

After the Diagnosis: Making a Plan for Alzheimer's

In a 2002 interview with Mike Wallace, former First Lady Nancy Reagan said she often reread the love letters written by her husband, former President Ronald Reagan. The letters, which had sustained and enriched their relationship, helped Mrs. Reagan reconnect with her husband and remember the man he was before Alzheimer's claimed him.¹ An excerpt from her book, *I Love You, Ronnie: The Letters of Ronald Reagan to Nancy Reagan* reads:²

"No matter what else was going on in his life, no matter where he was, Ronnie wrote to stay in touch. I found his letters funny, warm, and imaginative. I loved reading them, and found myself looking forward to receiving them. Whenever Ronnie went away, I missed him terribly, and when his letters arrived, the whole world stopped so I could read them."

Alzheimer's is the most common type of dementia. It affects more than five million people, of all ages, in the United States. Those who suffer from the disease develop memory, thinking, and behavior issues.³ As the disease progresses, the symptoms and challenges intensify. The *Alzheimer's Association* explained:⁴

"As Alzheimer's advances through the brain it leads to increasingly severe symptoms, including disorientation, mood and behavior changes; deepening confusion about events, time, and place; unfounded suspicions about family, friends, and professional caregivers; more serious memory loss and behavior changes; and difficulty speaking, swallowing, and walking."

Coping with Alzheimer's can be an extraordinary and often painful journey for patients, families, and caregivers. If you, or someone you love, has been diagnosed with the disease, act quickly to develop a plan of action that encompasses financial, legal, and end-of-life wishes.

Creating an Alzheimer's action plan can help restore a sense of control after an unwelcome diagnosis and help protect loved ones from potential uncertainty and conflict in the future. A good place to begin is by learning more about the disease.

Empower yourself. As you experience the gamut of emotions that often accompany a diagnosis, try to be proactive. Educate yourself about dementia and Alzheimer's. Join a support group. Keep a journal. Share information with loved ones. Understanding what may be ahead can help re-establish a sense of order and control.⁵

Begin building a care team. An Alzheimer's team may include family members, close friends, neighbors, doctors, professional caregivers, members of community organizations, and others.

Building a team means talking with potential team members about what may be needed and when. In the early stages, people with Alzheimer's may need assistance with:⁶

- Keeping appointments
- Managing money
- Taking medications
- Planning and organizing
- Shopping and preparing meals
- Exercising and relaxing

In later stages, they'll need experienced and patient caregivers who have been well trained. If family members want to provide care, the *AARP's* Dementia Friends Initiative can offer some insights about how to best interact with and support people who have dementia.⁷

If possible, decide on caregiving options while the individual with Alzheimer's has the clarity to make sound decisions. The care choices you make should include a thorough evaluation of costs so you can make affordable choices.

In 2016, *Genworth* reported on the median annual costs for long-term care in the United States:⁸

<u>Type of Long-term Care</u>	<u>Length of Stay</u>	<u>Annual Cost</u>
A Home Health Aid	44 hours a week for 52 weeks	\$46,322
Adult Day Health Care	5 days a week for 52 weeks	\$17,680
Assisted Living Facility	12 months of care, private, one bedroom	\$43,539
Nursing Home Care	365 days in a semi-private room	\$82,125
Nursing Home Care	365 days in a private room	\$92,378

Another option may be a dementia village. The first was established in Holland, and another will open in San Diego spring 2018. Villages rely on reminiscence therapy – using past activities and experiences to encourage positive memories and help people with dementia feel calmer.³

Review your financial plans. Once you have familiarized yourself with care options, take time to review your financial plans. Check in with your insurance provider to ascertain exactly what costs will be paid by insurance and what costs will be paid out of pocket.

Once you have a better understanding of potential costs, work with your financial representative to evaluate your budget and decide how to proceed. If your financial priorities and goals have changed, then your investment and allocation choices should reflect that.

Double-check legal documents. Make sure you've dotted the 'i's and crossed the 't's when it comes to your estate plan. Make sure to review:

- **Your will.** Make sure you have named the correct beneficiaries for your valuables and guardians for children and also have provisions in place for pets.⁹
- **Beneficiary designations.** In many cases, the beneficiaries named on retirement plan accounts and insurance policies take precedence over heirs named in a will, so make sure the correct person or people are named.⁹
- **Your living will or advance directive.** This legal document provides instructions that are implemented if you are unable to communicate or make decisions. An advance directive may include end-of-life wishes.¹⁰
- **Your Power of Attorney** gives another person the right to act on your behalf if you become incapacitated.¹¹
- **Your digital executor.** If you have digital accounts or assets, name a digital executor to access, manage, delete, or archive digital files after your death.¹²
- **Any trusts.** Depending on the complexity of your estate, you may have established a trust and a means for funding it after death.

Put critical financial documents in a safe place, and make sure at least one other trusted individual knows where they are.

Apply for Social Security Disability benefits. It has become easier for people who are younger than age 65 to qualify for benefits than it once was. Early-Onset Alzheimer's Disease was recently added to the Social Security Administration's Compassionate Allowances List.¹³

Alzheimer's is the most expensive disease in America, according to *CNBC*.³ It's critical to put a plan in place to help provide comfort and care for the person with Alzheimer's, and protect family and loved ones.

Sources:

¹ <http://blog.aarp.org/2016/03/06/nancy-reagan-she-helped-lead-fight-against-alzheimers/>

² Book Excerpt from *I Love You, Ronnie: The Letters of Ronald Reagan to Nancy Reagan* authored by Nancy Reagan, page 4: https://s3-us-west-2.amazonaws.com/peakcontent/Peak+Documents/Sep_2017_Book_Excerpt-I_Love_You_Ronnie-The_Letters_of_Ronald_Reagan_to_Nancy_Reagan-Footer_2.pdf

³ <https://www.cnbc.com/2017/08/03/dementia-villages-for-alzheimers-sufferers.html>

⁴ http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp

⁵ <http://www.alz.org/i-have-alz/just-diagnosed.asp>

⁶ <http://www.alz.org/care/alzheimers-early-mild-stage-caregiving.asp>

⁷ <http://blog.aarp.org/2017/02/27/dementia-friends-initiative-creates-respectful-communities-for-people-of-all-ages/>

⁸ <https://www.genworth.com/about-us/industry-expertise/cost-of-care.html>

⁹ <http://www.aarp.org/money/budgeting-saving/info-2016/the-ultimate-guide-to-estate-planning.html>

¹⁰ <https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives>

¹¹ <https://www.rocketlawyer.com/form/power-of-attorney.rl#/> (or go to https://s3-us-west-2.amazonaws.com/peakcontent/Peak+Documents/Sep_2017_RocketLawyer-Personal_Legal_Forms-Power_of_Attorney-Footer_11.pdf)

¹² <https://legaltemplates.net/blog/digital-executor-will-and-testament/>

¹³ <https://www.ssa.gov/compassionateallowances/conditions.htm>

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