

## LIVING WITH ALZHEIMER'S DISEASE WHAT YOU NEED TO KNOW

### 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 more than 6 million Americans.

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 a positive and fulfilling life. 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.

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## SADNESS OR DEPRESSION?

Visit [alz.org/takecare](https://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.
  - Join ALZConnected® ([alzconnected.org](https://alzconnected.org)), our online community, to connect with other individuals living in the early stages of Alzheimer's.
  - 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](https://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, two U.S. Food and Drug Administration (FDA)-approved treatments address the underlying biology. 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.

### Changes disease progression

Name (Generic/Brand)	Approved for	Side effects
Aducanumab Aduhelm™	Alzheimer's disease (MCI or mild dementia)	ARIA, headache and falls
Lecanemab Leqembi™	Alzheimer's disease (MCI or mild dementia)	ARIA, infusion-related reactions

#### Aducanumab (Aduhelm™)

Aducanumab (Aduhelm™) is an anti-amyloid antibody intravenous (IV) infusion therapy approved for Alzheimer's disease. Aducanumab works by targeting beta-amyloid, a protein that forms in the brain and makes plaques.

- This drug is approved for people with early Alzheimer's disease: mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease.
- Doctors should confirm the presence of elevated beta-amyloid in the brain prior to starting treatment.
- The most common side effects are amyloid-related imaging abnormalities (ARIA), headache and fall. ARIA does not usually cause symptoms but can be serious. It is typically a temporary swelling of the brain or small areas of bleeding in the brain. It usually resolves over time.

To learn more about aducanumab, visit [alz.org/aducanumab](https://alz.org/aducanumab)

#### Lecanemab (Leqembi™)

Lecanemab (Leqembi™) is an anti-amyloid antibody intravenous (IV) infusion therapy approved for Alzheimer's with confirmation of elevated beta-amyloid. Lecanemab works by targeting beta-amyloid, a protein that forms in the brain and makes plaques. Although lecanemab also targets beta-amyloid, it works in a different way than aducanumab.

- This drug is approved for people with early Alzheimer's disease: mild cognitive impairment (MCI) or mild dementia due to Alzheimer's disease.

- Doctors should confirm the presence of elevated beta-amyloid in the brain prior to starting treatment.
- The most common reported side effects were infusion-related reactions, headache, and amyloid-related imaging abnormalities (ARIA).
- ARIA does not usually cause symptoms but can be serious. It is typically a temporary swelling of the brain or small areas of bleeding in the brain. It usually resolves over time.

To learn more about lecanemab, visit [alz.org/lecanemab](https://alz.org/lecanemab)

## **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.

#### **Treats cognitive symptoms (memory and thinking)**

<b>Name (Generic/Brand)</b>	<b>Approved for</b>	<b>Side effects</b>
Donepezil Aricept®	Mild to severe dementia due to Alzheimer's	Nausea, vomiting, loss of appetite, muscle cramps and increased frequency of bowel movements.
Galantamine Razadyne®	Mild to moderate dementia due to Alzheimer's	Nausea, vomiting, loss of appetite and increased frequency of bowel movements.
Rivastigmine Exelon®	Mild to moderate dementia due to Alzheimer's or Parkinson's	Nausea, vomiting, loss of appetite and increased frequency of bowel movements.

Memantine Namenda®	Moderate to severe dementia due to Alzheimer's	Headache, constipation, confusion and dizziness.
Memantine + Donepezil Namzaric®	Moderate to severe dementia due to Alzheimer's	Nausea, vomiting, loss of appetite, increased frequency of bowel movements, headache, constipation, confusion and dizziness.

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 fifth 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)**

**Treats non-cognitive symptoms (behavioral and psychological)**

Name (Generic/Brand)	Approved for	Side effects
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](https://www.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](https://www.alz.org/TrialMatch) to learn more about clinical studies and Alzheimer's Association TrialMatch®, 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.



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- 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](https://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.

## PLAN 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](https://www.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](https://www.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](https://alz.org/IHaveAlz) for helpful information, tips and resources.
- Take our free program, *Managing Money*, online at [alz.org/education](https://alz.org/education).
- Visit [alz.org/publications](https://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](https://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.**

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Meet others living with Alzheimer's through **ALZConnected** ([alzconnected.org](http://alzconnected.org)) or a local support group ([alz.org/CRF](http://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](http://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](http://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](https://www.alz.org/advocacy) to learn more.

#### **Become a leader**

The Alzheimer's Association National Early-Stage Advisory Group offers a unique opportunity for some individuals living in the early stages of Alzheimer's to elevate their voices on a national platform.

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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/earllystage](https://alz.org/earllystage).

### **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®** ([alz.org/walk](https://alz.org/walk)), **The Longest Day®** ([alz.org/thelongestday](https://alz.org/thelongestday)), and **Ride to End ALZ®** ([alz.org/ride](https://alz.org/ride)).
- Volunteer at a local event ([alz.org/CRF](https://alz.org/CRF)).
- Make a donation ([alz.org/donate](https://alz.org/donate)).

TS-0064 | Updated February 2023