

## **Caring for Someone with Alzheimer's**

For many years, memory loss and senility were considered part of the normal aging process. Forgetting names and once-familiar faces, confusing dates and addresses were just part of "growing old."

Today scientific findings show that "growing old" is far too simple a description for these events.

In many cases, confusion and forgetfulness in elderly people stem from a physical cause that can be treated and sometimes slowed. If drug interactions are the cause, a doctor can modify or change prescriptions.

Sometimes, however, the cause for the confusion and forgetfulness may point to Alzheimer's. Alzheimer's is a progressive, irreversible brain disorder that affects an estimated 4 million Americans, most of whom are over 65 years of age (persons with Down Syndrome may develop Alzheimer's disease much earlier).

The Alzheimer's Association estimates that 10% of people over 65 years of age and nearly half of those over 85, have Alzheimer's or some form of dementia. Age is the biggest risk factor for Alzheimer's: 3% of seniors ages 65 to 74 have the disease; 19% of those ages 75 to 84; and, 47% of those ages 85 and older. As the population ages, the number of people with Alzheimer's is expected to climb from 4 million today to 14 million by 2050.

### **Alzheimer's Warning Signs**

There are many warning signs for Alzheimer's. For example, memory loss begins to affect daily activities like managing household finances.

The individual may become confused, get lost easily, exercise poor judgment, and generally lack a zest for life.

Often a person's memory troubles progressively increase and their attention span shortens. The individual may have trouble recognizing friends and family, organizing thoughts and speaking logically. Other characteristics may be that the individual becomes suspicious, may hide possessions, and can be terribly restless, especially in the late afternoons and evenings – referred to as Sundowners Syndrome.

Eventually people with Alzheimer's cannot recognize family members or even their own reflection in a mirror. Even with good nutrition, weight loss will occur along with loss of verbal communication and bowel or bladder control. Ultimately, Alzheimer's is a fatal disease.

## **Caring for Someone with Alzheimer's**

Providing care to persons with Alzheimer's can be particularly difficult; the disease can manifest a wide range of challenging or disruptive behaviors, including aggression, agitation, eating problems, delusions, excessive worry, wandering, and withdrawal.

Dealing with the behavior problems on a day-to-day basis can be very challenging. The caregiver must have patience, often handling the individual in the same manner as that of a child. Instructions need to be extremely clear and detailed, and often need repeating many times. When the person becomes upset or hostile, there is no point in trying to reason with him or her; rather the caregiver can refocus the situation on something else.

At the same time, the person with Alzheimer's is an adult and should be encouraged to be independent to the extent possible.

Often, caregivers become overwhelmed with the physical and emotional toll and the need to provide constant supervision. There may come a point when there is a need for more personal care and supervision than the family can provide. When this occurs it may be time to consider a nursing facility, assisted living residence or other supportive program.

## **Housing and Care Options**

If you feel a long term care setting may be needed, try to begin planning well in advance. Discuss the matter with your physician and other professionals; find out the type of services likely to be needed and the various care and housing options available.

Once you've narrowed the field to two or three facilities, make an appointment to tour the facility. If possible, visit each facility at several different times of day. Try to involve the prospective resident in the planning process to the extent possible.

Anticipate that you will have many questions about the admissions process and your feelings and concerns about the future. Discuss this with the appropriate staff at the facility, such as the administrator, director of nursing, director of health or wellness, social worker or admissions director.

The long term care professional team should be eager and able to help make this transition as calm and positive as possible.

Professional caregivers, trained in understanding persons with Alzheimer's, are knowledgeable in ways of preserving dignity and helping them to live a quality life.

The housing, care and services options available tend to fall into five categories: nursing facilities, assisted living residences, adult day care, respite care and hospice.

### ***Nursing Facility***

Some nursing facilities specialize in caring for Alzheimer's patients; many others have special care units designed to meet the unique needs of these patients. In general, nursing facilities are equipped to take care of people in the later stages of Alzheimer's, and increasingly facilities are providing a specialty in this type of care and supervision. Look for facilities with staff who are experienced in caring for Alzheimer's patients.

### ***Assisted Living Residence***

Likewise, some assisted living residences care solely for Alzheimer's residents and many others have designated units or wings for these residents. Options and accommodations may vary greatly from one assisted living residence to the next (e.g. private rooms, private baths, kitchenettes, etc.). Personal needs and preferences are important criteria for selecting a residence. Look for facilities with personnel who are experienced in caring for Alzheimer's residents.

Most assisted living residences allow individuals to stay as long as their physical and mental impairments can be supervised and maintained by the direct care staff or through contracted services. Many states allow for skilled nursing services to be temporarily provided in the assisted living setting. However, most assisted living residences do not deliver the level of ongoing health and nursing care found in nursing facilities.

### ***Adult Day Care***

These are community- or facility-based outpatient programs offering structured activities and meals. Most programs operate during the week and can be attended full- or part-time. Transportation may be provided.

### ***Respite Care***

Respite care is scheduled, short-term care provided on a temporary basis to an individual who needs this level of care but who is normally cared for at home. The goal is to provide relief for the caregiver while providing a safe and secure environment for the patient. Respite care under Medicare is generally not available. However, if the patient is receiving hospice care through Medicare, respite care is provided as a hospice benefit.

### ***Hospice***

These programs provide care and comfort, without using heroic lifesaving measures, to persons dying of Alzheimer's. This service is available through local hospice organizations and many home care agencies, hospitals, nursing facilities and assisted living residences.

### ***Other Help***

Many nursing facilities and assisted living residences often schedule group meetings to encourage Alzheimer's families to support each other. The Alzheimer's Association has chapters throughout the country that also organize support groups.

## **Paying for Care**

Following are some facts about paying for care:

- Contrary to popular belief, Medicare does not cover the cost of long term care. Medicare only provides limited coverage for long term care with many rules to qualify, such as requiring a 3-day hospital stay.
- Medicaid – the health insurance program for the poor – pays for almost 65% of the patients in nursing facilities, yet offers only limited, if any, funding for assisted living services in many states.
- Long term care insurance, depending on the policy, pays a daily rate and may cover a variety of long term care settings, possibly including home care.

### ***Private Pay and LTC Insurance***

Paying for care with your own funds provides you with greater choice as to the setting where care is provided, such as an assisted living residence, a nursing facility or your home. You may have the same choices if you own a private long term care insurance policy. (Request the AHCA/NCAL publication Understanding Long Term Care Insurance. See page 11 for details.)

### ***Medicare***

Medicare, administered by the federal Centers for Medicare and Medicaid Services (CMS), is a health insurance program for people 65 and over and certain disabled people under 65. Medicare covers only those services rendered to help a beneficiary recover from an acute illness or injury. While many persons with Alzheimer's and related dementias have significant chronic care needs, they often do not require the services of a skilled health care professional. As a consequence, the individual may not qualify for Medicare payments.

***Nursing facility*** coverage under Medicare is very limited. If a person qualifies (see previous description) and has a 3-day hospital stay, Medicare may pay for up to 100 days of care in a skilled nursing facility (SNF) if that many days are needed. Medicare will cover 100 percent of the first 20 days (if that many days are needed) in a SNF; for days 21-100, the individual pays a daily coinsurance amount, which is over \$100 per day.

Assisted living costs are not generally covered by Medicare, but it may pay for short-term services (e.g. physical and other therapies) contracted through a home health care agency and provided to the resident at the assisted living facility.

***Home care*** coverage under Medicare is available only if a patient:

- Is confined to the home; and,
- Requires physical, occupational or speech therapy, or skilled nursing care, which will be provided from a home health agency under a doctor's plan of treatment. The duration and number of visits will depend on the treatment care plan written by the attending physician.

The homebound patient may see his or her physician, psychiatrist, psychologist or social worker on an outpatient basis.

**Hospice** coverage under Medicare is available if:

- The person has Medicare Part A (Hospital Insurance).
- A physician certifies that the patient is terminally ill – that life expectancy is six months or less, assuming that the illness runs its normal course; and,
- The person chooses to receive hospice care.

The National Hospice and Palliative Care Organization has published guidelines to help identify which patients with dementia are likely to have a prognosis of six months or less to live. Individuals who do not have other medical complications must show all of the following characteristics in order to be eligible for a hospice program:

- Incapable of ambulating without assistance;
- Incapable of dressing without assistance;
- Incapable of bathing properly;
- Experience urinary and fecal incontinence; and,
- Unable to speak or communicate meaningfully.

For more information about Medicare or to request a Medicare Handbook, call 1-800-633-4337.

### ***Medicaid***

Medicaid is a joint federal-state program to provide health services to low-income people. It has become the major funding source for nursing facilities, covering nearly 65 percent of patients. Medicaid is administered by the states under broad federal guidelines. Reimbursement rates per day of care are also set by the states.

- Eligibility – Medicaid will pay for individuals who meet a state-determined poverty level.
- Benefits – Medicaid will pay for care in a nursing facility (NF) and Intermediate Care Facility for the Mentally Retarded (ICF/MR). States may offer Medicaid funds for Home and Community Based Service (HCBS) waiver programs.

## **Be a Wise Consumer**

As a consumer you need to find out exactly what costs are included in the monthly or daily charge given by the long term care facility or service. There may be extra charges you need to know about. Read all forms carefully and ask questions so that you understand the provider's services and costs.

## **Help Is Available**

Any form of dementia is a challenge to deal with. However, help is available. You may find comfort and sustenance from people who can help. Here are some information resources:

Alzheimer's Association  
919 North Michigan Avenue, Suite 1100  
Chicago, Illinois 60611-1676

American Health Care Association

National Center for Assisted Living

(800) 272-3900  
(312) 335-8700  
<http://www.alz.org>

American Health Care Association  
National Center For Assisted Living  
1201 L Street, NW  
Washington, DC 20005  
Phone: 1-800-628-8140  
[www.LongTermCareLiving.com](http://www.LongTermCareLiving.com)

Medicaid, Medicare and Medigap  
(The Centers for Medicare and Medicaid Services)  
7500 Security Boulevard  
Baltimore, MD 21244-1850  
Phone: 410-786-3000  
<http://cms.gov>

National Adult Day Services Association  
8201 Greensboro Dr., Suite 300  
McLean, VA 22102  
1-866-890-7357  
[www.madsa.org](http://www.madsa.org)

National Hospice and Palliative Care Organization  
1700 Diagonal Rd, Suite 625  
Alexandria, VA 22314  
Phone: 703-837-1500  
<http://www.nhpco.org>  
Social Security & Supplemental Security Income  
Social Security Administration,  
Office of Public Inquiries  
Windsor Park Building  
6401 Security Blvd.  
Baltimore, MD 21235  
Phone: 800-772-1213  
<http://www.ssa.gov>