UNDERSTANDING ALZHEIMER’S AND DEMENTIA

Geri T., living with Alzheimer’s, and her husband and care partner, Jim
THE IMPACT OF ALZHEIMER’S AND DEMENTIA

Currently, an estimated 50 million people worldwide are living with dementia, including more than 5 million Americans. Without changes in prevention or treatment, this number could reach nearly 14 million by 2050.

The disease also affects the 16 million Americans who provide unpaid care for people living with Alzheimer’s or another dementia. More than 80% of care provided at home is delivered by family members, friends or other unpaid caregivers.

The Alzheimer’s Association® is available across the country and online to help people understand Alzheimer’s and dementia, and receive information and support they can trust.
1. ALZHEIMER’S AND DEMENTIA

The terms “dementia” and “Alzheimer’s” are often used as though they mean the same thing. They are related, but there are important differences between the two.

**Dementia**

Dementia is a broad (“umbrella”) term for an individual’s changes in memory, thinking or reasoning. There are many possible causes of dementia, including Alzheimer’s.

**Alzheimer’s**

Alzheimer’s disease is the most common cause of dementia. It makes up 60% to 80% of all dementia cases. Alzheimer’s is not a normal part of aging — it’s a progressive brain disease, meaning it gets worse over time.

Two abnormal brain structures called plaques and tangles are the main features of Alzheimer’s disease. Scientists believe they damage and kill nerve cells. Plaques are pieces of a protein fragment called beta-amyloid that build up in the spaces between nerve cells. Tangles are twisted fibers of another protein called tau that build up inside cells.
Other common dementias

» **Vascular dementia** is a decline in thinking skills that happens when blood flow to the brain is blocked or reduced so that brain cells can’t get important oxygen and nutrients. Sometimes these changes occur suddenly, such as during a stroke that blocks major brain blood vessels. Vascular dementia is the second most common cause of dementia after Alzheimer’s disease.

» **Dementia with Lewy bodies** is a type of progressive dementia related to buildup of a protein called alpha-synuclein that damages brain cells. Early symptoms include hallucinations and sleep problems.

» **Frontotemporal dementia (FTD)** is a group of disorders. Progressive cell degeneration (or breakdown) causes FTD in two places. One is in the brain’s frontal lobes (the areas behind the forehead). The other is in the brain’s temporal lobes (the regions behind the ears).

Visit [alz.org/dementia](http://alz.org/dementia) to learn about other types of dementia.

*John W., living with dementia with Lewy bodies, and his wife and care partner, Gail*
More than 100 years ago, Dr. Alois Alzheimer described specific changes in the brain. Scientists now call them beta-amyloid plaques and tau tangles. Today we know that Alzheimer’s is a progressive brain disease. It is marked by these key changes and impacts memory, thinking and behavior.

**What goes wrong in the brain**

The brain has three main parts: the cerebrum, cerebellum and brain stem. Each has a job to do to make the body work properly.

The cerebrum fills up most of the skull. It’s the part of the brain most involved in remembering, problem-solving and thinking. There are about 100 billion nerve cells called neurons throughout the brain that send messages in order to make memories, feelings and thoughts.

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**TAKE A CLOSER LOOK**

Visit [alz.org/brain](http://alz.org/brain) to explore *Inside the Brain: A Tour of How the Mind Works.*
Alzheimer’s disease causes nerve cells to die. This causes the brain to lose tissue (also called shrinkage) and the loss of function and communication between cells. These changes can cause the symptoms of Alzheimer’s disease. These include memory loss; problems with thinking and planning; behavioral issues; and, in the last stage, a further decline in functioning, which can even include trouble swallowing.

3. RISK FACTORS

Scientists know that nerve cell failure is a part of Alzheimer’s disease, but they don’t yet know why this happens. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer’s.

Age
The greatest known risk factor for Alzheimer’s is age. After age 65, a person’s risk of developing the disease doubles every five years. Thirty-two percent of people age 85 or older have Alzheimer’s.

Family history
Researchers have learned that people who have a parent, brother or sister with Alzheimer’s are more likely to develop it than those who do not. The risk increases if more than one family member has the disease.

Genetics
Two types of genes influence whether a person develops a disease: risk genes and deterministic genes. Risk genes increase the chance of developing a disease but do not guarantee it will happen. Deterministic genes cause a disease. This means anyone who inherits a deterministic gene will develop a disorder.
Rare deterministic genes cause Alzheimer’s in a few hundred extended families worldwide. Scientists estimate these genes cause less than 1% of cases. Individuals with these genes usually develop symptoms in their 40s or 50s.

**Hispanics, African Americans and women**
Research shows that older Hispanics are about one-and-a-half times as likely as older whites to have Alzheimer’s and other dementias, while older African Americans are about twice as likely. No one knows the exact reason for these differences, but researchers believe they are connected to higher rates of vascular disease in these groups. Also, women live longer than men, making them more likely to develop Alzheimer’s. However, living longer doesn’t completely explain this difference. Researchers are exploring how genetic differences may impact disease risk.

**Lowering the risk of cognitive decline**
Age, family history and genetics are all risk factors we can’t change. However, research is starting to show clues about other risk factors that we may be able to influence. Studies show a strong connection between serious head injury and future risk of Alzheimer’s. For this reason, it’s important to protect your head by buckling your seat belt, wearing a helmet when playing sports and making sure your home is safe to avoid falls. Research also shows there are healthy lifestyle habits that people can adopt to help keep their brain healthy and lower their risk of cognitive decline. These include eating a healthy diet, staying socially active, and exercising the body and the mind. Not using tobacco and avoiding excess alcohol is also good for brain health. Science tells us there is a strong connection between brain health and heart health. The risk
of developing Alzheimer’s or vascular dementia appears to be increased by many conditions that damage the heart and blood vessels. These include heart disease, diabetes, stroke, high blood pressure and high cholesterol.

The Alzheimer’s Association used this research to develop 10 Ways to Love Your Brain, a collection of tips that can help lower the risk of cognitive decline. Learn more at alz.org/10ways.

4. STAGES OF ALZHEIMER’S DISEASE

Alzheimer’s usually progresses slowly in three general stages: early, middle and late. In a medical setting, these stages are sometimes called “mild,” “moderate” and “severe.”

The symptoms of Alzheimer’s worsen over time, but because the disease affects people in different ways, the rate of progression varies. On average, a person with Alzheimer’s may live four to eight years after diagnosis, but some people live as long as 20 years.

The following descriptions provide a general idea of changes at each stage. Stages of Alzheimer’s may overlap, which can make it difficult to know which stage a person is in.
Early-stage Alzheimer’s
In the early stage, a person may function independently, but people who know the individual well may begin to notice difficulties. These can include:

» Problems coming up with the right word or name for something.
» Trouble remembering names when introduced to new people.
» Difficulty with familiar tasks.
» Forgetting something that was just read.
» Getting lost in familiar places.
» Increasing trouble with planning or organizing.

Middle-stage Alzheimer’s
Middle-stage Alzheimer’s is usually the longest stage and can last for many years. As the disease progresses, the person living with Alzheimer’s will need more help. In the middle stage, symptoms will be noticeable to others and may include:

» Forgetting events or one’s own personal history.
» Feeling frustrated, angry or withdrawn, especially in socially or mentally challenging situations.
» Confusion about where they are or the day of the week.
» Needing help to choose the right clothes for the weather or occasion.
» Trouble controlling bladder and bowels.
» Changes in sleep patterns. This may include sleeping during the day and restlessness at night.
» A higher risk of wandering and becoming lost.
Personality and behavioral changes. The person may become suspicious or delusional, believing that others are lying. Or, the person might repeat a behavior over and over.

Late-stage Alzheimer’s
Major personality changes can happen in the final stage of Alzheimer’s. The person will need a lot of help with daily activities and personal care. In the late stage, individuals may:

- Lose awareness of recent experiences as well as of their surroundings.
- Go through changes in physical abilities. This may affect their ability to walk, sit and, eventually, swallow.
- Have more trouble communicating.
- Be at higher risk of infections, especially pneumonia.
Currently, there is no cure for Alzheimer’s, but non-drug treatments and medications may help with memory, thinking and behavioral symptoms for a while. It’s important to talk about treatments with your doctor, starting with non-drug options.

Non-drug treatments
Non-drug treatments for behavioral symptoms can offer physical and emotional comfort. Many of these strategies aim to identify and take care of the needs of the person living with Alzheimer’s.

Tips for coping with symptoms include:

» Check for personal comfort. Look for pain, hunger, thirst, constipation, full bladder, fatigue, infections and skin irritation. Keep the room temperature comfortable.

» Don’t argue about facts. For example, if a person would like to visit a parent who died years ago, don’t point out that the parent is no longer alive. Instead, say, “Your mother is a wonderful person. I would like to see her, too.”

» Redirect the person’s attention by getting them to think about something new. Try to be flexible, patient and supportive. Respond to the emotion, not the behavior.

» Create a calm environment. Avoid noise, bright lights and television, which causes distraction.

» Have rest times between lively events.

» Give the person an object to hold that makes them feel safe.
» Show the person that you hear them and answer his or her questions.

» Look for reasons behind each behavior. Talk to a doctor about behaviors that could be connected to medications or illness.

» Try to find more than one solution.

**Medications**

Three types of drugs are currently approved by the Food and Drug Administration (FDA) to treat cognitive symptoms of Alzheimer’s disease.

The first type is cholinesterase (KOH-luh-NES-ter-ays) inhibitors. These drugs prevent the breakdown of acetylcholine (a-SEA-til-KOH-lean). Acetylcholine is a chemical messenger important for memory and learning. These drugs support communication between nerve cells. The cholinesterase inhibitors most commonly prescribed are:

» Donepezil (Aricept®)

» Rivastigmine (Exelon®)

» Galantamine (Razadyne®)

The second type of drug works by regulating the activity of glutamate. Glutamate is a different chemical messenger that helps the brain process information. This drug is known as:

» Memantine (Namenda®)

The third type of drug is a combination of a cholinesterase inhibitor and a glutamate regulator:

» Donepezil and memantine (Namzaric®)
These treatments produce different results in different people. They might help symptoms for a while, but they do not slow or stop the brain changes that cause Alzheimer’s to become more severe over time.

6. ADVANCING ALZHEIMER’S RESEARCH

Research in the last 10 years shows that Alzheimer’s starts many years before people living with the disease notice symptoms. With this knowledge, researchers are working to find people who are at risk before they have symptoms and try to prevent the disease. This effort may lead to a medication to stop or slow the disease.

To help advance important research to understand Alzheimer’s and find treatments, the Alzheimer’s Association funds researchers looking at new treatment strategies and advocates for more federal research funding.

Clinical studies drive progress
Taking part in a clinical study is one way that everyone can help fight Alzheimer’s disease. Without volunteers for research, scientists cannot find ways to prevent, treat and, ultimately, cure the disease.

Clinical trials test new drugs to be sure they are safe and effective. Clinical studies test non-drug treatments to learn how they affect things such as quality of life. Every clinical trial or study gives us important knowledge, whether or not the study was successful.

For people currently living with dementia, there are other benefits to taking part in clinical trials, including access to expert medical care and promising treatments.
I don’t have a laboratory. I have Alzheimer’s disease.

And I’m helping to discover a cure.

You can, too.

alz.org/TrialMatch
800.272.3900
The Alzheimer’s Association is the leading voluntary health organization in Alzheimer’s care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer’s disease®.
About the Alzheimer's Association

The Alzheimer’s Association® is the leading voluntary health organization in Alzheimer’s care, support and research. Founded in 1980 by a group of family caregivers and individuals interested in research, the Association includes our home office in Chicago, a public policy office in Washington, D.C. and a presence in communities across the country.

An estimated 50 million people worldwide are living with dementia. In the United States alone, more than 5 million have Alzheimer’s, and 16 million are providing unpaid care. The Association addresses this crisis by providing education and support to the millions who face dementia every day, while advancing critical research toward methods of treatment, prevention and, ultimately, a cure.

We provide care and support to those affected.

- Our free 24/7 Helpline (800.272.3900), staffed by master’s-level clinicians and specialists, provides confidential support and information to all those affected in over 200 languages.
- Our website, alz.org®, is a rich resource designed to inform and educate multiple audiences, including those living with the disease, caregivers and professional health care providers.
- We conduct online and face-to-face support groups and education programs in communities nationwide, while ensuring these services reach underserved populations.
- We provide innovative resources to support those living with Alzheimer’s and their caregivers, including ALZConnected®, an online community, and LiveWell, a suite of online tools to empower those living with the disease.
- We make it easy for families to find programs and services using the Alzheimer’s Association & AARP Community Resource Finder, a comprehensive database of dementia and aging-related resources.
- To help individuals receive an accurate and timely diagnosis, and to improve access to care, we provide tools for clinicians, including continuing medical education and a cognitive assessment toolkit.
We accelerate research and create a path for global progress.

- As the world’s largest nonprofit funder of Alzheimer’s research, the Alzheimer’s Association is currently investing over $185 million in more than 540 best-of-field projects in 30 countries. This commitment provides funding for critical advances, such as the development of Pittsburgh Compound B (PIB), which made amyloid buildup, a hallmark of Alzheimer’s, visible in the living brain through a PET scan.

- We advance the field by convening the annual Alzheimer’s Association International Conference® (AAIC®), the world’s largest and most influential forum for the dementia research community.

- We play a key role in increasing knowledge about prevention and risk reduction. In 2018, the Association funded and implemented U.S. POINTER, a two-year clinical trial designed to evaluate whether lifestyle changes can protect cognitive function in people at risk of developing dementia. The Association is also funding SPRINT MIND 2.0, a study to clarify the role of lowering blood pressure in reducing dementia risk.

- We accelerate research through TrialMatch®, a free clinical studies matching service for people living with the disease, caregivers and healthy volunteers.

We advocate for the needs and rights of people facing Alzheimer’s and all other dementia.

- Working with the Alzheimer’s Impact Movement (AIM), a separately incorporated advocacy affiliate of the Alzheimer’s Association, we assemble and train a nationwide network of advocates who engage elected officials.

- We help pass landmark legislation such as the National Alzheimer’s Project Act, which mandated the creation of a national plan to fight Alzheimer’s and coordinates efforts to prevent and effectively treat the disease by 2025.

- In 2020, Alzheimer’s and dementia research funding at the National Institutes of Health (NIH) reached $2.8 billion annually. The Alzheimer’s Association, AIM and our advocates have driven bipartisan support for this rapid increase.

- We secure quality health care services for those affected. The Alzheimer’s Association, AIM and our advocates championed key provisions in the Older Americans Act to ensure that individuals living with younger-onset dementia, regardless of age, have access to critical care and support services.

Learn more and join our cause. Visit alz.org.
Understanding Alzheimer’s and Dementia
Participant’s Guide

Learning Objectives
- Compare Alzheimer’s and dementia.
- Recognize how Alzheimer’s disease affects the brain.
- List the risk factors of Alzheimer’s disease.
- Identify the three stages of the disease.
- Recognize current FDA-approved treatments that can address some of the symptoms of the disease.
- Describe how scientists are working to advance research.
- Name the resources available through the Alzheimer’s Association.
Alzheimer’s is a normal part of the aging process.

People younger than age 65 can get Alzheimer’s.
Glossary of Dementias

Dementia
- Alzheimer's
- Vascular dementia
- Dementia with Lewy bodies
- Frontotemporal dementia
Alzheimer’s in the Brain Recap

- More than 100 years ago, Dr. Alois Alzheimer described specific changes in the brain, the formation of plaques and tangles.
- Alzheimer’s causes nerve cells to die, which leads to shrinkage in the brain.
- The brain changes result in changes in memory, thinking and behavior.
What is the greatest known risk factor for Alzheimer’s disease?

- Genetics
- Family history
- Age

Dr. Heather Snyder
Alzheimer's Association
Populations at higher risk

- Hispanics are about 1.5 times as likely as whites to develop Alzheimer’s and other dementias.
- African Americans are about twice as likely to develop the disease as whites.
- Almost two-thirds of Americans with Alzheimer’s are women.

Risk Factors Recap

- Age is the greatest known risk factor for Alzheimer’s. An individual’s risk for developing the disease increases at age 65.
- Family history is also a known risk factor — having a parent or sibling with the disease increases an individual’s risk.
- Risk genes and deterministic genes are the two types of genes associated with Alzheimer’s.
- Hispanics, African Americans and women are at an increased risk for Alzheimer’s.
Stages of Alzheimer’s Disease
Early (Mild) Stage
- Functions independently, but has memory losses.
- Problems with concentration.
- Challenges performing tasks.
- Trouble remembering new information.

Middle (Moderate) Stage
- Confusion with words.
- Personality and behavioral changes.
- Forgetfulness of events or personal history.
- Changes in sleep patterns.

Late (Severe) Stage
- Requires round-the-clock assistance.
- Unable to respond to environment or hold a conversation.
- Changes in physical abilities.
- Unaware of recent experiences.

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Stages of Alzheimer’s Disease Recap

- The three stages of Alzheimer’s disease — early, middle, and late — are sometimes referred to as mild, moderate, and severe in a medical context.
- No two individuals experience the symptoms and progression of Alzheimer’s disease in the same way.
- While symptoms worsen over time, people progress through stages at different rates as their abilities change.
There are several drugs available to slow down the progression of Alzheimer's disease.

True  False
FDA-Approved Treatments for Symptoms

Cholinesterase inhibitors: Aricept (donepezil), Exelon (rivastigmine), Razadyne (galantamine)
Glutamate modulators: Namenda (memantine)
Combination of cholinesterase inhibitors and glutamate modulators: Namzaric (memantine + donepezil)

FDA-Approved Treatments Recap

- Three types of drugs are approved by the FDA to help manage Alzheimer’s symptoms.
  - Cholinesterase inhibitors: Aricept (donepezil), Exelon (rivastigmine), Razadyne (galantamine)
  - Glutamate modulators: Namenda (memantine)
  - Combination of cholinesterase inhibitors and glutamate modulators: Namzaric (memantine + donepezil)
- These treatments only address some symptoms of Alzheimer’s in some people; they do not treat the underlying cause of the disease.
Alzheimer’s Association

About the Alzheimer’s Association

Our mission:
The Alzheimer’s Association is the leading voluntary health organization in Alzheimer’s care, support and research. Our mission is to eliminate Alzheimer’s disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer’s disease®.

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Alzheimer’s Association Key Resources

We’re available wherever and whenever you need reliable information and support

- On the phone – 24/7 Helpline, 800.272.3900
- Online – alz.org
- In communities nationwide – alz.org/CRF
Alzheimer’s Association Resources

- Call the 24/7 Helpline (800.272.3900). Care specialists and master’s-level clinicians provide reliable information and support all day, every day.
- Visit alz.org®, a robust repository of up-to-date dementia-related information and resources.
- Join ALZConnected® (alzconnected.org), our free online community, to connect with other caregivers or people living with dementia.
- Explore Alzheimer’s Association & AARP Community Resource Finder (alz.org/CRF) to locate dementia resources, programs and services in your area, including your local Association office.
- Assess your needs and create customized action plans with Alzheimer’s Navigator® (alzheimersnavigator.org).
- Check out alz.org/research to learn more about Alzheimer’s and other dementias and the Association’s involvement in advancing the field of research.
- Go to alz.org/publications to access our catalog of brochures and topic sheets covering a variety of dementia-related topics.

For people living with dementia:

- Visit alz.org/IHaveAlz to start learning and planning in order to live your best life today.
- Access LiveWell Online Resources (alz.org/livewell) for free interactive tools and personalized steps for living well with the disease.
- Take our free Living with Alzheimer’s: For People with Alzheimer’s workshop online at alz.org/education or through your local Alzheimer’s Association office (alz.org/CRF).

For caregivers:

- Find support and information for all stages of the disease at alz.org/care.
- Visit the alz.org/safety for a comprehensive offering of safety information, tips and resources.
- Take our free Living with Alzheimer’s: For Caregivers workshop series online at alz.org/education or through your local Alzheimer’s Association office (alz.org/CRF).

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