I have younger-onset Alzheimer’s disease

What you need to know to prepare and live well

Sandy O., living with younger-onset Alzheimer’s disease
About younger-onset Alzheimer’s

Younger-onset Alzheimer’s disease, also referred to as early-onset, is when symptoms of dementia occur before the age of 65. Those diagnosed can be in any stage of the disease — early, middle or late (may be referred to as mild, moderate or severe, respectively, in a medical context). Of the more than 200,000 individuals living with younger-onset Alzheimer’s in the United States, the majority have the form not directly attributed to genetics. However, in some instances, genetics do play a role. Doctors do not yet understand why most cases of younger-onset appear at such an early age.

“After receiving my diagnosis, I knew that my life was not going to continue as planned. However, I’ve chosen to live well by staying socially active and engaging with others living with the disease. I’m at peace with myself and enjoying life.”

- Sandy O., living with younger-onset Alzheimer’s disease
Barb C., living with younger-onset Alzheimer’s disease, and her daughter

The Alzheimer’s Association® offers information and guidance for living well with younger-onset Alzheimer’s.

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1. impact of younger-onset

A diagnosis of younger-onset Alzheimer’s disease is life changing. However, you can empower yourself by preparing for what’s ahead and focus on the things that bring you joy. While each family experiences the impact of the disease differently, common experiences include:

**Stigma**
The social stereotypes and prejudices surrounding Alzheimer’s are the result of myths and misperceptions caused, in part, by a lack of public awareness and understanding of the disease. Because of your age, people may question or dismiss your diagnosis. Some relationships may change, as friends might shy away, unsure of how to respond. Others may react by only communicating with your care partner or family members, which can minimize your ability to interact and be open about your experience.

Stigma can have a significant impact on your well-being and quality of life. It may cause you to withdraw from your relationships, and community and social obligations. But you don’t have to let it. Fight it instead.

- **Be open and direct.** Engage others in discussions about Alzheimer’s disease and the need for prevention, better treatment and an eventual cure.

- **Communicate the facts.** Share accurate information to help dispel misconceptions about the disease. Visit [alz.org](https://alz.org) or call 800.272.3900 for reliable information.

- **Seek support and stay connected.** It’s important to stay engaged in meaningful relationships and activities. Build a support network of family, friends and others living with the disease.

- **Don’t be discouraged.** Other people’s denial of the disease is not a reflection of you; it’s simply due to lack of understanding. If people think that Alzheimer’s disease is normal aging, help to educate them.
Changing parental role

Many people diagnosed with younger-onset are raising families. It’s normal to worry about the changes in your parental role both now and in the future. You may also have to help your children as they face their own challenges related to the disease.

Children may have questions about the disease progression that may cause fear and anxiety. Older kids and teens may have concerns about additional responsibilities or about the future. Visit alz.org/helpingkids to learn more about helping kids and teens.

Loss of income

It’s not uncommon for people with younger-onset to be terminated from one or multiple jobs. A change or loss of employment may have a significant impact on your family’s financial situation. It can be helpful to discuss with your family what financial changes may need to occur and start planning for the future while you can still participate in the decision making. If you need assistance, consider speaking with a financial advisor who can help you outline a plan to make your financial resources last as long as possible.
If you receive a diagnosis while still employed, it’s critical that you educate yourself about the benefits available through your employer. Benefits may include:

- **Disability insurance**
  Disability insurance provides income for an employee who can no longer work due to illness or injury.

- **Family and Medical Leave Act (FMLA)**
  You may be able to use benefits offered under the Federal Family and Medical Leave Act (FMLA), which allows you to take up to 12 weeks of unpaid leave each year for family and medical reasons with continuation of group health insurance coverage.

- **Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA)**
  COBRA is a federal law that allows individuals to continue their health care coverage for up to 18, 29 or 36 months after leaving a job.

Tips for seeking employee benefits:

- Review your employer’s benefits handbook.

- Ask what benefits may be available and about your eligibility. The employer may provide paid sick leave or other short-term disability benefits. Often, these must be taken prior to using long-term disability benefits.

- Keep written confirmation of all benefits.

### Social Security Disability

The Social Security Administration (SSA) has added younger-onset (early-onset) Alzheimer’s disease 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). Learn more at [alz.org/SSDI](http://alz.org/SSDI).
3. health insurance

If you were diagnosed after leaving your job, you may not have had the opportunity to take advantage of programs that continue your health insurance. Lack of coverage for you and your family and high out-of-pocket expenses for medical care can put a significant strain on your financial situation and your ability to receive the necessary medical care.

Affordable Care Act (ACA)
The Affordable Care Act creates a Health Insurance Marketplace in each state where Americans can more affordably purchase and receive subsidies, if you qualify, for health insurance. The ACA eliminates pre-existing conditions, meaning you cannot be charged more or denied health insurance coverage for health-related reasons. Every state has “navigators” who can help walk you through the process. To learn more, including how to sign up for a plan, visit healthcare.gov.

Medicare
Individuals with younger-onset Alzheimer’s disease are eligible for Medicare once they have been receiving Social Security disability benefits for at least 24 months. Medicare is a federal health insurance program generally for people age 65 or older who are receiving Social Security retirement benefits. Medicare covers inpatient hospital care, some doctor’s fees, some medical items and outpatient prescription drugs. The program also provides some home health care, including skilled nursing care and rehabilitation therapy, under certain conditions. It does not cover long-term nursing home care.

Retirement benefits
You may be able to tap into financial resources from retirement plans, even if you have not yet reached retirement age. Retirement plans include Individual Retirement Accounts (IRAs) and annuities.
4. take care of yourself

Living a healthy life with Alzheimer’s involves examining the influences that impact your experience with dementia. The health benefits associated with maintaining your physical, emotional, social and spiritual health may help improve your daily life. By educating yourself about the disease, developing effective coping strategies and planning for your future, you can create a solid foundation from which to cope with new challenges and changes.

These tips may help you maintain your overall health:

› Take care of your body. Get regular checkups. Establish a diet and exercise routine 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. Meet with friends or a counselor to explore how the diagnosis has affected you emotionally. Sharing your feelings with others who are also living with the disease may help you cope with difficult emotions and come to terms with your diagnosis.

› Stay social. Connect with others who are also living with younger-onset Alzheimer’s through ALZConnected® (alzconnected.org).

› Explore your spiritual side. Focus on the pursuits that bring meaning to your life and help you experience peace.
5. take action

Some individuals living with Alzheimer’s find that getting involved and raising awareness about the disease provides a sense of purpose. You have an opportunity to turn your experience into inspiration for others. Your voice and the actions you take, big or small, are powerful tools that can help to raise concern and awareness and encourage others to do the same.

Advocate

By speaking to others about the issues you face every day, you can help shape local, state and federal laws. Alzheimer’s advocates may sign petitions, write letters, make phone calls or meet with elected officials in support of the cause. To learn more about becoming an advocate, call 800.272.3900 or visit alz.org/advocate.

Advance Research

As a person living with Alzheimer’s disease, you can make a tremendous impact on future generations by volunteering to take part in clinical research. Without clinical studies, there can be no better treatments, no prevention and no cure.

To learn more or to find possible studies in your area, use Alzheimer’s Association TrialMatch® — a free, easy-to-use clinical studies matching service. Visit alz.org/TrialMatch or call 800.272.3900.
Become a leader
The Alzheimer’s Association offers an opportunity for individuals living with early-stage Alzheimer’s or other dementias to raise their voices on a national platform through the National Early-Stage Advisory Group (alz.org/earlystage).

Early-Stage Advisors help the Association:

› Raise awareness of early-stage issues by sharing their stories through national speaking engagements and media interviews.

› Advocate with legislators to increase funding for research and support programs.

› Educate the public about the impact of the disease and help reduce stigma.

› Provide input about programs designed to meet the growing needs of early-stage individuals.

Raise needed funds
Your participation in national fundraising efforts brings the work of the Alzheimer’s Association to life. However you choose to participate, you are helping the Association to fund care, support and research.

Here are some of the ways that those living with the disease participate in fundraising activities:

› Register as a participant or Team Captain for the Alzheimer’s Association Walk to End Alzheimer’s® at alz.org/Walk and The Longest Day® at alz.org/TheLongestDay.

› Volunteer at an Alzheimer’s Association event in your area. Call 800.272.3900 or visit alz.org/findus to learn more.

› Make a donation by calling 800.272.3900 or visiting alz.org/donate.
Learn more with our free workshop

Living with Alzheimer’s for Younger-Onset Alzheimer’s is a workshop offering answers to questions about younger-onset Alzheimer’s disease. Hear from those affected and learn what you need to know, what you need to plan for, and what you can do to ease the impact throughout the course of the disease. Participate in this free workshop online (alz.org/education) or live at a location near you (alz.org/findus; 800.272.3900).

You are not alone

Visit alz.org/IHaveAlz to start learning, planning and living well today.

Call our 24/7 Helpline: 800.272.3900. (TTY: 866.403.3073)

Locate a support group online at alzconnected.org or in your area at alz.org/CRF.

Use Alzheimer’s Navigator® to assess your needs and create an action plan of support and resources at alz.org/alzheimersnavigator.
I Have Alzheimer’s — an online resource created with input from individuals living with Alzheimer’s and other dementias — offers information and strategies to help those in the early stage of the disease live their best life for as long as possible.

Free online workshops, including:

› The Basics: Memory Loss, Dementia and Alzheimer’s Disease.

› Living with Alzheimer’s for Younger-Onset Alzheimer’s.

We’re in communities across the country.

24/7 Helpline — Available all day, every day. (TTY: 866.403.3073)

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

Our vision is a world without Alzheimer’s®.