In other cases, while transmission is unusual, it can be due to inherited genetic mutation or, in even rarer cases, contamination from medical procedures. There are only around 350 diagnoses each year.

Creutzfeldt-Jakob Disease Foundation, Inc.

Early warning signs are similar to Alzheimer's but tend to progress more rapidly. They include:
- Insomnia
- Personality changes
- Diminished thinking and reasoning skills
- Language difficulties
- Change in physical movements

Common age of onset is **60**
70% die within one year of onset

Sources: National Institute of Neurological Disorders and Stroke (NINDS), Mayo Clinic

CJD progresses very quickly, so caregivers are often advised to connect with hospice providers as soon as possible to develop a care plan. Through that care plan, you'll decide steps to ensure your loved one's safety and quality of life—either at home or care facility. Because most patients don't live beyond a year of onset, the focus should be providing as much end-of-life comfort as possible.

Dementia With Lewy Bodies (DLB)

Dementia with Lewy bodies, also called DLB or Lewy body dementia, occurs when abnormal protein deposits, called Lewy bodies, affect brain chemicals. DLB usually affects the areas of the brain controlling thinking and memory. More than a million people in the United States live with this disease.

Lewy Body Dementia Association

Early warning signs include:
- Hallucinations
- Decrease in cognitive function
- Visual impairment
- Memory loss

Common age of onset is **60+**
Life expectancy after diagnosis is **five to eight years** on average, but could range from two to 20 years

This accounts for **3-5%** of all dementia cases (research is limited around incidence rates; this percentage reflects a recent study)

Sources: Mayo Clinic, Practical Neurology

Upon diagnosis, patients and their caregivers should meet with a neurologist to determine the level of progression. Specific treatments will largely depend on the symptoms. For example, speech therapy can help with speech challenges, and occupational therapy can help perform everyday activities. As the disease progresses and mobility and cognitive functioning decreases, caregivers will want to seek a palliative care team to put quality end-of-life care in place.

Frontotemporal Dementia (FTD)

Frontotemporal dementia (FTD) is an overarching term covering various conditions affecting the brain's temporal and frontal lobes. When a part of these lobes shrinks, the effects are usually seen in behavior, language, and personality changes.

The Association for Frontotemporal Degeneration

Early warning signs include:
- Changes in speech
- Trouble with movement (e.g., tremors, lack of coordination, muscle weakness)
- Changes in behavior (e.g., more compulsive, loss of inhibition or judgment, displaying inappropriate social behaviors)

Common age of onset is **60 years** or younger
Life expectancy after diagnosis is **2-20 years**

This accounts for **10-15%** of all dementia cases

Sources: National Institute on Aging, The Association for Frontotemporal Degeneration, Mayo Clinic

Because it's less common and has symptoms similar to Parkinson's or Alzheimer's, diagnosis of FTD can be difficult—The Association for Frontotemporal Degeneration says it can take an average of 3.6 years for an accurate diagnosis. While there's no cure or treatment for FTD, there are still ways to maintain an active lifestyle for quite some time. Keeping your loved one active and engaged with the world is a big part of that, and you can support them in managing their symptoms and creating expectations for the "new normal."

Huntington's Disease

Huntington's disease (HD) is a rare genetic disorder involving the breakdown of nerve cells in the brain. It affects around three to seven people per 100,000 and causes a deterioration in mental and physical abilities. The Huntington's Disease Society of America says symptoms are often described as a simultaneous coalescence of Alzheimer's, Parkinson's, and ALS/Lou Gherig's Disease. Because it's passed down from generation to generation, children whose

parents have HD have a 50% chance of inheriting the disorder. HD tends to more frequently affect people with European ancestry.

> **Huntington's Disease Society of America**
>
> Early warning signs include:
> - **Psychiatric symptoms:** depression, social withdrawal, irritability or apathy, suicidal thoughts
> - **Cognitive impairments:** lack of impulse control, lack of flexibility, difficulty processing information
> - **Movement challenges:** involuntary twitching or jerking, muscle problems
>
> Common age of onset is **30-50** (even rarer form can develop in childhood or adolescence)
> Life expectancy after diagnosis is **10-25 years**
>
> *Sources: Huntington's Disease Society of America, Huntington's Disease Foundation*

There's no cure for Huntington's Disease at this time, but some treatments may help slow the disease's progression. The first step to understanding treatment options is getting a clearer picture of the condition's state through brain imaging and psychiatric evaluations. Medication can help in the early to mid-stages of the disease development, as well as treat depression and other psychiatric conditions related to HD.

Mixed Dementia

Mixed dementia occurs when a person experiences multiple forms of dementia simultaneously. The most common type is Mixed Vascular-Alzheimer Dementia (MVAD).

> **Alzheimer's Association**
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> Early warning signs vary by types of dementia, but like many forms of the disease, symptoms can overlap and often relate to a decline in cognitive and physical abilities
>
> Common age of onset **varies**
> Life expectancy after diagnoses **varies**

It may be hard to detect multiple forms of dementia in some cases, and treatment typically focuses on one of the diseases in the mix. There aren't any specific drug treatments available for mixed dementia, but treatments for Alzheimer's have shown to help with vascular dementia. Like other forms of dementia, family and loved ones should work with healthcare teams to create a care plan.

Normal Pressure Hydrocephalus

Normal Pressure Hydrocephalus is a condition where there's excess cerebrospinal fluid in the ventricles connecting the spinal cord to the brain, causing pressure on the brain tissue. This may lead to dementia-like symptoms.

> **Hydrocephalus Association**
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> Early warning signs include:
> - Difficulty walking
> - Mild dementia symptoms
> - Loss of bladder control

- In some cases, there may be no symptoms

Common age of onset is in one's **60s or 70s**
Life expectancy after diagnosis is **five years** if left untreated or treatment doesn't work; some people can recover with treatment

Sources: Dementia Central, Hydrocephalus Association, National Institute of Neurological Disorders and Stroke

While treatment for most types of dementia merely alleviate symptoms or slow down the progression, Normal Pressure Hydrocephalus can be practically cured if caught in time. Studies have shown surgery involving a shunt in the brain can help drain excess fluid, helping ventricles retract to their normal sizes. In many cases, the disease can be misdiagnosed, so it's important to have the proper scans to understand the condition.

Parkinson's Disease Dementia

As a progressive nervous system disorder affecting movement, Parkinson's gets consistently worse over time. Around 60,000 people in the United States and 10 million worldwide live with Parkinson's Disease, with men experiencing it 1.5 times more often than women.

Parkinson's Foundation

Early warning signs include:
- Tremors
- Difficulty with balance
- Lack of coordination
- Forgetfulness

Common age of onset is **around 60** (5-10% develop early-onset Parkinson's before age 50)
Life expectancy after diagnosis **varies**. Some recent studies suggest lifespan may not be too different than normal life expectancy, but other dementias related to Parkinson's can affect life expectancy

Sources: National Institute on Aging, Parkinson's Foundation

There's currently no cure for Parkinson's Disease. However, there are some potentially helpful treatments, like physical therapy, surgery, or deep brain stimulation, which may help control tremors. While the early stages of Parkinson's largely affect mobility, an estimated 50-80% of patients experience dementia as the disease progresses. Some studies show dementia develops an average of 10 years after the onset of Parkinson's. Because the disease can progress slowly, some of these forms of dementia can begin to show later. A few Alzheimer's treatments may also help Parkinson's patients.

Vascular Dementia

This form of dementia involves impaired cognitive abilities due to injury (e.g., stroke) or conditions that sometimes cut off blood flow from the brain, such as diabetes and high blood pressure. Vascular dementia commonly occurs concurrently with Alzheimer's and is often considered the second most common form of dementia.

Alzheimer's Association

Early warning signs include:
- Memory loss
- Confusion

- Difficulty with concentration

Common age of onset is **65+** with the highest risk at age 80+
Life expectancy after diagnosis is **around five years**

This accounts for **5-10%** of all dementia cases and **6.2%** of dementia deaths

Sources: UCSF Weill Institute for Neurosciences, Alzheimer's Society, Alzheimer's Association, CDC

Symptoms following a stroke might be most notable, but in some cases, vascular dementia creeps in slowly. Treatment usually involves medications to help decrease the risk of further brain damage. Treatments for related illnesses such as diabetes and high blood pressure may also reduce the chances of future damage. In many cases where there is irreversible brain damage, you'll want to work with a palliative care team to create a plan to ensure quality end-of-life arrangements as the disease progresses.

Wernicke-Korsakoff Syndrome

Wernicke encephalopathy is caused by a deficit of B1 vitamins (thiamine), which causes degenerative brain damage attributed to alcohol abuse or dietary deficiencies. Korsakoff syndrome is the resulting condition that causes memory loss and other declines in cognitive functions. The condition tends to affect more men than women.

National Organization of Rare Diseases

Early warning signs include:
- Memory loss
- Confusion
- Disorientation
- Vision issues
- Tremors or loss of control of movement
- Walking with an abnormal gait

Common age of onset is **30-70**
If detected and treated early, Wernicke's encephalopathy **can be reversed**

Source: National Organization for Rare Diseases

If detected early enough, the symptoms can be reversed through thiamine replacement therapy. Patients should abstain from alcohol and maintain a healthy diet. For later-stage Korsakoff syndrome, treatment may stave off further brain damage, but those with the syndrome may have long-term physical and cognitive challenges.

Health Issues Resembling Dementia

The following health conditions can prompt symptoms that are similar to dementia symptoms but are not dementia:

ADHD
Both ADHD and dementia can manifest with forgetfulness, challenges with multitasking, organizational challenges, and more. This can make both harder to diagnose in older adults.

Head trauma
Symptoms resulting from head trauma—whether acute or sustained over time, such as chronic traumatic encephalopathy (CTE)—can look very similar to dementia. Some head trauma can be treated through therapy, but chronic trauma can cause similar brain degeneration to dementia.

Heart or lung disease
Because the heart and lungs send oxygen to the brain, diseases to those important organs can also affect brain function.

Niemann-Pick Disease
The three types of this disease—usually forming in early-childhood to mid-childhood depending on the condition—affect how the body metabolizes fats due to abnormal lipids storage. The loss of brain function and related symptoms mimic dementia.

Sanfilippo Syndrome
This disease usually develops between ages two and six among children missing an enzyme that breaks down the sugar molecules (mucopolysaccharides) that help build connective tissue. The behavioral and physical challenges it causes can look similar to dementia.

Vision or hearing loss
Loss of hearing or vision might not affect the brain specifically, but symptoms—lack of concentration, spatial reasoning, frequent injuries—could look like dementia.

What to Do if You Think Someone May Have Dementia

Do your research and understand the signs of dementia. While some symptoms might overlap, understand what symptoms link to which condition. Then, talk to your loved one about what you've noticed, express your concern, and encourage them to see their doctor. Support them through all stages of seeking evaluation, treatment, and any other related steps.

What to Do if You Think You Have Dementia

Make a note of the changes or concerns you've experienced, then seek guidance and evaluation from your doctor. Additionally, ask your family and loved ones for support, explain your concerns, and let them know what you need from them.

Supporting Someone With Dementia

While your loved one is in the earlier stages of dementia, make sure to sit down with them to make a plan. Help them get their affairs in order, discuss their wishes for their care, decide who will function as a caregiver, and make any decisions they need to make before they don't have the ability to be involved anymore. These conversations can be very difficult, so know feeling hurt or frustrated is natural.

It's challenging to see your loved one's abilities decline, so make sure to practice self-care. Continue to do the things you enjoy. Additionally, seek support from family support groups and dementia care teams to know how to plan for the future. The various dementia associations listed above provide links and resources to find support networks.

There will be a time when your loved one can't live independently, and you'll want to make decisions about when they'll need round-the-clock care, such as hiring a home-based care team or finding a long-term memory care facility. You'll want to find a facility or care team specializing in dementia or Alzheimer's patients, as their staff, especially, especially certified nursing assistants, are trained to serve their needs.

Living With Dementia

Each type of dementia has different symptoms and manifestations. You can learn more about these earlier in this article. It's also important to prepare yourself for being cared for. It can be really difficult to lose your independence, and that's natural.

Have that discussion with your loved ones, express your concerns and fears, and seek their support. It's also important to get all of your affairs in order before dementia progresses. Discuss how care decisions will be made, who can make them,

who will be your power of attorney, and finalize any other legal decisions needing to be made. Additionally, determine whether you want to be in a long-term care facility or have an in-home caregiver, who you want to give you that care, and when you want to begin that level of assistance.

Finally, stay active as much as you can and enjoy the present with your loved ones. Those moments will mean even more to you and them as your condition progresses.

Dementia Resources

These resources provide general information about dementia.

General Dementia Support and Information

Alzheimer's Association
This is the premier organization for Alzheimer's and other dementias, providing resources, support, and advocacy for those in the community. They also can help find support groups.

Centers for Disease Control & Prevention
As the leading public health agency in the United States, the CDC provides overarching epidemiological information and details about all sorts of diseases, including dementia.

Dementia Care Central
This website serves as a clearinghouse for dementia-related information, including resources for caregivers and paying for care. You can find online support groups via their site.

Dementia Society of America®
This national volunteer-driven 501(c)(3) nonprofit serves others with Dementia and Brain Health education, resources, life-enrichment, and programs that recognize caregivers, innovators, and researchers. They can be reached at 1-800-DEMENTIA.

National Institute on Aging
As one of the institutes making up the National Institutes of Health, the NIA conducts and supports research around aging and the diseases and conditions associated with aging, including dementia.

World Health Organization
As the international public health body for the United Nations, the WHO leads efforts on research and information dissemination on diseases worldwide.

Support for Specific Types of Dementia

Cruetzfeldt-Jakob Disease Helpline

Lewy Body Dementia Association Lewy Line and Support Groups

Lewy Body Dementia Resource Center's live helpline: (516) 218-2026 or (833) LBD-LINE

The Association for Frontotemporal Degeneration Resources

Huntington's Disease Society of America Resource Locator and Community and Social Support

Hydrocephalus Association Community Support

Parkinson's Foundation Living With Parkinson's (resources for both those affected and loved ones)

National Organization for Rare Disorders Patient and Caregiver Resource Center