

Alzheimer's Awareness



Alzheimer's vs. Dementia

Think of dementia as an umbrella term. It's defined as a decline in mental ability severe enough to interfere with daily life, the Alzheimer's Association says, while Alzheimer's is a specific disease and the most common cause of dementia.

WHAT IS DEMENTIA?

Dementia is a term that describes a group of symptoms associated with a decline in memory or other thinking skills. There's more than one cause of dementia, and patients may have more than one dementia-causing disease at a time.

A common misconception is that dementia is a normal part of aging. It's not; it's caused by damage to brain cells that affects their ability to communicate. While Alzheimer's accounts for 60-80% of dementia cases, there are other causes, such as Creutzfeldt-Jakob disease, Huntington's disease, Lewy body dementia, Parkinson's disease and more.

No matter the root cause, research has shown that maintaining a healthy lifestyle, such as eating properly, not smoking, exercising regularly and getting routine



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cognitive stimulation can decrease the risk of dementia.

WHAT IS ALZHEIMER'S?

Alzheimer's disease is a degenerative brain disease caused by complex brain damage. The symptoms worsen gradually over time and most commonly affect the part of the brain associated with learning first. This is why, many times, the first symptom

of Alzheimer's is an inability to remember new information.

As the disease progresses, symptoms get more severe. They can, in time, include confusion, behavior changes and difficulty speaking, swallowing and walking. Other early signs and symptoms to watch for include difficulty planning or solving problems, challenges with completing

familiar tasks, confusing times and places, difficulty understanding spatial relationships, losing the ability to retrace steps, poor judgment and withdrawal from activities.

WHAT IS YOUNGER-ONSET OR EARLY-ONSET ALZHEIMER'S?

Alzheimer's isn't just related to age. Younger-onset or

early-onset Alzheimer's affects people younger than 65, with most people exhibiting symptoms in their 40s and 50s. Because there's no one cause for Alzheimer's at any age, it can be more difficult to diagnose. Doctors simply don't always look for Alzheimer's as the cause of memory problems at younger ages, and may attribute symptoms to stress or other diagnoses.

Organizations to Support

Nonprofit organizations help support Alzheimer's disease patients and their families in myriad ways, including funding research into new treatments, providing funding to keep patients at home, supporting caregivers and more.

Here are some Alzheimer's organizations to consider supporting from Charity Navigator, a group that evaluates charities.

ALZHEIMER'S DRUG DISCOVERY FOUNDATION, 97%

The Alzheimer's Drug Discovery Foundation, headquartered in New York, seeks to accelerate the discovery of drugs to prevent and treat Alzheimer's disease and related dementias. Donations to this group are tax deductible, and Charity Navigator gives it high marks for culture and community and accountability and finance.

ALZHEIMER'S FAMILY CENTER, 100%

This California organization provides care solutions for patients Monday through Saturday, including therapeutic activities, health and care coordination, counseling, education for families and caregiver support. It is part of the Pickup



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Family Neurosciences Institute at Hoag, and also offers free memory checkups for the community. Donations are tax deductible and it gets high marks for accountability and finance.

ALZHEIMER'S FOUNDATION OF AMERICA, 100%

The foundation provides support, services and education to patients, families and caregivers affected by

Alzheimer's disease and related dementias. While the organization is headquartered in New York City, it serves people across the country. It also funds research to find better treatments and,

eventually, a cure. Donations are tax deductible. Charity Navigator ranked it highly in accountability and finance, culture and community, and leadership and adaptability.

ALZHEIMER'S RESEARCH & PREVENTION FOUNDATION, 95%

Since 1993, this Arizona-based organization has sought to reduce the incidence of Alzheimer's disease by conducting clinical research and providing educational outreach. It advances a holistic approach to preventing memory loss and Alzheimer's. Donations are tax deductible and it gets high marks for accountability and finance and culture and community.

ALZHEIMER'S RESOURCE CENTER, 97%

Based in Alabama, this organization seeks to enhance the quality of life, dignity and respect for people with Alzheimer's disease, their families and caregivers. It conducts educational programs, support groups, advocacy activities and more. Donations are tax deductible. It scored well in accountability and finance.

ALZHEIMER'S DISEASE INTERNATIONAL, 97%

This group aims to build and strengthen Alzheimer's associations and raise awareness worldwide. It scored well in accountability and finance and donations to this group are tax deductible.

Caring for Caregivers

Alzheimer's patients will, as the disease progresses, need a team of people responsible for their care. Here's what the Alzheimer's Association says caregivers can expect as the disease progresses.

EARLY-STAGE CARE PARTNERSHIP

Early in the disease, many Alzheimer's patients still function independently. They may still drive, go to social activities and even work. As a care partner, a term the Association says may be more palatable than caregiver in this stage, be supportive and help the patient make decisions about the future, such as legal, financial and long-term care planning.

Care partners can also coordinate treatment and participation in clinical trials.

MIDDLE-STAGE CAREGIVING

The middle stages of Alzheimer's can last for many years, the Association says, and are marked by a progressively greater level of care. Damage to the brain during this stage of the disease can make it difficult to express thoughts and perform routine tasks. Patients may have trouble



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getting dressed, jumble their words, and get frustrated or angry. Be patient and try to be flexible and adapt daily routines as needed. The Association says structure is important during this stage, and workshops and other support can be beneficial for both the caregiver and the patient.

LATE-STAGE CAREGIVING

This stage, the final one,

can last weeks or years. It typically requires intensive, around-the-clock care. The patient may have difficulty eating and swallowing and may need assistance and eventually be unable to walk. Late-stage Alzheimer's patients are vulnerable to infections, especially pneumonia.

Caregivers should focus on preserving quality of life and

dignity for the patient. While the patient may be severely diminished, research shows some core of the self remains. Show care through touch, sound, sight, taste and smell. Play favorite music and read parts of meaningful books. Look at old photos together or prepare a favorite food.

This stage of caregiving may mean leaving the home and moving into a facility to get

the care they need. Families making such a stressful decision may benefit from support from local resources and groups as they navigate this challenging time.

The Alzheimer's Association stresses that discussions about end-of-life care should take place while the patient still has the capacity to make decisions and share wishes about life-sustaining treatments.



New Treatments and Research

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The U.S. Food and Drug Administration approved three new drugs in recent months to treat Alzheimer's disease.

KISUNLA (DONANEMAB)

Manufactured by Eli Lilly, Kisnula was approved in July for people with early symptomatic Alzheimer's disease, including mild cognitive impairment and the mild dementia stage of Alzheimer's disease with confirmed amyloid plaques.

"This is real progress," says Joanne Pike, Alzheimer's Association president and CEO. "Having multiple treatment options is the kind of advancement we've all been waiting for."

REXULTI (BREXPIRAZOLE)

Approved last year, Rexulti treats agitation associated with Alzheimer's disease. The Alzheimer's Association says around 45% of people living with Alzheimer's experience symptoms of agitation, including pacing, gesturing, profanity, shouting, shoving and even hitting.

"People living with moderate and severe Alzheimer's and other dementia need and deserve treatment that improves the quality of their life, including effective treatments for behavioral and psychiatric symptoms associated with dementia," says Nicole Purcell, the Association's senior director of clinical practice.

LEQEMBI (LECANEMAB)

The FDA approved Leqembi in 2023 for the treatment of early Alzheimer's.

It was the first treatment granted traditional FDA approval that changes the underlying course of the disease.

"This treatment, while not a cure, can give people in the early stages of Alzheimer's more time to maintain their independence and do the things they love," Pike says. "This gives people more months of recognizing their spouse, children and grandchildren. This also means more time for a person to drive safely, accurately and promptly take care of family finances, and participate fully in hobbies and interests."

ADUHELM (ADUCANUMAB) DISCONTINUED

In January, drugmaker Biogen discontinued the drug Aduhelm (aducanumab), which was approved by the FDA via an accelerated

approval process in 2021. It was the first FDA-approved treatment to address an underlying cause of the disease, not just the symptoms, the Alzheimer's Association says.

Medicare coverage was denied for Aduhelm unless the patient was in a clinical trial, a move the Association says restricted access to the treatment and confused both patients and doctors.

PART THE CLOUD

The Alzheimer's Association is part of an effort called Part the Cloud, a funding initiative designed to accelerate the transition of research findings from the lab to clinical trials to practice.

Part the Cloud has raised more than \$60 million for 19 high-risk, high-reward research projects.

Early-Onset Alzheimer's

While most patients affected by Alzheimer's disease are more than 65 years old, the disease can strike people as young as their 30s, 40s and 50s, Johns Hopkins says. This is known as early-onset or younger-onset Alzheimer's disease.

TWO FORMS

There are two forms of this more-rare occurrence of Alzheimer's disease. Most patients who have early-onset Alzheimer's disease have the common form of the disease. It progresses in about the same way as it does in older patients.

Genetic, or familial, Alzheimer's disease is very rare. Patients have genes that contribute directly to Alzheimer's disease. People with this form of the disease start showing symptoms of the disease in their 30s, 40s and 50s.

SYMPTOMS

Symptoms of early-onset Alzheimer's disease are similar to the common form of the disease. They include:

- Forgetting things, particularly newly learned information or important dates.
- Asking for the same information over and over.
- Trouble solving basic



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problems, such as keeping track of expenses or following a recipe.

- Losing track of the date or time.
- Losing track of where you are and how you got there.
- Trouble with depth perception.
- Trouble finding the right word for something.
- Increasingly poor judgment.
- Withdrawal from work and social situations.

Later symptoms of the dis-

ease include:

- Severe mood swings and behavior changes.
- Confusion about time, place and life events.
- Being suspicious of friends, family or caregivers.
- Trouble speaking, swallowing or walking.
- Severe memory loss.

DIAGNOSIS

Early-onset Alzheimer's is diagnosed by cataloging symptoms and running a few tests.

Health care professionals may do cognitive tests along with neuropsychological tests, blood tests, urine tests and spinal fluid tests. There may also be CT and MRI tests to see how much damage has been done to the brain. Research is being done, Johns Hopkins says, on biomarkers that will allow experts to diagnose the disease more quickly.

TREATMENTS

Early-onset Alzheimer's, like

the more common form of the disease, has no cure. But there are some treatments that can help patients maintain mental function and slow the progress of the disease. These include:

- Donepezil.
- Rivastigmine.
- Galantamine.
- Memantine.
- Lecanemab-irmb.

Physical activity, antioxidants and cognitive training may also slow the progress of the disease, Johns Hopkins says.

What Are Silver Alerts?

In 2006, 68-year-old Mattie Moore, an Alzheimer's disease patient from Atlanta, disappeared from her home.

Eight months later, her body was found 500 yards from her home. In response, Atlanta created Mattie's call, an effort to support city law enforcement, emergency management and broadcasters to issue an urgent bulletin in the case of a missing senior citizen.

The Alzheimer's Association says roughly 60% of people living with dementia will wander off at least once. Many states have enacted unique public messages, often called Silver Alerts, to help locate missing seniors. Thirty-seven states and the District of Columbia now have Silver Alert or similar programs in place. A federal program hasn't yet been implemented, but there have been efforts in Congress to make it nationwide.

Because the programs vary from state to state, there are different activation criteria depending on where you are. Some states limit Silver Alerts to people over 65 who have been diagnosed with Alzheimer's disease, dementia or a mental disability. Other states include other adults with mental or developmental disabilities. Across state lines, however, Silver Alerts usually consist of a name and



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description of the missing person and a description of any vehicle that may be involved.

The Alzheimer's Association says these are some signs a dementia patient may be at risk of wandering:

- Returning from a regular walk or drive later than usual.
- Forgetting how to get to familiar places.
- Talking about fulfilling former obligations, such as going to a regular appointment that they no longer attend or going to work.

- Trying or asking to go home, even when they are at home.

- Becoming restless, pacing or making repetitive movements.
- Having difficulty locating familiar places.
- Asking the whereabouts of past friends and family.
- Acting as if doing a hobby or chore, but nothing gets done.
- Appearing lost in a new or changed environment.
- Becoming nervous or anx-

ious in crowded areas.

The Association says caregivers can reduce the risk of wandering by:

- Providing opportunities for the patient to be engaged in structured, meaningful activities during the day.
- Identify the time of day the patient is most likely to wander. Some patients experience sundowning, a worsening of symptoms in the early evening. Caregivers can plan to do activities that may help reduce the patient's agitation.

- Ensure basic needs are met, including toileting, food and hydration.

- Involve the patient in daily activities such as household chores.
- Reassure the patient if they feel lost or abandoned.
- Avoid busy places that can cause disorientation.
- Observe the patient's response to new surroundings. Do not leave the patient unsupervised if new surroundings may cause confusion or agitation.

How Alzheimer's Is Diagnosed

Diagnosing Alzheimer's disease can be a difficult and trying journey.

Once a person or friends and family notice early symptoms of the disease, health care professionals can begin to run a series of tests to make a definitive diagnosis. Getting a correct diagnosis as early as possible can gain patients valuable time to continue to live a full, productive life.

EARLY SYMPTOMS

The Mayo Clinic says early symptoms of Alzheimer's disease include:

- Trouble remembering events and other memory impairment.
- Having a hard time concentrating, problem-solving or planning.
- Difficulty finishing daily tasks at home or work.
- Confusing locations or the passage of time.
- Having visual or spatial issues, including not understanding distances or misplacing items.
- Trouble with language.
- Using poor judgment.
- Withdrawing from work or social events.
- Changes in mood, such as experiencing depression or other personality changes.

GETTING A DIAGNOSIS

You should see your health care professional as soon as you notice symptoms of Alzheimer's disease. You may



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start seeing your general practitioner, but then move on to a neurologist or a gerontologist, a doctor who specializes in treating seniors.

In addition to reviewing symptoms and medical history, health care professionals may give patients memory or cognitive tests, lab tests or brain imaging tests. These tests can help the care team

rule out other health conditions that could be causing or contributing to the symptoms.

RESEARCH

While there are no definitive tests for Alzheimer's before symptoms start, researchers are working to change that. Tests are under development that would measure amyloid, or tau, in a patient's blood, the

Mayo Clinic says.

These tests may be used to pinpoint who is at risk for Alzheimer's disease and whether Alzheimer's is the cause of a patient's dementia.

Getting an early diagnosis of Alzheimer's disease means treatments can start earlier to slow the decline in the patient's condition. Patients may also be able to participate

in clinical trials to treat the disease, and conversations about future treatments and the patient's wishes can happen earlier.

Working as a team, caregivers and health care professionals can work with the patient to answer questions and make a plan to maintain their independence, health and safety.