

I HAVE YOUNGER-ONSET ALZHEIMER'S

WHAT YOU NEED TO KNOW
TO PREPARE AND LIVE WELL



*Jeff B., living with
younger-onset Alzheimer's*

ABOUT YOUNGER-ONSET ALZHEIMER'S DISEASE

Younger-onset Alzheimer's, sometimes referred to as early-onset, is when symptoms of dementia occur before age 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 Americans living with younger-onset Alzheimer's, 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.

“**I went through moments of doubt and pain, but after receiving my diagnosis I decided to do as much as I can, for as long as I can.**”

- Eric T., living with younger-onset Alzheimer's





Barb C., living with younger-onset Alzheimer's disease, and her daughter

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1. IMPACT OF YOUNGER-ONSET

A diagnosis of younger-onset Alzheimer's is life-changing. However, you can empower yourself by preparing for what's ahead and focus on what brings 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 — you can fight it instead.

» **Be open and direct.**

Talk to people about Alzheimer's disease and the need for prevention, better treatment and a cure.

» **Communicate the facts.**

Share information with others to help dispel misconceptions about the disease. Visit 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 is normal aging, help to educate them.

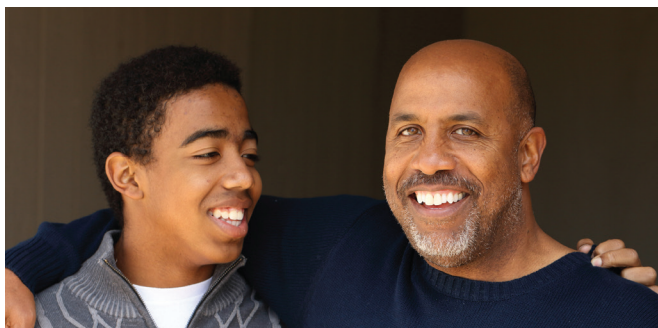
Loss of income

It's not uncommon for people living 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. Consider working with a financial advisor to outline a plan that will make your financial resources last as long as possible.

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 need to help your children face their own challenges related to the disease. Young children may have questions that cause fear and anxiety. Older kids and teens may have concerns about additional responsibilities or the future. Visit [alz.org/helpingkids](https://www.alz.org/helpingkids) to learn more about addressing the disease with kids and teens.



2. RECEIVING A DIAGNOSIS WHILE WORKING

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 FMLA, which allows you to take up to 12 weeks of unpaid leave annually 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 your eligibility for them. Your employer may provide paid sick leave or other short-term disability benefits. Many times these must be taken prior to using long-term disability benefits.
- » Keep written confirmation of all benefits.

3. HEALTH INSURANCE

If you were diagnosed while no longer employed, you may not have had the opportunity to take advantage of programs through your job that continue your health insurance.

Other sources of insurance include:

Affordable Care Act (ACA)

The Affordable Care Act created a Health Insurance Marketplace in each state where Americans can purchase and receive subsidies for health insurance, if you qualify. 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](https://www.healthcare.gov).

Social Security Disability

The Social Security Administration has added 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). Learn more at [alz.org/SSDI](https://www.alz.org/SSDI).

Medicare

Individuals with younger-onset Alzheimer’s are eligible for Medicare, a federal health insurance program generally for people age 65 or older, once they have been receiving Social Security disability benefits for at least 24 months. 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, including Individual Retirement Accounts (IRAs) and annuities, even if you have not yet reached retirement age.

4. TAKE CARE OF YOURSELF

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 address new challenges and changes.

Tips for maintaining 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. Talking with others who are also living with Alzheimer's 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), our online community.

» **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 can increase awareness and encourage others to get involved.

Advocate

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

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 the participation of people like you, finding a cure is nearly impossible.

To learn more or to find 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

Individuals living with early-stage Alzheimer's or other dementias can raise their voices on a national platform through the Association's 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 needs of individuals living in the early stage of the disease.

Raise needed funds

Your participation in fundraising efforts brings the Association's work to life, helping to fund important care, support and research efforts.

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 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.

YOU ARE NOT ALONE



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



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 at **alz.org/alzheimersnavigator**.



LEARN MORE ABOUT LIVING WITH YOUNGER-ONSET

Living with Alzheimer's: For Younger-Onset Alzheimer's is a free workshop offering information about younger-onset. Hear from those affected and learn what you need to plan for and what you can do to ease the impact throughout the course of the disease.

- » Online: **alz.org/education**
- » In person: **alz.org/CRF**



alz.org/IHaveAlz

I Have Alzheimer's — an online resource created with input from individuals living with Alzheimer's or other dementias — offers information and strategies to help those in the early stage of the disease.



alz.org/education

Free online workshops, including:

- » *The Basics: Memory Loss, Dementia and Alzheimer's Disease.*
- » *Living with Alzheimer's for People with Alzheimer's.*



alz.org/findus

We're in communities across the country.



800.272.3900

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

alzheimer's association®

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 disease®.

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