

Early-Onset Alzheimer's: Financial and Legal Planning Essentials

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Navigating the challenges of an early-onset Alzheimer's diagnosis? This guide covers financial planning, legal considerations, support resources and more to help you prepare for the future.

By Sandra D. Adams

According to the Alzheimer's Association, less than 5% of Americans are diagnosed with early-onset Alzheimer's disease (EOAD). When this diagnosis comes, the recipients are typically in their 40s or 50s. This is in contrast to older onset Alzheimer's disease which is more familiar to the public. Older onset Alzheimer's is diagnosed after age 65 and impacts over 10% of those over age 65, over 13% of those between age 75 and 84 and 33.3% of those over age 85.

From a planning perspective, it is not uncommon for us to have conversations about the more traditional/older-age form of dementia because we have more time to plan for it. Conversations about early-onset Alzheimer's disease are less common. When it has come up, we and the clients impacted have found ourselves unprepared in many ways.

Once there is an early onset Alzheimer's diagnosis, the client and family have the challenge of learning about the disease and what the changes will mean for them going forward. Just the day-to-day changes in physical and emotional needs and changing future care needs can be overwhelming for the family to deal with.

From a financial and legal planning standpoint, there are many things to think about and plan for, and time can be of the essence. With an early onset diagnosis, the speed of progression of the disease can be unknown (and is often much faster than that of older onset Alzheimer's), making timely planning even more important.

What to think about:

1. **Make sure estate planning documents are up-to-date:** Review and update estate planning documents to make sure that they name appropriate parties for durable powers of attorney, health care advocates, successor trustees, executors, etc. It's important these documents are designed to work with any future government and other benefits that might be needed for care.

2. **Determine if the person diagnosed might be eligible for Social Security Disability:** The Social Security Administration (SSA) has added early 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).

3. **Disability insurance:** If the diagnosis is received while the person is still working, they may be eligible for disability insurance through their employer (if the insurance plan was in place before symptoms of the disease appeared). The disability policy would provide a percentage of the person's salary for an insured period (could be short or long-term, depending on the policy). If the benefits are paid out of an employer plan, they may be taxed as income.

4. **Family Medical Leave:** If the diagnosed person (or spouse/family member) works for an employer with fifty or more employees, they may be able to use benefits offered under the federal Family and Medical Leave Act (FMLA). FMLA allows employees to take up to 12 weeks of unpaid leave each year for family and medical reasons with continuation of group health insurance coverage.

5. **COBRA:** The Consolidated Omnibus Budget Reconciliation Act of 1985 is available to those who work for companies with more than twenty employees. COBRA allows an employee to continue group plan coverage up to 18, 29 or 36 months, depending on the circumstances, if he/she leaves the employer or has work hours reduced to the point where he/she no longer qualifies for employee health care.

6. **Medicare:** Individuals with early onset Alzheimer's are eligible for Medicare 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.

7. **Retirement Plans:** Individuals with early onset Alzheimer's may qualify for access as a result of a disability to retirement plans (including IRA accounts and annuities) and pension plans before the age of 59 ½ without the typical 10% early withdrawal penalty. Any withdrawals will usually be considered taxable income. Social Security benefits are also available before retirement age if Social Security disability requirements are met.

The challenge with planning for the family of someone with early onset Alzheimer's is

making sure there are funds to care for the impacted individual and support the rest of the family long-term. The typical life expectancy of someone diagnosed with early-onset Alzheimer's is 8 years (but can be much longer). If the person has children that may need to be supported through college and a spouse that may live a normal life expectancy, protecting the family nest egg from drawdown can be difficult. Often, the family makes great sacrifices to make sure that the diagnosed family member gets the care they need for the time that they need it.

In a perfect world, we would know in advance the challenges that will face us, and we would know the risk-fighting measures to put into place in advance. The reality is, no one knows if they will be impacted by this or other debilitating diseases. For those who feel they might be more at risk for getting Alzheimer's of any kind, we would recommend buying long-term care insurance to protect their family's financial future. It just makes sense to plan, and plan early, to make sure you're in the best position possible to protect yourself and your family.

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Sandra D. Adams, CFP®, is a partner and CERTIFIED FINANCIAL PLANNER professional at Center for Financial Planning, Inc.®. Having joined The Center team in 1996, Sandy has more than 25 years of financial planning industry experience.

She was nationally recognized by Forbes as a Top Woman Wealth Advisor Best-in-State in 2023 for the fourth consecutive year, and recognized on Forbes' 2022 Best-in-State Wealth Advisors list. Sandy specializes in longevity planning and is a frequent speaker on related topics with the Michigan Association of CPAs, Wayne State University Institute of Gerontology (WSU IOG), SOAR (Society for Active Retirees), AICPA (Association of International Certified Professional Accountants) and other public and professional groups.

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