

younger-onset alzheimer's

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 (or 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 several rare genes that directly cause Alzheimer's. People who inherit these rare 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.

Living with Alzheimer's was not what you had planned. But 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

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

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1. possible reactions to diagnosis

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

Relief

Many people have known there was a problem for a long time. 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 you are facing.

Isolation

No one seems to understand what you are going through.

Sense of loss

It's hard to accept changes in your abilities, or ways you interact with your community or job.

What you can do:

- Join an Alzheimer's Association support group. Some groups are just for people with younger-onset.
- Get involved. Tell your story. Volunteer. Become an advocate.
- Explore new hobbies or interests that are meaningful to you.
- Work with a well-qualified counselor.
- Share your feelings with friends and family, and someone who can help with spiritual needs.
- Visit the message boards and chat rooms on the Alzheimer's Association Web site at www.alz.org and other Alzheimer-related Web sites.★

★*While the Alzheimer's Association Web site at www.alz.org contains reliable information, please discuss the accuracy of any information you receive on the internet with your doctor.*

2. family

Your spouse or partner

Many people with Alzheimer's continue to live at home after their diagnosis and it is helpful to work with your family to prepare for changes in the household.

In particular, your spouse or partner may feel a sense of loss or loneliness as a result of the changes the diagnosis brings.

What you can do to help your spouse or partner:

- Continue to take part in all the activities that you can. Adapt activities to fit what you are comfortable with and enjoy doing.
- 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 support group for caregivers 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 for helping 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 who specializes in children who have a loved one with Alzheimer's.
- Notify school social workers and teachers about your situation. Give them information about the disease.
- Invite children to attend support group meetings. Include them in counseling sessions.
- Don't pull away. Try to find activities together you can still enjoy together. If you can't drive, plan a hike or bike ride. Check out public transportation in your area.
- Make it okay 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.

Important life stages you might want to discuss include:

- Graduation
- Dating
- Marriage
- Births
- Deaths

3. friends

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 disease.
- 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.
- Let your friends know what you are still comfortable doing.
- Let them know when you need help and support – and tell them what they can do.





4. job

You may find work-related tasks more difficult to perform as the disease advances. Talk to your doctor to plan when and what you'll tell your employer about the disease, and at what point you should no longer work. If available, use employee assistance programs offered at work.

The Alzheimer's Association has information about the disease that you can share with your employer. Visit www.alz.org or contact your local chapter.

What you can do about your job:

- Continue to work as long as you, your employer and your doctor feel you are able.
- If you feel overwhelmed at work, take time off. Talk to your doctor and employer about leave of absence options.
- If you are still able to work, ask your employer for work accommodations available to you under the Americans with Disabilities Act.
- Use a daily planning calendar, memos and other memory aids to help you organize the details of your job.
- Ask your employer if you can switch to a position that better matches your abilities and strengths – or consider reducing your work hours.
- Look into early retirement options.
- Educate yourself, as well as your spouse, partner or close friend or relative, about the benefits available to you and how to claim them.

5. planning for the future

When you are in the early stages of Alzheimer's, it's 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.
- 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.

Legal Documents include:

- Birth certificate
- Insurance policies
- Retirement accounts
- Social Security information
- Wills
- Research college scholarship and grant money for your children

Access to Social Security

The Social Security Administration (SSA) has added early-onset Alzheimer's (or younger-onset) 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 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.

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 to your loved ones. Work together on family projects to celebrate the past and present.



6. well-being & safety

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 according to directions
- Cut down on alcohol – it can make your symptoms worse
- 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
- Arrange for an in-home helper to assist you when your spouse, partner or caregiver needs to be away from home
- Arrange for other ways to get around when it is no longer safe for you to drive
- Enroll in MedicAlert[®] + Alzheimer's Association Safe Return[®] for services to assist you should you ever become lost
- Purchase the Alzheimer's Association Comfort Zone[™], a new Web-based GPS location management service that can help families achieve some peace of mind. Comfort Zone[™] uses the Internet and a small device to ensure that you and your family are always connected.

10 quick tips living with younger-onset

- 1 Expect to have good days and bad days.
- 2 Share your story—educate others and express yourself.
- 3 Discuss changes in relationships with a counselor.
- 4 Talk openly with loved ones and others about the changes the disease is causing.
- 5 Get involved. Volunteer in your community.
- 6 Talk to your employer about adapting your job hours or duties.
- 7 Get professional legal and financial help.
- 8 Maintain your health and reduce stress.
- 9 Take steps to make your home a safer place.
- 10 Stay active. Keep making memories with your loved ones. Use your experience to enlighten others.

alzheimer's  association®

The Alzheimer's Association is the leading voluntary health organization in Alzheimer 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.

For reliable information and support,
contact the Alzheimer's Association:

1.800.272.3900
alz.org

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