

# LIVING WITH YOUNGER-ONSET ALZHEIMER'S

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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 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*





*Mary T., living with younger-onset Alzheimer's disease, and her husband and care partner, Steve*

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# 1. IMPACT OF YOUNGER-ONSET

A diagnosis of younger-onset Alzheimer's may be life-changing. However, you can empower yourself by preparing for what's ahead and focusing on what brings meaning and purpose to your life. While each family experiences the impact of the disease differently, common experiences include:

## Stigma

The social stereotypes and prejudices surrounding Alzheimer's are often the result of myths and misperceptions caused 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 may cause you to withdraw from relationships as well as community and social obligations, which can have a significant impact on your well-being and quality of life. But you don't have to let it — you can fight it instead.

### » Be open and direct.

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

### » Communicate the facts.

Share information to dispel misconceptions about the disease. Visit **alz.org** or call **800.272.3900** for information.

### » Seek support and stay connected.

Stay engaged in relationships and activities, and build a support network of family, friends and others living with the disease.

Visit **alz.org/CRF** to find early-stage programs and local resources.

## » Try not to 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 a part of normal aging, help to educate them.

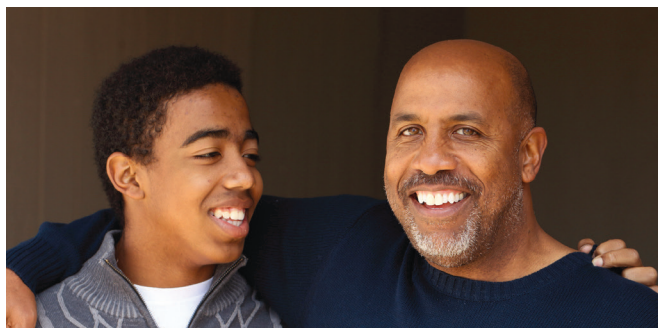
### Loss of income

When symptoms of the disease are present, 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 these issues with your family 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

If you are diagnosed with younger-onset and still raising a family, it's normal to worry about the ways your parental role may change as the disease progresses.

You may also need to help your children face their own challenges related to the diagnosis. 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) for tips on how to discuss the disease with kids and teens.





## 2. RECEIVING A DIAGNOSIS WHILE WORKING

If you receive a diagnosis while still employed, it's critical to be aware of your employer-provided benefits, which may include:

- » **Disability insurance**

Provides income for an employee who can no longer work due to illness or injury.

- » **Family and Medical Leave Act (FMLA)**

Allows people 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)**

A federal law that allows individuals to continue 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 or inquire about which benefits may be available and your eligibility.
- » Your employer may provide paid sick leave or other short-term disability benefits. Often times these must be taken prior to using long-term disability benefits.
- » Keep written confirmation of all benefits.



## 3. HEALTH INSURANCE

If diagnosed while no longer employed, you may need to seek alternative sources of insurance.

Other sources include:

### Affordable Care Act (ACA)

The Affordable Care Act created a Health Insurance Marketplace in each state where qualifying Americans can purchase and receive subsidies 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 walk you through the process. Visit **[healthcare.gov](https://healthcare.gov)**.

### Social Security Disability

The Social Security Administration includes early-onset Alzheimer’s (the administration’s preferred term for younger-onset) on its list of conditions under its Compassionate Allowance Initiative. As a result, those with the disease receive an expedited review process to determine qualification for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Visit **[alz.org/SSDI](https://alz.org/SSDI)**.

### Medicare

Individuals living with younger-onset Alzheimer’s are eligible for Medicare, a federal health insurance program generally for people over 65 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. Be sure to check with your provider in regard to policies specific to your plan.

### 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. LIVE YOUR BEST LIFE

Focusing on living well with dementia and identifying your needs can help you to build a solid foundation from which to address new challenges and changes.

Tips for maintaining your overall health:

» **Take care of yourself.**

Take care of your social, emotional and physical needs. Get regular checkups. Establish a diet and exercise routine and rest when you are tired. Talk with friends or a counselor about how the diagnosis has affected you emotionally.

» **Stay connected.**

Identify the activities and relationships that bring meaning and purpose to your life. Build a strong support network by connecting with your community and exploring new relationships, including with others living with younger-onset Alzheimer's. Visit **alzconnected.org** to meet others facing the disease.

» **Maximize your independence.**

Develop strategies to live well. Visit **LiveWell Online Resources (alz.org/livewell)** for free interactive tools to help you navigate the challenges accompanying a diagnosis and access personalized steps for living your best life.





## 5. TAKE ACTION

Find a sense of purpose while turning your experience into inspiration for others. Your voice and actions 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. To learn more about becoming an Alzheimer's Association advocate, visit [alz.org/advocate](https://alz.org/advocate).

### Advance research

You can make an impact on future generations by taking 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](https://alz.org/TrialMatch).

## Become a leader

Some individuals living with early-stage Alzheimer's can use their voice on a national platform through the Association's National Early-Stage Advisory Group ([alz.org/earlystage](https://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:

- » Participate in our signature fundraising events: **Walk to End Alzheimer's®** ([alz.org/walk](https://alz.org/walk)) and **The Longest Day®** ([alz.org/thelongestday](https://alz.org/thelongestday)).
- » Make a donation at [alz.org/donate](https://alz.org/donate).

## Volunteer

Support the cause while finding personal fulfillment by getting involved.

- » Explore volunteer opportunities through your local Alzheimer's Association office. Visit [alz.org/CRF](https://alz.org/CRF) to find a location near you.

## YOU ARE NOT ALONE



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



Call our 24/7 Helpline: **800.272.3900**.



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



Use Alzheimer's Navigator<sup>®</sup> to assess your needs and create an action at **alz.org/alzheimersnavigator**.



Take our free workshop, *Living with Alzheimer's: For Younger-Onset Alzheimer's*, online at **alz.org/education** or at an Alzheimer's Association office near you (**alz.org/CRF**).





## [alz.org/livewell](https://alz.org/livewell)

LiveWell Online Resources offers free interactive tools to help you navigate the challenges accompanying a diagnosis and provides personalized steps for living your best life.



## [alz.org/education](https://alz.org/education)

Free online workshops, including:

» *Understanding Alzheimer's and Dementia.*

» *Living with Alzheimer's: For Younger-Onset Alzheimer's.*



## [alz.org/CRF](https://alz.org/CRF)

We're in communities nationwide.



## **800.272.3900**

24/7 Helpline – Available all day, every day.

# 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®.**

**800.272.3900 | [alz.org](https://alz.org)®**

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