Caring for a Loved One Who Has Late Stage Alzheimer’s Disease

by PATRICIA BRATIANU

Late Stage Dementia

Providing care with a loved one who has late stage dementia can be heartbreaking and exhausting. It is critical that you take care of yourself so that you do not become ill or unable to care for your parent, spouse, or other individual that you look after.

Medical professionals and the general public are becoming more aware about dementia. This has led to a wider availability of services for people who have Alzheimer’s disease.

Signs of Severe, Late Stage Dementia

Here are some signs which may indicate that your loved one’s disease is progressing to the late stage.

- People who have advanced dementia are unable to remember basic information even for a few minutes.
- They may be unable to speak or say only a few words. Some people who have dementia may say a few repetitive phrases. They are unable to make their needs known.
- Most people who suffer from late stage Alzheimer’s disease are incontinent of urine, feces, or both.
- Many people who have advanced Alzheimer’s disease are unable to recognize people, including themselves.
- They are unable to perform simple activities of daily living. Bathing, mouth care, and the application of clothing must be done by others. People who have advanced Alzheimer’s disease are unable to feed themselves. They are totally reliant on others for safety and survival.
- If a person suffers from late stage Alzheimer’s disease; sleep patterns may be interrupted. Some people sleep for long periods. Others are restless and fidgety, especially at night.
- Aggressiveness and combativeness may occur.
- As Alzheimer’s disease continues to advance, the person may become completely bedbound.

Communication with a Person Who has Advanced Alzheimer’s Disease

Communication with a person who has late stage dementia is difficult. Speak in a normal tone of voice, using short simple sentences.

Body language and gentle touch are often more effective than communication with words, as the person may not understand what you are saying. Use gentle touch to guide your loved one during position and diaper changes. Holding their hand and smiling at them can be soothing for some people.

Some people who have advanced dementia respond in the presence of young children or pets. Keep in mind all communication must be flexible. Keep stimulation to a minimum as overstimulation can be upsetting.

Next page: nutritional challenges in late stage dementia, finding community supports, and hospice services.

Nutritional Challenges

People who have end stage Alzheimer's disease may not recognize thirst or hunger. Some people are unable to recognize when they are full, or may not remember how to swallow.

Food and liquids may not always go down to the stomach – small amounts may end up in the lungs, which can lead to pneumonia. While at earlier stages of dementia, your loved one may have been able to feed him or herself finger foods; now it is likely that you need to feed him or her. Pureed foods are generally needed. Liquids may need to be thickened.

Ask your health care provider to order a swallow evaluation with a speech therapist to learn the best techniques to use for your loved one.

Take Advantage of Community Supports

National and local organizations offer support and educational resources for people who provide care to loved ones with Alzheimer's disease. Find out what your loved one's insurance coverage will pay for.

Some jurisdictions pay for home health services as a means to keep people out of nursing homes and in their own homes. These are known as diversion programs. In the USA, if a person has Medicaid, they may be eligible for nursing home diversion programs.

Local associations may provide respite care. Qualified sitters come to the home and sit with the afflicted individual so that family members can get a break. Churches and religious organizations sometimes offer similar services to members of the spiritual community.

Find Out About Hospice Services

While Alzheimer's disease is one of the top killers, people do not usually think of it as a fatal illness. When most people think of the word "hospice", they think of cancer. In the US, hospice services are available for any person who has a life expectancy of six months or less, not just people who are diagnosed with cancer. Other countries have similar rules. Ask your health care provider for a hospice referral. Hospice services are provided free of charge.

If your loved one qualifies for hospice services, you will receive support from a nurse and a social worker. Hospice aides generally provide direct care services for a few hours each week. Hospice volunteers may be available to sit with your loved one.

If you live in the USA, and your loved one receives hospice services, you are eligible to receive extended respite services for five days each quarter of the year. Where the service is provided depends upon your locale.

Next page: challenges people with advanced dementia face, and the importance of looking after yourself.

Challenges People With Advanced Dementia Face

The main reasons to seek hospice care for a loved one with late stage Alzheimer's disease are to ensure that he or she receives the best care possible, and to help you cope with the ongoing loss and care of your loved one as he or she declines. Researchers have discovered that individuals who have diagnosis of Alzheimer's disease face challenges at end of life that many other hospice recipients don't.

Determining the life expectancy of a person who has Alzheimer's disease can be difficult. As a result, many people who would benefit from services do not receive them until very late in the disease process. Signs of end

stage dementia include more confusion, lack of appetite, increased incontinence, pain, weight loss, being withdrawn or having an increase in agitation. Your loved one may become ill due to urinary or respiratory infections. Mobility may be very limited, even in bed.

People who have advanced dementia may suffer from pain that goes unrecognized. Sometimes poor appetite, impaired sleep and agitation are due to pain. If the person has contracted limbs, arthritis or bed sores it is likely that he or she is having pain.

A hospice nurse can help you determine if pain is a factor for your loved one. Sometimes administering a mild analgesic gives a clue to whether or not pain is a factor. For example, if a person doesn't sleep well at night and you give a mild analgesic such as acetaminophen or ibuprofen and they start sleeping at night, you may realize that pain is an issue.

You may face difficult decisions regarding nutrition and hydration for your loved one. Some people consider the use of feeding tubes; however tube feedings increase the risk of pneumonia and other infections. They do not improve quality of life or functional abilities. Simply offering foods and drink as long as the person shows interest is much more humane, in my opinion.

Take Care of Yourself

Many people who provide care to loved ones who have advanced Alzheimer's disease struggle with clinical depression, guilt, and exhaustion. You must get help for yourself. Whether you talk to a friend who "gets it" or seek professional help; do not expect that you will be able to provide all of the care that your loved one needs all of the time.

As the disease progresses, you may feel that your loved one has already "left you" even though he or she is physically present. This grief is normal; it comes with the territory when you care for a loved one with Alzheimer's disease.

It's okay to ask for help. Help in the face of end stage Alzheimer's is not a luxury; it is a necessity.