

alzheimer's  association®

# younger-onset alzheimer's

I'm too young to have  
Alzheimer's disease



the compassion to care, the leadership to conquer®

## I'm too young to have Alzheimer's disease

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Alzheimer's is not just a disease of old age. Younger-onset (also known as early-onset) Alzheimer's disease affects people who are under age 65.

Many people with younger-onset are in their 40s and 50s. They have families, careers or are even caregivers themselves when Alzheimer's disease strikes.

Up to 5 percent of people with Alzheimer's have younger-onset. In the United States, that's about 200,000 people. It's important to know you are not alone.

### Genetic link

Most people with younger-onset have the common type of Alzheimer's, which is not directly linked to genes. Doctors do not know why symptoms appear at an unusually young age in these cases.

In a few hundred families worldwide, scientists have found three rare genes that directly cause Alzheimer's. People who inherit these genes tend to develop symptoms in their 30s, 40s and 50s.

### Living with younger-onset Alzheimer's

If you have younger-onset Alzheimer's, it's important to know that even after diagnosis, you can live a meaningful and productive life. You can remain active and take part in activities you enjoy. You can work with family and friends to plan for the future and educate others. Even though living with Alzheimer's is not what you had planned, you have the power to make a new plan with Alzheimer's in the picture.

### It's important to know that:

- › You are not alone.
- › There are many ways to stay active and involved.
- › The disease affects each person differently and symptoms will vary.
- › The Alzheimer's Association can help you and your family.

## Quick tips for living with younger-onset

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- 1** Expect to have good days and bad days.
- 2** Share your story — educate others and express yourself. Use your experience to enlighten others.
- 3** Discuss with a counselor any changes in relationships.
- 4** Talk openly with others about the changes the disease is causing.
- 5** Get involved. Volunteer in your community.
- 6** Get professional legal and financial help.
- 7** Maintain your health and reduce stress.
- 8** Take steps to ensure your safety inside and outside of the home.
- 9** Stay active and keep making memories.

### The Alzheimer's Association offers helpful ideas. Inside, you'll find ways to approach:

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# 1. possible reactions to diagnosis

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## After the diagnosis, you may experience a range of emotions:

- › **Relief.** It can be validating to know there is a cause for what you are experiencing.
- › **Anger.** Your life is taking a different course than the one you and your family had planned.
- › **Denial.** The diagnosis seems impossible to believe.
- › **Depression.** You may feel sad or hopeless about the life changes.
- › **Isolation.** No one seems to understand what you're going through.
- › **Sense of loss.** It's hard to accept changes in your abilities, or ways you interact with your community.

## What you can do:

- › Join an Alzheimer's Association support group. Some are specifically for people with younger-onset.
- › Visit ALZConnected® ([alzconnected.org](https://alzconnected.org)), an online social networking community powered by the Alzheimer's Association that allows you to connect with others living with dementia.
- › Explore new hobbies or interests.
- › Work with a well-qualified counselor.
- › Share your feelings with friends and family, and someone who can help with spiritual needs.
- › Get involved. Tell your story. Volunteer. Become an advocate.

## 2. family

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### Your spouse or partner

Many people with Alzheimer's continue to live at home after their diagnosis. If you do so, it is helpful to work with your family to prepare for household changes. In particular, your spouse or partner may feel a sense of loss or loneliness as a result of the diagnosis.

### What you can do to help your spouse or partner:

- ▶ Continue participating in as many activities as you can. Adapt them to fit what you're comfortable doing and enjoy.
- ▶ Find new activities that you can do together. Sometimes befriending another couple in the same situation offers new possibilities for support.
- ▶ Talk with your spouse or partner about how he or she can assist you — and what you can still do on your own.
- ▶ Work with your spouse or partner to put together a file with information you may need later about caregiver services and their costs, including housekeeping and respite (caregiver relief) care.
- ▶ Discuss with a professional counselor any role changes in the relationship as well as sexuality issues.
- ▶ Continue to find ways for you and your spouse or partner to fulfill the need for intimacy.
- ▶ Encourage your spouse or partner to attend a caregiver support group, connect with other caregivers online through ALZConnected and stay connected with family and friends.

## Your children

Children often experience a wide range of emotions. Younger children may be afraid that they will get the disease or that they did something to cause it. Teenagers may become resentful when they have to take on more responsibilities around the home. Or, they may feel embarrassed that their parent is “different.” College-bound children may be reluctant to leave home to attend school.

### What you can do to help your children:

- › Talk openly about the changes you are experiencing because of the disease.
- › Find out what their emotional needs are. Find ways to support them, like meeting with a counselor specializing in children who have a family member with Alzheimer’s.
- › Notify school social workers and teachers about your situation. Give them information about the disease.
- › Don’t pull away. Try to find activities you can still enjoy together. If you can’t drive, plan a hike or bike ride. Check out local public transportation.
- › Make it OK to laugh. Sometimes humor lightens the mood and makes coping easier.
- › Record your thoughts, feelings and wisdom in writing, audio or video. Your children will appreciate this when they grow older.
- › Direct them to [alz.org/kids](https://www.alz.org/kids) for helpful information and videos for kids and teens.

### Important life stages you might want to discuss with your children include:

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- › Graduation
- › Births
- › Marriage
- › Dating
- › Deaths

## 3. friends

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Friends, co-workers and neighbors may not understand what is happening to you. Some may keep their distance or resist keeping in touch. Often they may not know what to do or say. They may be waiting for you to reach out to them.

### **What you can do to help your friends:**

- › Share your experiences of living with Alzheimer's.
- › Invite them to Alzheimer's Association education programs and events.
- › Continue social activities as much as possible. Seek out local programs specifically for people with dementia.
- › Tell them what you're still comfortable doing.
- › Let them know when you need help and support — and what they can do.



## 4. planning for the future

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When you are in the early stage of Alzheimer's, it is important to take steps immediately to plan for the future.

### Finances

If your earnings are the family's main source of income, you may be concerned about financially supporting your family now and in the future. Insurance and other benefits may be more difficult to obtain. Future health care costs should be considered.

### Steps to plan for your financial future:

- › Meet with a qualified financial consultant or an attorney to discuss current and future investments, insurance and retirement options. See if long-term care insurance is still an option.
- › Find out about government assistance programs such as Social Security, Medicare and Medicaid.
- › If diagnosed while working, review your employer-provided or personal disability insurance policies.
- › Organize financial documents and other important information in one place. Go over them with your spouse or partner.





## Access to Social Security

The Social Security Administration (SSA) has added early-onset/younger-onset Alzheimer's to the list of conditions under its Compassionate Allowance Initiative, giving those with the disease expedited access to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

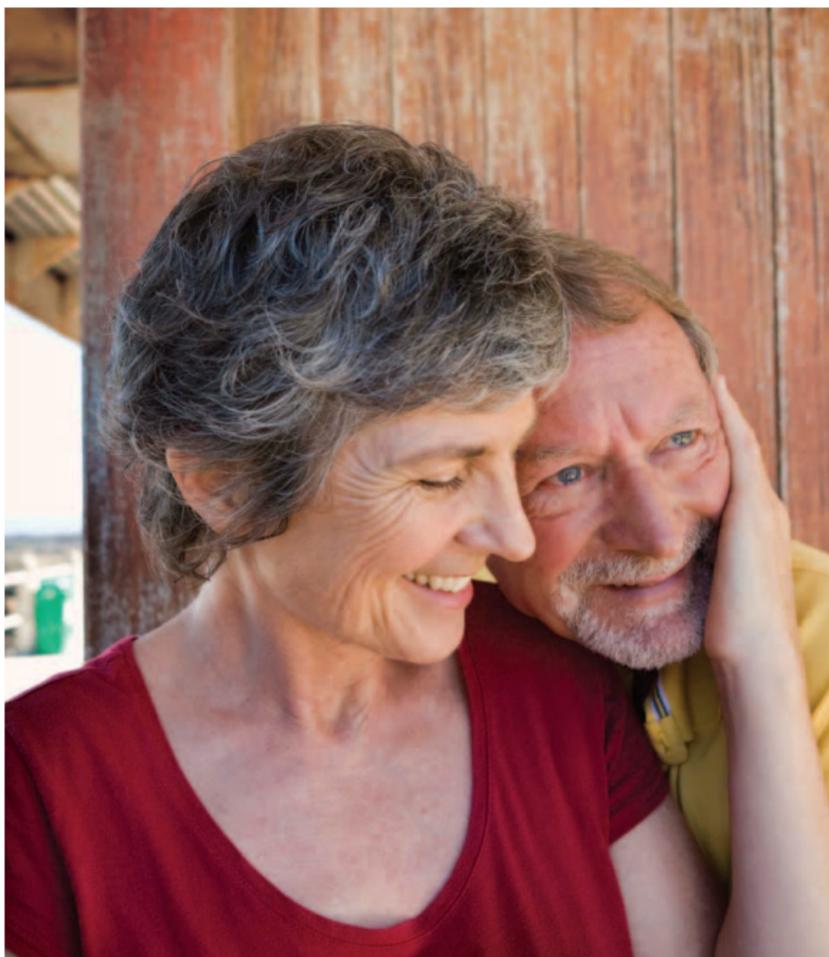
Use our helpful checklist to make sure you have the information and resources you need to apply for Social Security Disability and Supplemental Income benefits. Find the checklist and get more information at [alz.org/SSDI](https://alz.org/SSDI).

## Legal issues

- › Work with a well-qualified attorney to make legal plans.
- › Legally appoint a person you trust to make financial and health care decisions on your behalf when you cannot. Tell the person your wishes for the future, including where you want to live and what types of treatments you want or don't want.

## Care and family

- › Find adult day care programs and residential care settings that know how to assist people with younger-onset Alzheimer's.
- › Gather all of the thoughts, memories and family history you want to pass on. Work together on family projects to celebrate the past and present.



## 5. well-being and safety

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Two of the most important ways you can take good care of yourself are to stay healthy and safe.

### **What you can do about your health:**

- › Get regular check-ups.
- › Exercise regularly, with your doctor's approval.
- › Rest when you are tired.
- › Adopt a healthy diet.
- › Take any prescribed medications as directed.
- › Cut down on alcohol — it can worsen symptoms.
- › Ask for help when you need it.
- › Reduce stress in your daily life, and learn new ways to relax.
- › Stay socially engaged.

## Safety

Symptoms of Alzheimer's, like loss of memory and decision-making ability, can bring about new safety needs.

### What you can do about your safety:

- › Keep important phone numbers nearby.
- › Post reminders to lock doors and turn off electrical appliances.
- › Find other ways to get around when it is no longer safe for you to drive. Visit [alz.org/driving](https://www.alz.org/driving) to learn more about driving and dementia.
- › Visit the Alzheimer's Association online Safety Center at [alz.org/safety](https://www.alz.org/safety) for information tips and resources to assist you with safety inside and outside of the home, wandering and getting lost, and driving and dementia.





**alz.org**<sup>®</sup>

Get reliable information and easy access to tools, such as:

- › **Alzheimer's Navigator**<sup>™</sup> — assess your needs and create customized action plans.
- › **Community Resource Finder** — find local resources.
- › **ALZConnected**<sup>®</sup> — connect with others who are living with dementia and can relate.



**800.272.3900**

24/7 Helpline — available all day, every day.

**alzheimer's**  **association**<sup>®</sup>

The Alzheimer's Association is the world's 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<sup>®</sup>.**

**800.272.3900 | alz.org**<sup>®</sup>

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