

A diagnosis of younger-onset Alzheimer's is probably not what you had planned for at this time in your life. You will face unique challenges when it comes to family, work, finances and future care. But you have the power to make a new plan and determine how you choose to live your best life with the disease.

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## **About younger-onset Alzheimer's**

### **I am more**

Learn how your diagnosis does not have to define you.

### **Get Started**

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Alzheimer's disease is considered to be younger-onset Alzheimer's if it affects a person under 65. Younger-onset can also be referred to as early onset Alzheimer's. People with younger-onset Alzheimer's can be in the early, middle or late stage of the disease.

The majority of people with younger-onset have sporadic Alzheimer's disease, which is the most common form of Alzheimer's and is not attributed to genetics. Doctors do not understand why most cases of

younger-onset Alzheimer's appear at such a young age.

However, researchers know genetics play a role in Alzheimer's. There are risk genes, which increase the likelihood of developing a disease, but do not guarantee it will happen. And there are deterministic genes that directly cause a disease, guaranteeing that anyone who inherits them will develop the disorder.

Learn more: [Younger-Onset Alzheimer's and Alzheimer's and Genetics](#)

Like many people with younger-onset Alzheimer's, receiving an accurate diagnosis may have been difficult. Age or medical history can cause doctors to overlook or rule out Alzheimer's disease. It's also not uncommon to be told your symptoms may be related to stress, menopause or depression. This can lead to misdiagnosis (sometimes multiple times) and incorrect treatment.

Learn more: [Free online workshop: Living with Alzheimer's for Younger-Onset Alzheimer's](#)

### **Help advance research with LEADS**

To move toward more effective treatments, scientists need to understand the genetic, biological and clinical processes involved in early-onset Alzheimer's disease. By participating in the Longitudinal Early-Onset Alzheimer's Disease Study (LEADS), you can help them learn about the causes, identification and treatment of early-onset Alzheimer's disease.

[\*\*Learn How to Participate\*\*](#)

*I am not the face, the effect, the energy or the personality that people conjure up in their heads when they picture someone with this disease.*

**Lonni S., Living with Alzheimer's**

## **Impact on you and your family**

Learning about the unique challenges of living with younger-onset is the first step in understanding the impact the disease will have on you and your family. While this may be difficult for you at first, it can help relieve some of the anxieties and fears you may have about the future, and allow you more time to focus on the things that bring you joy. While each family experiences the impact of younger-onset Alzheimer's disease differently, there are common issues:

### **Your role as a parent**

You may be one of the many people diagnosed with younger-onset who is raising a family. It can be painful to know that family dynamics will change. It is normal to grieve now about the anticipated changes in your parental role. It is also normal to wonder what role you will play in the significant events of your child's life as he or she grows older and as the disease progresses. Remaining strong for your child can be difficult as you cope with your own emotions. The best way you can help your child work through the challenges of living with the disease is to take good care of your own physical and emotional needs.

Talking with your child about your Alzheimer's diagnosis may be difficult; it is something that you never anticipated having to do. You may want to protect your young family members and avoid the subject or delay sharing your diagnosis. Only you and your partner know the type of information your child is capable of understanding and how much he or she can handle.

Learn more: [Kids and Teens](#)

## **Stigma**

There are many myths, misconceptions and stereotypes about Alzheimer's disease. Because of your young age, people may not believe you have the disease, may question your diagnosis or dismiss it. Stigma can have a significant impact on your well-being and quality of life. It may cause you to withdraw from your relationships and become isolated. Don't fear stigma, fight it instead.

Learn more: [Overcoming Stigma](#)

### **Full-court press**

WNBA star Candace Parker honors legendary coach Pat Summitt who faced younger-onset Alzheimer's.

[\*\*Read More\*\*](#)

## **Planning ahead**

Prior to your diagnosis, you may have been saving for your child's college education or your retirement. As someone in the early stage of the disease

education of your requirements. As someone in the early stage of the disease, you have the ability to put critical financial and legal plans in place. Be confident about the decisions your family will need to make on your behalf when it becomes too demanding or unsafe for you to make your own decisions. Talk with your family or consider speaking with a financial planner and an attorney.

Learn more: [Plan for Your Future](#)

### **You may be eligible for Social Security Disability**

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

[\*\*Read More\*\*](#)

### **Loss of income**

Like many people diagnosed with younger-onset Alzheimer's, you may have a career. If your employment is the primary source of income for your family, the loss of this income can have a significant impact on your family's financial situation. Now you have to think about your finances in terms of living with dementia: Can you keep working? Will you lose income? Will your spouse or partner have to quit work to provide care? What will future care costs be?

It is also important that you begin discussing with your family what changes may need to occur. For example, you may need to reassess your family budget and make significant changes to how you live.

Learn more: [Financial Planning](#)

## **Receiving a diagnosis while working**

If you have been diagnosed while still employed, it is critical that you educate yourself about the benefits available to you through your employer. Maximize these benefits before you leave your job.

### **Disability insurance**

Disability insurance provides income for a worker who can no longer work due to illness or injury. The insurance plan must be in place before symptoms of Alzheimer's disease appear. With an employer-sponsored disability policy, a percentage of your salary may be provided. Benefits paid out of an employer plan may be taxed as income. If you bought a personal disability policy, then the benefits paid will be the amount specified in your policy. Personal disability policy benefits are not taxed as income.

Below are some questions that can help ensure you maximize the disability benefits offered by your employer:

1. What long- and short-term disability benefits are available through my employer?
2. What are my employer's policies around disability benefits and what do I need to do to access them?
3. How do I apply for disability benefits?
4. When should I file my claim?
5. What is the percentage of my total salary that is provided through my

company's disability insurance? Can this change over time?

6. How soon after disability are benefits payable?
7. How long will the benefits last?
8. Are there any factors that may change the benefit payment I receive?
9. What happens if my employment is terminated?
10. Who is my company's benefits administrator?

### **Tips when seeking employee benefits**

- Review the employer's benefits handbook.
- Ask the benefits staff what benefits may be available, such as the 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.

### **Family and Medical Leave Act (FMLA)**

You may be able to use benefits offered under the Federal Family and Medical Leave Act (FMLA). The law covers employers with 50 or more employees. FMLA allows you to take off up to 12 weeks of unpaid leave each year for family and medical reasons with continuation of group health insurance coverage. Talk with your human resources department about your eligibility for FMLA and any return to work requirements.

Learn more: [FMLA information from the U.S. Department of Labor](#)

### **COBRA**

COBRA is a federal law that allows individuals to continue their health care coverage after leaving a job. COBRA refers to the Consolidated Omnibus Budget Reconciliation Act of 1985 and is available to those who work in companies with 20 or more employees. Under COBRA, an employee may continue group plan coverage for up to 18, 29 or 36 months, depending on the circumstances, if he or she:

1. Leaves the employer.
2. Has work hours reduced to the point that he or she no longer qualifies for the employee health plan.

The COBRA-insured employee must pay the full cost of coverage, plus up to two percent to cover administrative costs. Talk with your human resources department about your eligibility for COBRA.

Learn more: [COBRA information from the U.S. Department of Labor](#)

## **Health insurance**

### **Maximize your independence**

Develop strategies to help you live day by day.

**Get Started**



If you were diagnosed after you left your job, you may not have had the opportunity to take advantage of programs that continue your health

insurance coverage such as COBRA. Lack of health insurance for you and your family and high out-of pocket expenses for medical care can put a significant strain on your financial situation and ability to get the appropriate medical care needed.

- Affordable Care Act (ACA) 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.

Learn more: [HealthCare.gov](http://HealthCare.gov)

- 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.

Learn more: [SSDI and Medicare information from Social Security Administration](http://SSDI and Medicare information from Social Security Administration)

## **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.

Pension plans will typically pay benefits before retirement age to a worker defined as disabled under the plan's guidelines. You may also be able to