



Alzheimer's & Dementia

A disease unlike any other, Alzheimer's will forever alter you, your loved one and your entire family. Facing these changes may seem impossible but understanding the whole spectrum from mental, physical, emotional, medical and financial will help you meet the challenges. Find some insights and support here, to face Alzheimer's with strength and grace.

What to Expect as Alzheimers's Progresses

The first question many people have after a family member has been diagnosed with Alzheimer's disease is, "What can I expect?"

It's a query without a concrete answer, since cognitive impairment progresses differently in different people. Your mother may maintain her sweet, nurturing demeanor, in spite of the disease, or she may start exhibiting uncharacteristically selfish behavior. Your husband's sense of suitable behavior may stay intact, or it may become warped, causing him to make inappropriate sexual and racial remarks in public.

A few things, however, become relatively certain when Alzheimer's invades your life:

Your role will change – and it won't be easy

Cognitive decline in your loved one may happen fast or slow, and it will likely be unpredictable. One minute, your wife may be chatting away, happy as a clam, and the next, she may become violent, lashing out for no apparent reason. Like your loved one's mood, your role as a caregiver will always be in flux. In the beginning, you might be mostly called upon to help with simple tasks – laundry, shopping and cooking.

As your loved one's cognitive abilities decline, you might eventually need to provide more hands on care with activities such as bathing, dressing and going to the bathroom. There may also come a time when you and the rest of the family will have to seriously consider having professional in-home help or placing a loved one with Alzheimer's into an assisted living Facility (ALF) or nursing home. The variability of your journey as a caregiver will cause emotional, relational and financial stress, which you need to prepare for properly.

You're in it for the long haul

Nearly one-third of Alzheimer's caregivers provide assistance to their loved ones for more than 5 years. When the billions of unpaid hours of care provided by relatives are divided amongst these informal caregivers, the typical family member will look after their loved one for about 22 hours each week.



Your loved one won't be the same

Alzheimer's disease causes the death of neurons and the shrinkage of brain tissue. Depending on which area of the brain are impacted, an individual's personality can become permanently altered. There may come a day when your wife of 40 years no longer remembers who you are, or your once loving father starts screaming at you every time you walk in the room. When faced with these heart-rending situations, the only way to cope is to give yourself permission and time to grieve the loss of the loved one you once knew and try to make peace with who they are right now.

You won't be the same

As any long-term caregiver will tell you, caregiving *can change your personality*. Experts say these changes may be either positive or negative. Much depends, of course, on personal insight, general openness to change, feelings for the person you are caring for and your own physical and mental health. In the end, whether the changes that remain with you are positive or negative rest with how you view life in general.

The most important thing to remember is how your loved one was, not how they are now. Chances are they belonged to a generation that was proud, patriotic and private. Hardly ever complaining and used to doing things themselves. They hated asking anyone for help and certainly did not want to be a burden on anyone.

But all this goes out the window when you reach the mid-to-late stage of this disease.

An emergency responder said, "I used to make life and death decisions, sometimes in seconds. Now I stand in front of my sock drawer for minutes thinking, 'Which pair?'"

It cannot be stressed enough how everything changes with this disease. Most family members and caregivers see this change, yet treat their loved one as things once were. It's natural, but in the end, it won't work.

So, what can you do? The short answer is – Nothing. Nothing – meaning you can be there for them, you can assist them with daily activities, you can their caregiver ... but you can't change what is happening. Try to learn all you can about what is happening to them, but understand that you can't fix it

What is Alzheimer's Disease?

Alzheimer's disease is a brain disease and the most common form of a group of brain diseases called dementias, accounting for 40% to 75% of dementia cases. Other kinds of dementia include vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia.



Alzheimer's disease, like all dementias, progressively gets worse over time, and currently has no known cure. As many as 5.3 million Americans are living with Alzheimer's disease. Alzheimer's destroys brain cells, causing problems with memory, thinking, and behavior severe enough to affect work, lifelong hobbies, social life, and eventually, the ability to carry out routine daily activities. Today it is the sixth leading cause of death in the United States. For more information, see www.alz.org.

What is known about caregiving for a person with Alzheimer's disease or another form of dementia?

- Family members have traditionally been responsible for the care of people with Alzheimer's disease and other dementias. The vast majority (80%) of these people are cared for in their homes. As lifespans lengthen and the population ages, an increase is anticipated in the number of people providing care, the length of time spent caregiving, and the breadth of required tasks.
- Caregivers of people with dementia spend much more time providing care than caregivers of people with other conditions.
- The average length of time caregivers report providing care is 4.6 years, but in the case of dementia, the caregiving span may range from 4 to 20 years.
- In 2011, over 15 million Americans spent an average of 21.9 hours per week caring for a family member with dementia—a total of 17.5 billion hours at a value of \$216 billion dollars.
- The demands of caregiving can take a toll on caregivers' health, at times compromising the ability of the caregiver to take care of themselves, much less their family member. Family caregivers of people with dementia are at greater risk for anxiety, depression, and poorer quality of life than caregivers of people with other conditions.
- An estimated 25-29% of caregivers of persons age 50 or older provide assistance to someone with a cognitive impairment, a memory problem or a disorder like Alzheimer's.
- The average age of a caregiver to a person with Alzheimer's disease is 48 years old.
- The vast majority (87%) of individuals with Alzheimer's are cared for at home by family members.