# ALZHEIMER'S R ASSOCIATION

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# Your requested information

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# **Understanding Alzheimer's And Dementia**

# The Impact Of Alzheimer's And Dementia

Currently, over 55 million people worldwide are living with Alzheimer's or another dementia, including nearly 7 million Americans. Without changes in prevention or treatment, it is estimated there will be nearly 140 million people living with Alzheimer's disease worldwide by 2050, including nearly 13 million Americans.

The disease also affects the more than 11 million Americans who provide unpaid care for people living with Alzheimer's or another dementia.

The Alzheimer's Association<sup>®</sup> is available across the country and online to help people understand Alzheimer's and dementia, and receive information and support they can trust.

# **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 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.

- Lewy body dementia (LBD) 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 to learn about other types of dementia.

# Alzheimer's In The Brain

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.

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.

Visit alz.org/brain to explore Inside the Brain: A Tour of How the Mind Works.

# **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-three percent of people age 85 or older have Alzheimer's.

#### **Family history**

Researchers have learned that people who have a parent or sibling with Alzheimer's are more likely to develop it than those who do not. The risk is due to shared genetic, environmental and lifestyle factors, and increases if more than one family member has the disease.

#### Genetics

Two types of genes may 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.

#### Ethnicity, race and sex

Research shows that Hispanic and Black older adults are disproportionately more likely than White older adults to have Alzheimer's or another dementia.

No one knows the exact reason for these differences, but researchers believe the connection may be due to higher rates of cardiovascular disease in these groups — and likely other contributing factors, such as health and socioeconomic disparities. Scientists need to learn more about other potential causes behind this increased risk. To do so, it is critically important to increase the participation of individuals from underrepresented communities in clinical research.

Also, women live longer than men, making them more likely to develop Alzheimer's. However, longevity doesn't completely explain this difference. Researchers are exploring how biological, social and cultural differences in women 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 there are lifestyle habits that may help keep your brain healthy and lower your risk of cognitive decline.

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 high blood pressure, diabetes, stroke and obesity. Therefore, eating a balanced, heart-healthy diet and getting regular exercise may benefit both your heart and your brain.

Other healthy lifestyle habits that may also be good for your brain include avoiding tobacco and excess alcohol, regularly getting a good night's sleep, and staying socially and mentally active.

Science also shows a strong connection between serious head injury and future risk of cognitive decline. For this reason, it's important to protect your head by buckling your seat belt and taking home safety measures to help prevent falls.

# **Stages Of Alzheimer's Disease**

Alzheimer's disease progresses in stages with a range of symptoms that increase in severity over time.

Because the disease affects people in different ways, the rate of progression will vary. 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.

# Asymptomatic

On the earliest end of the continuum are people who are asymptomatic (i.e., without symptoms). This means that they may have the biological changes of the disease in their brain but do not show any cognitive symptoms. Researchers are working hard to develop tools that could diagnose Alzheimer's disease in people before they have noticeable symptoms.

# Mild cognitive impairment (MCI) due to Alzheimer's disease

Mild cognitive impairment (MCI) is an early stage of memory loss or other loss of cognitive ability in individuals who can still independently perform most activities of daily living. MCI can develop for multiple reasons, and some individuals living with MCI may go on to develop dementia while others will not. MCI can be an early stage of Alzheimer's disease if hallmark changes in the brain, such as beta-amyloid buildup, are present. Symptoms of MCI can include:

- Forgetting important information such as appointments, conversations or recent events.
- Difficulty with making sound decisions, judging the time or recalling a sequence of steps needed to complete a complex task.

#### Mild dementia due to Alzheimer's disease

Those with MCI due to Alzheimer's typically progress to the next stage of the disease called mild dementia due to Alzheimer's disease (sometimes referred to as early stage,

although it is important to note that MCI and mild dementia due to Alzheimer's disease are both early stages).

A person in the early stage will typically start to experience symptoms that interfere with some daily activities, such as:

- 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.

# Moderate dementia due to Alzheimer's disease

Moderate dementia (sometimes referred to as the middle stage) is typically the longest stage and can last for many years. Significant personal details may still be recalled, but as biological changes of the disease progress, symptoms such as gaps in memory and thinking are more noticeable, and assistance with daily tasks is required. Challenges can 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.
- Trouble controlling bladder and bowels.
- Needing help to choose the right clothes for the weather or occasion.
- Changes in sleep patterns, such as sleeping during the day and restlessness at night.
- A higher risk of wandering and becoming lost.
- Personality and behavioral changes, such as becoming suspicious or delusional, believing that others are lying, or repeating a behavior over and over.

# Severe dementia due to Alzheimer's disease

In the severe dementia stage (sometimes referred to as the late stage), symptoms will interfere with most daily activities as biological brain changes continue to progress. The person will need a lot of help with personal care. In this 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.

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# **FDA-Approved Treatments**

Progress in Alzheimer's and dementia research is creating promising new treatments for people living with the disease. It is important to talk with a doctor to learn as much as possible about which drugs are available and whether they may be appropriate.

The U.S. Food and Drug Administration (FDA) has approved medications for Alzheimer's. These fall into two categories:

- Drugs that temporarily ease some symptoms of Alzheimer's disease.
- Drugs that change disease progression in people living with Alzheimer's.

For more information on FDA-approved treatments for Alzheimer's disease, visit **alz.org/medications**.

# Talk with your doctor

When considering any treatment, it is important to have a conversation with a health care professional to determine whether it is appropriate, and weigh potential benefits and risks. A doctor who is experienced in using these medications should monitor people who are taking them and provide information that can help people make informed decisions about their usage and care.

To prevent drug interactions and unwanted side effects, make sure the doctor, pharmacist and care team are aware of all current medications, including over-the-counter and alternative remedies. Visit **alz.org/doctor** for guidance on questions to ask.

# Importance of early diagnosis

It is important to seek a diagnosis as early as possible. The earlier a diagnosis is made, the more treatment options may be available. Some medications are only available to people in the early stages of the disease, including those with MCI and mild dementia due to Alzheimer's disease.

# Advancing Alzheimer's Research

Research shows that Alzheimer's starts many years before people living with the disease notice symptoms. With this knowledge, researchers are working to identify people who are most at risk before symptoms appear, and driving the effort to develop treatments to slow, stop or prevent the disease.

As the world's largest nonprofit funder of dementia research, the Alzheimer's Association has played a vital role in every significant development in Alzheimer's science, and paves the way for future progress.

#### **Clinical studies drive progress**

Taking part in a clinical study is one way that anyone can help fight Alzheimer's disease. Without volunteers for research, scientists cannot find ways to prevent, treat and, ultimately, cure the disease. Researchers are seeking people of all racial and ethnic backgrounds to participate in clinical trials to ensure diagnostics and treatments are safe and effective for everyone.

Some clinical studies involve drugs and physical tests, while others involve observation and questionnaires. Every clinical study gives us important knowledge, whether or not the study was successful.

For people living with dementia, there are other benefits to taking part in clinical studies, including access to expert medical care and promising treatments.

Visit **alz.org/trialmatch** to learn more about Alzheimer's Association TrialMatch<sup>®</sup>, a free service that provides customized lists of clinical studies based on user-provided information. The easy-to-use platform allows people living with dementia, caregivers and healthy volunteers to find studies and actively fight against the disease. Search for studies, sign up for study updates, or connect with researcher teams with the click of a button.

# Resources

- **alz.org**: Access reliable information and resources, such as:
  - ALZNavigator<sup>™</sup> Assess your needs and create a custom action plan
  - Community Resource Finder Find resources, including your local Association chapter.
  - ALZConnected® Connect with other caregivers or people with dementia.
  - Online Caregiver Resources Get information for all stages of the disease.
- **alz.org/education**: Benefit from free online programs, including: *Understanding Alzheimer's & Dementia*
- **800.272.3900**: Contact the 24/7 Helpline Available all day, every day.

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# Living With Alzheimer's Disease

# Alzheimer's Disease And You

Alzheimer's is the most common form of dementia, which leads to changes in memory, thinking and behavior.

If you have been diagnosed with Alzheimer's or another dementia, you are not alone. Today, more than 55 million people worldwide are living with dementia, including nearly 7 million Americans living with Alzheimer's.

Learning as much as you can is the first step toward taking control of your life. In the early stage of the disease, you can live well by empowering yourself with the right information and resources.

We encourage you to take your time and learn at your own pace, as some information may be difficult to deal with.

# **Feelings After A Diagnosis**

It's normal to experience a range of emotions after receiving a diagnosis of Alzheimer's or another dementia. Understanding your emotions will help you move forward and discover ways to live well. Common feelings include:

- **Anger.** Your life is taking a different direction than you planned and you cannot control the course of the disease.
- **Relief.** Your diagnosis validated the concerns you had about the changes you were experiencing and provided an explanation.
- **Depression.** Feeling depressed or anxious is common. If feelings of sadness persist, it may be time to seek the help of your doctor, as depression can be treated.
- Fear. You may be fearful of the future and how your family will be affected.
- **Isolation.** It might feel as if no one understands what you're going through or you may lose interest in maintaining relationships with others.
- Sense of loss. It may be difficult to accept changes in your abilities.

# Is it sadness or depression?

Visit **alz.org/takecare** to learn the warning signs of depression. Talk to your doctor if you or others are concerned about your emotional well-being.

# **Take Care Of Your Emotional Needs**

Although it can be difficult, taking care of your emotional needs can help you come to terms with your diagnosis and feelings. The following tips may be helpful:

- Write down your thoughts in a journal.
- Share your feelings openly and honestly with family members and friends.
- Surround yourself with support.
  - o Join ALZConnected<sup>®</sup> (alzconnected.org), our online community, to connect with other individuals living in the early stages of Alzheimer's.
  - o Join an early-stage support group, which can provide you with a safe and supportive peer environment. Call 800.272.3900 or visit alz.org/CRF to find a group in your area.
- Stay engaged by continuing to do activities you enjoy for as long as you're able, or consider trying new ones.
- Take time to feel sad, mourn and grieve.

# **Disease Progression**

Alzheimer's affects everyone differently. By learning what to expect as the disease progresses, you can reduce the fear of the unknown and develop a strategy to help you manage the challenges you may face.

Alzheimer's usually progresses slowly with the severity of symptoms increasing over time. There are five stages of the disease:

- Asymptomatic (no symptoms, but may have biological changes in the brain)
- Mild cognitive impairment (MCI) due to Alzheimer's
- Early stage (mild dementia due to Alzheimer's disease)
- Middle stage (moderate dementia due to Alzheimer's disease)
- Late stage (severe dementia due to Alzheimer's disease)

Because the disease affects people in different ways, the rate of progression will vary.

# Mild cognitive impairment (MCI) due to Alzheimer's disease

An early stage of the disease is MCI due to Alzheimer's disease. During this stage, you may notice changes in your memory, thinking and reasoning. You will still be able to perform most of your daily responsibilities and activities. Common symptoms of MCI due to Alzheimer's disease include:

- Forgetting important information such as appointments, conversations or recent events.
- Difficulty with making sound decisions, judging the time or recalling a sequence of steps needed to complete a complex task.

# Early stage (mild dementia due to Alzheimer's disease)

Those with MCI due to Alzheimer's typically progress to the next stage of the disease, often referred to as early-stage Alzheimer's. You will start to experience symptoms that interfere with some daily activities. While you will still be able to perform many daily routines, these tasks may become more difficult over time. Friends, family or co-workers may notice changes. Common difficulties in the early stage may include:

- Problems coming up with the right word or name for something.
- Trouble remembering people's names after being introduced.
- Difficulty with familiar tasks.
- Forgetting something that was just read.
- Getting lost in familiar places.
- Increased trouble with planning or organizing.

# Middle stage (moderate dementia due to Alzheimer's disease)

In the middle stage, symptoms are more noticeable and will interfere with many daily activities. This is typically the longest stage of the disease and can last for many years. Significant details about oneself and family may still be recalled, but gaps in memory and thinking are noticeable and assistance with daily tasks is required. Challenges can include:

- Forgetting events or one's own personal history.
- Feeling frustrated, angry or withdrawn, especially in socially or mentally challenging situations.
- Confusion about where you are or the day of the week.
- Trouble controlling bladder and bowels.
- Needing help to choose the right clothes for the weather or occasion.
- 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, such as becoming suspicious or delusional, believing that others are lying, or repeating a behavior over and over.

#### Late stage (severe dementia due to Alzheimer's disease)

In the late stage, symptoms are severe and will interfere with most daily activities. People in the late stage lose the ability to carry on a conversation, respond to the environment, and, eventually, control movement. Assistance or supervision is required to complete most daily personal care. People may be at higher risk of infections, especially pneumonia. Changes in physical abilities will also worsen, affecting the ability to walk, sit and eventually, swallow.

# **Treatments And Research**

The more you know about Alzheimer's medications, the better prepared you will be to discuss them with your physician and make informed choices about your treatment plan.

Although current medications cannot cure Alzheimer's, there are multiple U.S. Food and Drug Administration (FDA)-approved treatments that address the underlying biology of the disease. Other medications may help lessen symptoms, such as memory loss and confusion.

# FDA-approved drugs for Alzheimer's

The FDA has approved medications that fall into two categories: drugs that change disease progression in people living with early Alzheimer's disease, and drugs that may temporarily mitigate some symptoms of Alzheimer's dementia.

When considering any treatment, it is important to have a conversation with a health care professional to determine whether it is appropriate. A clinician who is experienced in using these types of medications should monitor people who are taking them and ensure that the recommended guidelines are strictly observed.

Be sure to discuss all medications with your doctor to understand why they were prescribed and how to take them. To prevent drug interactions and unwanted side effects, make sure your physician, pharmacist and care team are aware of any over-the-counter and alternative remedies you are taking.

#### Drugs that change disease progression

Drugs in this category slow disease progression. They slow the decline of memory and thinking, as well as function, in people living with Alzheimer's disease.

The treatment landscape is rapidly changing. For the most up-to-date information on FDA-approved treatments for Alzheimer's disease, visit **alz.org/medications**.

#### Amyloid-targeting approaches

Anti-amyloid treatments work by removing beta-amyloid, a protein that accumulates into plaques, from the brain. Each works differently and targets beta-amyloid at a different stage of plaque formation.

These treatments change the course of the disease in a meaningful way for people in the early stages, giving them more time to participate in daily life and live independently. Clinical trial participants who received anti-amyloid treatments experienced reduction in cognitive decline observed through measures of cognition and function.

Examples of cognition measures include:

- Memory.
- Orientation.

Examples of functional measures include:

- Conducting personal finances.
- Performing household chores such as cleaning.

Anti-amyloid treatments do have side effects. These treatments can cause serious allergic reactions. Side effects can also include amyloid-related imaging abnormalities (ARIA), infusion-related reactions, headaches and falls.

ARIA is a common side effect that does not usually cause symptoms but can be serious. It is typically a temporary swelling in areas of the brain that usually resolves over time. Some people may also have small spots of bleeding in or on the surface of the brain with the swelling, although most people with swelling in areas of the brain do not have symptoms. Some may have symptoms of ARIA such as headache, dizziness, nausea, confusion and vision changes.

Some people have a genetic risk factor (ApoE  $\epsilon$ 4 gene carriers) that may cause an increased risk for ARIA. The FDA encourages that testing for ApoE  $\epsilon$ 4 status should be performed prior to initiation of treatment to inform the risk of developing ARIA. Prior to testing, doctors should discuss with patients the risk of ARIA and the implications of genetic testing results.

Learn more about ARIA at https://training.alz.org/products/1018/living-with-alzheimers-for-people-with-alzheimers

These are not all the possible side effects, and individuals should talk with their doctors to develop a treatment plan that is right for them, including weighing the benefits and risks of all approved therapies.

#### Donanemab (Kisunla™)

Donanemab (Kisunla) is an anti-amyloid antibody intravenous (IV) infusion therapy delivered every four weeks. It has received traditional approval from the FDA to treat early Alzheimer's disease, including people living with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease who have confirmation of elevated beta-amyloid in the brain. There is no safety or effectiveness data on initiating treatment at earlier or later stages of the disease than were studied.

Donanemab was the third therapy to demonstrate that removing beta-amyloid from the brain reduces cognitive and functional decline in people living with early Alzheimer's.

Visit alz.org/donanemab for more information.

#### Lecanemab (Leqembi<sup>®</sup>)

Lecanemab (Leqembi) is an anti-amyloid antibody intravenous (IV) infusion therapy that is delivered every two weeks. It has received traditional approval from the FDA to treat early Alzheimer's disease, including people living with mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease who have confirmation of elevated beta-amyloid in the brain. There is no safety or effectiveness data on initiating treatment at earlier or later stages of the disease than were studied.

Lecanemab was the second therapy to demonstrate that removing beta-amyloid from the brain reduces cognitive and functional decline in people living with early Alzheimer's.

Visit **alz.org/lecanemab** for more information.

Name (Generic/Brand)	Indicated for	Common side effects
Donanemab	Alzheimer's disease	ARIA, headache

#### Changes disease progression

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Kisunla™	(MCI or mild dementia)	
Lecanemab Leqembi <sup>®</sup>	Alzheimer's disease (MCI or mild dementia)	ARIA, infusion-related reactions

# Drugs That Treat Symptoms Cognitive symptoms (memory and thinking)

As Alzheimer's progresses, brain cells die and connections among cells are lost, causing cognitive symptoms to worsen. While these medications do not stop the damage Alzheimer's causes to brain cells, they may help lessen or stabilize symptoms for a limited time by affecting certain chemicals involved in carrying messages among and between the brain's nerve cells.

The following medications are prescribed to treat symptoms related to memory and thinking.

Name	Indicated for	Common side effects
(Generic/Brand)		
Donepezil	Mild to severe	Nausea, vomiting, loss of appetite,
Aricept®	dementia due to	muscle cramps and increased
	Alzheimer's	frequency of bowel movements.
Galantamine	Mild to moderate	Nausea, vomiting, loss of appetite and
Razadyne®	dementia due to	increased frequency of bowel
	Alzheimer's	movements.
Memantine +	Moderate to severe	Nausea, vomiting, loss of appetite,
Donepezil	dementia due to	increased frequency of bowel
Namzaric®	Alzheimer's	movements, headache, constipation,
		confusion and dizziness.
Memantine	Moderate to severe	Headache, constipation, confusion
Namenda®	dementia due to	and dizziness.
	Alzheimer's	
Rivastigmine	Mild to moderate	Nausea, vomiting, loss of appetite and
Exelon®	dementia due to	increased frequency of bowel
	Alzheimer's or	movements.
	Parkinson's	

# Treats cognitive symptoms (memory and thinking)

Donepezil, galantamine and rivastigmine are cholinesterase inhibitors, which treat symptoms related to memory, thinking, language, judgment and other thought processes. Memantine regulates the activity of a different chemical messenger in the brain that is also important for learning and memory. These two types of drugs work in different ways to help manage symptoms. The third drug on the chart combines donepezil (a cholinesterase inhibitor) with memantine (a glutamate regulator).

These four types of drugs work in different ways to help manage symptoms. The effectiveness of the types of treatments varies from person to person. While they may temporarily help symptoms, they do not slow or stop brain changes that cause Alzheimer's to become more severe over time.

# Drugs that treat non-cognitive symptoms (behavioral and psychological symptoms)

Name (Generic/Brand)	Indicated for	Common side effects
Brexpiprazole Rexulti <sup>®</sup>	Agitation associated with dementia due to Alzheimer's disease	Weight gain, sleepiness, dizziness, common cold symptoms, and restlessness or feeling like you need to move. Warning for serious side effects: increased risk of death in older adults with dementia-related psychosis. Rexulti is not approved for the treatment of people with dementia-related psychosis without agitation that may happen with dementia due to Alzheimer's disease.

# Treats non-cognitive symptoms (behavioral and psychological)

Suvorexant Belsomra®	Insomnia, has been shown to be effective in people living with mild to moderate Alzheimer's disease	Impaired alertness and motor coordination, worsening of depression or suicidal thinking, complex sleep behaviors, sleep paralysis, compromised respiratory function.
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Alzheimer's affects more than just memory and thinking. A person's quality of life may be impacted by a variety of behavioral and psychological symptoms that accompany dementia, such as sleep changes. Suvorexant can be prescribed to treat insomnia for individuals living with mild-to-moderate Alzheimer's.

To learn more about these drugs, including the different types available, who is eligible and potential side effects, visit **alz.org/medications** 

# **Clinical studies**

As a person living with Alzheimer's, you have an opportunity to participate in clinical research. Some participants receive cutting-edge treatments and expert medical care. All participants provide valuable insight to help investigators accelerate research progress. It is important that people of all racial and ethnic backgrounds participate in clinical research so that any treatments discovered work for all populations.

Visit **alz.org/TrialMatch** to learn more about clinical studies and Alzheimer's Association TrialMatch<sup>®</sup>, a free, easy-to-use clinical studies matching service.

# **Sharing Your Diagnosis**

As the disease progresses, you will need the support of those who know and understand you in order to cope with the challenges ahead. Some relationships may be tested when you reveal your diagnosis, but others may be strengthened.

It's normal to experience fear or discomfort. However, talking openly with those you trust is a powerful way to engage their support and educate them about the disease.

Some individuals choose to share their diagnosis with only their closest family and friends, while others are comfortable sharing it with a broader group of people. Assess your personal comfort level to determine your approach.

Negative reactions based on stigma or misconceptions about Alzheimer's may reflect a person's need for more time or education before he or she can respond to you in helpful ways. Allow your family and friends time to digest your news so everyone can move forward positively.

#### Disclosing your diagnosis: Advice from people living with Alzheimer's

- You don't need to talk about everything in one sitting. If a person's reaction is difficult for you, consider continuing the conversation at a later time.
- It's important to keep the lines of communication open as the disease progresses. Your thoughts and feelings, as well as other people's, may change.
- Remind people that you're still the same person. Even though you're now living with an Alzheimer's diagnosis, what has made you close to each other continues unchanged.

Visit alz.org/IHaveAlz for more tips.

# **Changes In Relationships**

After sharing your diagnosis, some people you were once close with may pull away. It can be hurtful to realize that certain family and friends you thought would be there for you can't meet your expectations. They may have discomfort about your diagnosis, since it may stir up fears about their own future. People who can't be a part of your support circle now may join later once they have time to adjust.

# **Role changes**

Your roles and responsibilities will change as the disease progresses. Some of these changes — and how you may feel about them — include:

- Loss of independence. Some of your primary responsibilities may be passed on to someone else.
- Less involvement. Family members may have conversations or make plans for the future without your presence or feedback.
- **Concern.** You may worry about burdening others with caregiving roles or responsibilities you once managed.

# Asking for help

It can be difficult, but adapting to changes and accepting help from others may help you remain independent longer. Be specific when asking for help. You will benefit from their support and they may gain fulfillment from helping you.

#### Keep your relationships positive and productive

- Be open about your feelings and experience living with the disease.
- Learn how to ask for help. Tell others what type of support you need and how they can assist.
- Re-evaluate your relationships. Don't dwell on people unable to support you or who don't provide a positive presence in your life. Give them time to adjust to your diagnosis and try not to take their behavior personally.

# **Plans For Your Future**

Putting legal, financial and safety plans in place after receiving your Alzheimer's diagnosis is extremely important. It may be difficult to look ahead to the future, but it's critical to keep sight of planning and conversations that should take place while you're in the early stages of the disease and can fully participate. Having future plans in place can also provide comfort and confidence to you and your family.

# Legal plans

Making legal plans will help ensure your wishes are met in regard to future health and end-of-life care. Although it can be emotional, you may find comfort in knowing that your expressed wishes will be followed and your family members will not be tasked with making difficult decisions when you no longer can.

Legal planning should include:

- Taking inventory of existing legal documents, reviewing them and making the necessary updates.
- Putting plans in place for future health care and long-term care.
- Establishing advance directives legal documents (e.g., durable power of attorney for health care and living will) that allow you to record your preferences regarding treatment and care, including your end-of-life wishes.

# **Preparing Important Documents**

Many documents, including advance directives, can be prepared without the help of an attorney. However, if you are unsure about how to complete legal or financial documents, you may want to seek assistance from an attorney specializing in elder law and/or a financial advisor who is familiar with elder or long-term care planning.

Visit alz.org/IHaveAlz to learn more.

# **Financial plans**

Financial planning often gets pushed aside because of the stress and fear the topic

evokes. However, you can reduce this stress by planning ahead. To make a financial plan, you should:

- Organize your documents to take inventory of your assets and debts.
- Identify family members who should be included.
- Research potential care costs. Get started at alz.org/carecosts.
- See if you are eligible for government benefits that can help with prescription costs, transportation and meals.
- Review long-term care insurance to see how it can help with covering costs of future care.
- If you have served in the armed forces, consider any benefits for veterans.

# Learn more about legal and financial planning

- Call our 24/7 Helpline: 800.272.3900
- Visit **alz.org/IHaveAlz** for helpful information, tips and resources.
- Take our free program, *Managing Money*, online at **alz.org/education**.
- Visit **alz.org/publications** to download our *Money Matters* and *Legal Plans* topic sheets or call **800.272.3900** to request information.

# Safety plans

In the early stages of the disease, you can still lead an independent life. However, there are some preparations you should make to help you remain independent as long as possible and ensure your safety as the disease progresses.

Addressing potential safety issues now can allow you to work with your family to prepare for difficult decisions later, including when to stop driving and when to consider services to help prevent wandering.

Visit **alz.org/safety** to learn more.

# Live Your Best Life

You can live well with Alzheimer's, particularly in the early stages of the disease. Consider these tips to help you live your best life:

# • Take care of your body.

Try to eat well and stay active. Visit your doctor regularly and rest when you are tired.

• Engage in mentally stimulating activities.

Learning new information, taking a class or challenging yourself to try a new hobby or activity may help increase your brain activity.

- **Connect with your feelings.** Talking with friends or a counselor about your diagnosis can help you cope with difficult emotions.
- Stay social. Meet others living with Alzheimer's through ALZConnected (alzconnected.org) or a local support group (alz.org/CRF).

• Explore your spiritual side. Focus on the pursuits that bring meaning to your life and help you experience peace.

# **Daily living**

Things you once did easily will become increasingly difficult, such as maintaining a schedule or managing money. Accepting changes in your abilities and adopting coping skills can help restore balance to your daily life and reduce stress as you continue to live with the disease.

Tips for developing your own coping strategies:

- **Identify:** Make a list of tasks that have become more challenging. Focus on the activities that are most important in your daily life.
- **Prioritize:** Determine if the task is necessary. If so, consider asking for help.
- Strategize: Develop a daily routine and approach one task at a time.

What works well for one person may not work for another, and coping strategies that work one day may not work the next. Try to find which strategies work best for you in various situations.

Developing effective coping strategies can help you:

- Remain engaged and active.
- Respond to challenges that will maximize your independence and well-being.
- Gain a sense of control over your life.

To view a list of coping strategies developed by people living with the disease, visit **alz.org/dailylivingtips**.

Tools to help you live well

Live Well Online Resources is a collection of free interactive tools that helps users navigate the personal and emotional challenges accompanying an Alzheimer's diagnosis and provides personalized steps for living well with the disease. Visit **alz.org/livewell** to learn more.

#### **Reduce stress**

Living with Alzheimer's or another dementia can be overwhelming at times, which can affect your health and ability to function. Taking steps to reduce stress can help improve your concentration, decision-making ability and overall quality of life. To help reduce stress:

- Identify sources of stress in your life. Remove yourself from these situations whenever possible.
- Establish boundaries and let others know your limits.
  What are you willing and unwilling to tolerate? Be as open as possible about this with others.
- Change your environment.

If you're in an environment that has too much stimulation and is causing you stress, take a break and find a quiet place to relax and regroup.

• Let it go. If something becomes too difficult for you, consider whether you need to complete it now or if you can return to it later.

# Get Involved

Some individuals living with Alzheimer's have found that by getting involved and raising awareness about the disease, they can strengthen their sense of purpose and connection to others.

You have a unique opportunity to contribute to the Alzheimer's cause by turning your experience into inspiration. The Alzheimer's Association offers ways to join the fight by raising awareness and funds.

# Advocate

As an individual living with Alzheimer's disease, you can add your voice to the thousands of others advocating for government action. By speaking out on the issues you face every day, you can help to shape local, state and federal laws. Visit **alz.org/advocacy** to learn more.

# Become a leader

The Alzheimer's Association National Early-Stage Advisory Group offers a unique

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opportunity for some individuals living in the early stages of Alzheimer's to elevate their voices on a national platform.

Early-Stage Advisors work with the Association to raise awareness about early-stage issues, advocate with legislators to increase funding for research and support programs, and provide input on the most appropriate services for people living with early-stage Alzheimer's.

By educating the public about the impact of Alzheimer's disease, advisors also help to reduce the stigma surrounding dementia. Learn more at **alz.org/earlystage**.

# Raise awareness and needed funds

Your involvement in national fundraising efforts helps us work toward our vision of a world without Alzheimer's and all other dementia. By participating, you are helping the Association to raise awareness and funds for care, support and research efforts.

- Participate in our signature fundraising events: Walk to End Alzheimer's<sup>®</sup> (alz.org/walk), The Longest Day<sup>®</sup> (alz.org/thelongestday), and Ride to End ALZ<sup>®</sup> (alz.org/ride).
- Volunteer at a local event (alz.org/CRF).
- Make a donation (alz.org/donate).

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