

# How to Deal With Alzheimer's as a Caregiver

**Alzheimer disease** is the most common type of dementia, accounting for about 50% to 75% of dementia cases worldwide. It is characterised by short-term memory loss, apathy and depression in the early stages. Onset is gradual and decline is progressive. This form is most common among older people with dementia, particularly among women<sup>1</sup>.

Alzheimer's disease is a neurodegenerative disease that progressively destroys cognitive abilities. An individual may gradually lose the ability to communicate, make decisions, or perform activities of daily living. They might experience memory loss, abnormal behaviour, a change in personality, and an increase of anxiety and dementia. If you're caring for a person with Alzheimer's, here are a few steps you can take to minimise stress and maximise comfort.

## 1. Understand the disease and stages of progression.

Look on the Internet or at the library. Find local organisations that offer Alzheimer's education. It will be difficult to face some facts, but you need to know what to expect. There are 7 described stages to the progression of Alzheimer's disease. Many patients are not diagnosed until they have reached Stage 4. Determine which stage the person is in, and what the symptoms are now and as the disease progresses.

## 2. Seek medical treatment.

A physician makes the diagnosis. Typically a MMSE (Mini Mental State Exam) is administered. PET scans and CAT scans are also done to rule out stroke as a cause of dementia (stroke-caused dementia appears to have more step-like decline in cognitive ability whereas Alzheimer's is a steady downward arc).

Although there is currently no cure for Alzheimer's, there are many medications (cholinesterase inhibitors) that will slow the progression of the disease, and in some cases, extend a patient's cognition longer than they would have had without medications. These medications include: Cholinesterase inhibitors: Aricept, Exelon, and Razadyne (a version of Reminyl). Cholinesterase inhibitors can be taken in very early to late stages of Alzheimer's. Namenda is a glutamate reducer that is taken as adjunctive therapy to cholinesterase inhibitors in moderate to late stage Alzheimer's. Alzheimer's patients live an average of 8 years after diagnosis. Some patients will survive only 3 years, and others survive up to 20 years.

## 3. Plan ahead.

In caring for a person with Alzheimer's be prepared for the long haul. Once you are aware of how Alzheimer's disease may affect your loved one, think ahead and be ready for the changes that will follow, both in the short term and in the long run. You will need to prepare both materially and emotionally. Eventually, you will probably need to do the following: assist with toileting and personal hygiene; adapt mealtime rituals to suit their condition; and obtain a wheelchair when mobility becomes a problem.

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<sup>1</sup> *Dementia in Australia - Australian Institute of Health and Welfare 2012*

### **4. Create a safe environment.**

Make changes in your home that will protect the person you are caring for. Limit access to dangerous areas and medicine cabinets. Install child-safety locks and automatic shut-off devices. Install grab-bars in the bath. It may become necessary to take measures that will prevent them from leaving the house and wandering off.

### **5. Create a supportive environment.**

Your loved one may forget names for common objects. It will not help to reprimand. A person with dementia will not benefit from an argument. Offer love, emotional support, spiritual support, interesting activities, and social interaction with understanding people.

### **6. Anticipate behaviour and personality changes.**

A sufferer of Alzheimer's will lose the ability to perform complex tasks, then later, even simple tasks. The sleep-wake cycle will become disrupted, keeping you up some nights. They may suffer hallucinations, even the delusion that you are an enemy or impostor. Remember: As a caregiver, you are assisting a person—not a disease. Try to treat this person as you, yourself, would like to be treated.

### **7. Share memories.**

Enjoy sharing memories from the person's past for as long as you and they are able. As the person with Alzheimer's is losing their capacity to retain or learn new information, talking about their past may enable them to revisit happier times.

### **8. Share laughter as much as possible.**

Although a person with Alzheimer's may not be able to say who you are, or recognize even the closest relatives or friends, often their feelings can be expressed through interactions geared towards their current capabilities. Almost everyone is capable of receiving love and kindness.

### **9. Maintain yourself.**

Try to maintain a sense of compassion, humour, and a willingness to learn new strategies to assist the person with Alzheimer's, as well as yourself. The person with Alzheimer's (and you, as their caregiver) will experience many changes over the course of time. This can be frightening and requires flexibility. You are both experiencing unknown territory. Be kind to the person with Alzheimer's and yourself.

Never make a promise that should not be kept.

The best option for most families is to engage an in-home care provider to help take off some of the pressure and provide a break (respite). They can provide experienced healthcare professionals who have a deep understanding of the needs of Alzheimer sufferers. It may be that placing your loved one in a high-care nursing home will be necessary as the condition reaches the final stages.

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Caregiving is very stressful and you'll need all the help that you can get. Consider attending a caregiver support group such as is offered by organisations like the Alzheimer's Association.

### Summary

- Provide appropriate health care. Be ready to treat symptoms. Some medications will help give them greater quality of life, even if they cannot cure Alzheimer's disease. Be watchful for illnesses and injuries, such as infections or skin tears. Watch for urinary tract infections and other problems related to incontinence.
- Try not to treat people with the diseases as if they were a child or incapable of simple tasks. Just offer help in a way that doesn't seem pushy or demanding. Often start a sentence with "Don't worry let me help you with that". Spoken in a soft, friendly voice.
- Start coping with anticipatory grief. There is no known cure for Alzheimer's disease. It is fatal. The affected person did not invite this disease. You did not deserve this situation. You have suffered a great loss and should expect to experience pain. You should also look for ways to begin healing after the grief.
- Don't forget to care for yourself. Dementia caregivers frequently forgo their own self-care in order to care for their loved ones and, as a result, suffer from increased risk for depression, anxiety, and stress-related physical illnesses. Don't skip your own doctor and dentist appointments.
- Remember that sometimes making a task that the person you care for seem easy may upset this person so sometimes reassure them that it's okay saying things like "I find that really difficult sometimes, I must just be having one of those days" and offering a gentle smile always helps.
- Don't try to correct their beliefs too often. In losing their memory, patients often recall things that didn't actually happen (they might say they had lunch with a friend who died years ago!) Whenever possible, do not try to change their thinking. It will frustrate you and them. Often, correcting these mistakes will bring on periods of anxiety and stress. Live in their world if you can, playing what you think of as "make believe" in order to keep them happy and stable.
- Remember that not all memory loss suggests Alzheimer's disease. Similarly, not all dementia suggests Alzheimer's disease.
- Enlist help from professionals. There are paid caregivers and health care workers that can come into your home.
- Seek help from a hospice when appropriate.