

TAKING CARE OF LOVED ONES  
WITH DEMENTIA AND  
ALZHEIMER'S DISEASE

AGING ADULT SERVICES AT STANFORD



**STANFORD**  
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*Stanford University Medical Center*

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*Welcome to Aging Adult Services at Stanford. This is a program devoted to meeting the needs of older adults and their families and providing them a continuum of care with support and resources. Aging Adult Services offers coordination of services, assessments, home visits, consultations, advocacy, assistance with appointments, physician referrals, access to community resources and educational workshops.*

## **GROWTH AMONG OLDER ADULTS**

Statistics have predicted the increase of longevity and the growth in the number and proportion of older adults worldwide. For example, in 1950 adults above 65 were 5.2% of the population, and by contrast, by 2050 one out of ten will be 65 years or older. With increasing age comes the high risk of dementia and Alzheimer's disease.

One of the primary needs of families just beginning their experience with dementia and Alzheimer's disease is information. The following is a comprehensive package on the management of dementia and Alzheimer's disease. Caring for a person with dementia presents challenges and this information may help you take care of your loved one with confidence and compassion.

## **1. WHAT IS DEMENTIA?**

Dementia refers to an organically caused brain disorder resulting in memory loss, personality changes, and overall loss of intellect or essential mental capacity. Dementia usually results from a widespread destruction of cells in diverse areas of the brain, with consequent loss of mental functions previously controlled by those cells. There are many kinds of dementia and Alzheimer's disease is the most prevalent one. Another common condition is Mild Cognitive Impairment (MCI), characterized by losses in memory, language, and other mental functions, severe enough to be noticeable and show up on tests, but not serious enough to interfere with daily life. Because the

problems do not interfere with daily activities, the person with MCI does not meet the criteria for being diagnosed with dementia. Dementia is common in the elderly with 5% of people over the age of 65 affected to some extent.

## **2. CAUSES OF DEMENTIA**

**Reversible Dementias Can Be Caused by the Following:**

- **Reactions to medications.** Adverse drug reactions are one of the most common reasons older adults experience symptoms that mimic dementia. All medications, prescriptions, over-the-counter pills and herbal remedies should be monitored by a physician.
- **Endocrine abnormalities.** The conditions of low or high thyroid levels, parathyroid disturbances or adrenal abnormalities can cause confusion that mimics dementia.
- **Metabolic disturbances.** Confusion and changes in appetite, sleep and emotions can be caused by medical conditions including kidney and liver failure, electrolyte imbalances (blood chemistry levels), hypoglycemia (low blood sugar), hypercalcemia (high calcium), and diseases of the liver and pancreas.
- **Emotional distress.** Depression or major life changes such as retirement, divorce or loss of a loved one can affect one's physical and mental health.
- **Vision and hearing.** Undetected problems of vision or hearing may result in inappropriate responses and be misinterpreted.

- **Infections.** Confusion can be a symptom of an infection.
- **Nutritional deficiencies.** Deficiencies of B vitamins (folate, niacin, riboflavin and thiamine) can produce cognitive impairment.

### Degenerative (Irreversible) Dementias

If reversible dementias are ruled out and it is determined that the person has a degenerative or irreversible dementia, it is important that families and medical personnel seek the cause of the problem. The following are the most common degenerative dementias:

- **Alzheimer's disease** is the most common cause of dementia in people over 65, although the disease also occurs in people much younger. Alzheimer's affects approximately 50 percent of those over 85. Presently, researchers cannot definitely say what causes the disease, and there is no cure. Symptoms differ from person to person, but declines in memory, thinking and ability to function gradually progress over a period of years, ending in a severe loss of function.
- **Ischemic Vascular Dementia** is the second most common dementia, characterized by an abrupt loss of function or general slowing of cognitive abilities that interferes with what are called "executive functions" such as planning and completing tasks. When symptoms appear suddenly, the person has usually experienced a stroke.
- **Dementia with Lewy Bodies** is a progressive degenerative disease that shares symptoms with Alzheimer's and Parkinson's. People affected by this disease have behavioral, motor and memory symptoms.
- **Frontotemporal Dementia** is a degenerative condition of the front (anterior) part of the brain, and frequently occurs after age 40 and usually before age 65. Symptoms appear in two seemingly opposite ways: some individuals are overactive, restless, distracted and disinhibited (showing poor social judgment), while others are apathetic, inert and emotionally blunted.
- **Creutzfeldt-Jakob Disease** is a rapidly progressive, fatal brain disease. This may be very difficult to diagnose as it has many different symptoms, including behavioral, movement and cognitive changes, as well as sleep problems, loss of appetite and headaches.
- **Parkinson's Dementia** is the name given to a collection of symptoms and signs consisting of tremor, stiffness, slowness of movement and unsteady gait. Many neurological disorders have features of parkinsonism, including many of the dementias.
- **Progressive Supranuclear Palsy** involves the gradual loss of balance, trouble walking, loss of control of voluntary eye movements, and dementia and is frequently misdiagnosed as Parkinson's disease.
- **Normal Pressure Hydrocephalus** is characterized by gait instability, urinary incontinence and dementia. Traditionally, treatment is surgical implantation of a shunt to reduce the pressure caused by the build up of cerebrospinal fluid.
- **Huntington's disease** is a fatal disease typically characterized by involuntary movements (chorea) and cognitive decline.
- **Mixed Dementias.** At times, two of these conditions can overlap.

### 3. SYMPTOMS NOT TYPICAL OF NORMAL AGING

- Forgetting things more often
- Forgetting how to do things done before
- Trouble learning new things
- Repeating phrases in the same conversation
- Trouble making choices or handling money
- Not being able to keep track what happens each day

### 4. COMMON SYMPTOMS OF DEMENTIA

Symptoms usually develop slowly over a number of years, often beginning with memory loss and progressing to mood changes, personality changes and severe dementia. It can be difficult to determine exactly when dementia starts, as it usually begins with mild forgetfulness. Although the speed of progression varies widely, Alzheimer's disease typically takes 7 to 10 years from the first signs of memory loss to severe dementia and death. Common symptoms include:

1. Memory loss, confusion, difficulty performing tasks, disorientation to time and place, unsettled behavior evident in the late afternoon or early evening, poor or decreased judgment, problems with abstract thinking, misplacing things, problems with language, repeating things over and over again, difficulty with word finding, driving difficulties or getting lost.
2. Changes in mood or behavior, changes in personality, loss of initiative, wandering and /or pacing, incontinence, and neglect of self-care and household chores. Inappropriate behaviors include being flirtatious, suspiciousness, paranoia, withdrawal or apathy, abnormal beliefs or hallucinations, irritability, being accusatory, tearful, combative, aggressive, mean, and clinging and shadowing the person caring for them.

#### Areas Of Difficulty For The Patient

- Losing the right to drive
- Knowing something is wrong
- Losing friends
- Becoming isolated

## 5. HOW IS DEMENTIA DIAGNOSED?

Memory loss in dementia is often first noticed by relatives and friends of the affected person. Dementia can be diagnosed by a specialist (a neurologist, geriatrician, or psychiatrist). The diagnosis of dementia involves a comprehensive evaluation of the person with cognitive and/or behavioral changes. The evaluation may encompass the following: medical examination, extensive history taking, neuro-psychological testing, blood work — including a comprehensive chemistry panel, thyroid function studies, B12 level, folate level, lyme titer, and serum protein electrophoresis, and several types of brain scans- including a computerized tomography (CT) scan, a magnetic resonance imaging (MRI) scan or a positron emission tomography (PET) scan. Specialty organizations such as the Alzheimer's Association offer information on where to turn for an evaluation.

## 6. LEGAL, FINANCIAL & MEDICAL PLANNING

The cost of providing long-term care for a person with dementia can be very high. Many people assume that government programs, such as Medicare and others will pay for it. To reduce the financial burden that can come from paying for care requires advance planning. Legal, financial and medical planning is something everyone ought to do, regardless of dementia. It is best to consider life-planning decisions while the person with dementia is able to thoughtfully consider options and voice their values. It is good to be prepared for urgent situations that may occur.

### LEGAL PLANNING

Primary areas of legal planning include formulating the following:

- **Advance Directive** is important for the patient's treatment and care. There are two forms of Advance Directive:
  1. **Living Will** outlines choices for medical care, including the use of artificial life support.
  2. **Durable Power of Attorney for Health Care** allows the patient to appoint an agent (someone they trust) to make all decisions regarding health care.
- **Living Trusts** manage assets and investments by an appointed agent.
- **Conservatorship** in which the court, along with an individual appointed by the court, makes decisions for the person who is not able to make decisions for themselves.

### FINANCIAL PLANNING

The following is a financial checklist.

- List bank and brokerage accounts.
- List all documents of title such as mortgage papers or ownership statements, deeds, stock, bond certificates, loan papers, contracts or other legally binding documents, major debts, bank statements, passbooks, CD'S, existing wills or Durable Powers of Attorney.
- List major assets (real estate, stocks, cash, jewelry, insurance, etc.).

- Review pension, retirements benefit summaries, social security payment information, monthly or outstanding bills.
- Know all insurance coverage for health, long-term care or custodial care.
- Investigate private insurance or government benefit programs for long-term care, at home/assisted living/skilled nursing facility.

### **OTHER FINANCIAL PLANNING TIPS**

#### **Consider the following costs of care:**

- Ongoing medical treatment, including diagnosis and follow-up visits
- Treatment for other medical conditions
- Prescription drugs and supplies
- Skilled and non skilled care at home
- Adult day services, residential care services, including assisted living and nursing homes

#### **Financial resources that may help cover costs:**

- Insurance – includes government insurance programs such as Medicare and Medicaid; disability insurance from an employer-paid plan or personal policy; group employee plan or retiree medical coverage; life insurance and long-term care insurance
- Personal savings and assets
- Community support – includes local support services at low or no cost, such as respite care, support groups, transportation and meal delivery

#### **Caregivers may need to determine financial assistance by the following:**

- Reviewing savings, investments, long term care insurance plans
- Assessing the need to increase life insurance or disability insurance
- Using their own workplace flexible spending account to cover the person's medical costs or dependent care expenses
- Talking with other family members about pooling resources together to pay for care

Professional financial advisers and banks can be valuable sources of information and assistance. They can help you identify potential financial resources.

### **MEDICAL MANAGEMENT**

The person with dementia will require considerable medical attention. They may also have other concurrent health conditions requiring attention and treatment. Treatment decisions should be individualized according to the patient's stated preferences, known values, a consideration of the severity of the patient's dementia and the prognosis. Early planning is essential for end-of-life decisions.

#### **This may include discussion regarding:**

Having Do Not Resuscitate (DNR) or Do Not Intubate (DNI) orders. These are written orders from a doctor that resuscitation and intubation should not be attempted if a person suffers cardiac or respiratory arrest. Such an order may be instituted on the basis of an advance directive from a person, or from someone entitled to make decisions on their behalf.

## **7. HANDLING DIFFICULT BEHAVIORS**

Individuals who suffer from dementia can often be difficult to live with or care for, which is why many caregivers turn to assistance outside of the home. The following are suggestions to help manage these difficult behaviors.

- The person you are caring for has a brain disorder that shapes who he/she has become. When you try to control or change his/her behavior, you'll most likely be unsuccessful or be met with resistance.
- Some of the greatest challenges of caring for a loved one with dementia are the personality and behavior changes that often occur. You can best meet these challenges by using creativity, flexibility, patience and compassion. Remember the worth of the person as a human being. It also helps to not take things personally.
- Research suggests not to overwhelm the person with dementia by mental exercises such as reading, playing games, painting.

- Behavioral problems may have an underlying medical reason; perhaps the person is in pain or experiencing an adverse side effect from medications. In some cases, like incontinence or hallucinations, there may be some medication or treatment that can assist in managing the problem. Check with the physician for options.
- Behavior for dementia patients is often triggered. It might be something a person did or said that triggered the behavior or it could be a change in the physical environment. *The root to changing behavior is recognizing the triggers.* Try a different approach, or try a different consequence.
- What works today, may not work tomorrow. The multiple factors that influence troubling behaviors and the progression of the disease means that solutions that are effective today may need to be modified tomorrow – or may no longer work at all. The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.
- Get support from others. You are not alone – there are many others caring for someone with dementia. Call the local chapter of the Alzheimer's Association, or a Caregiver/Senior Resource Center.

## 8. MANAGING DAY TO DAY ROUTINES

- Maintain a positive attitude and remember the worth of the person as a human being.
- Learn to agree and redirect. Don't argue or try to change the person's mind, even if you believe the request is irrational.
- Remember that the patient has a brain disorder – accommodate the behavior, do not control the behavior.
- Structure the day; routines are reassuring.
- Keep the environment familiar. Put things in expected places.
- Provide consistent environmental cues about time of day and date.
- Recognize triggers – keep a diary.
- Phrase diagnosis as a “memory problem.”

- Be near the person. Many dementia patients feel most comfortable if their caregiver is nearby.
- Help the person to look forward to milestones of the day, such as bathing, dressing, meal preparation, getting ready for bed, etc.
- Enlist the patient in accomplishing small tasks around the house or yard.
- Get help for activities of daily living – such as –bathing, dressing and personal hygiene, toileting and eating.
- Manage expectations of family and close friends.

## 9. DRIVING AND DEMENTIA

When an individual is diagnosed with dementia, one of the first concerns that families face is whether or not that person should drive. A diagnosis of dementia may not mean that a person can no longer drive safely. In the early stages of dementia, some individuals may still possess skills necessary for safe driving. Most dementias, however, are progressive, meaning that symptoms such as memory loss, visual-spatial disorientation, and decreased cognitive function will worsen over time. This also means that a person's driving skills will decrease and, eventually, he or she will have to give up driving. Physicians in the United States will notify the authorities to make the individual with dementia stop driving.

**Make arrangements for alternative transportation such as asking family and friends, using public transportation and “Senior and Special Needs” transportation services. As a last resort, you may have to prevent access to a car. Some methods to do that include:**

- Hiding the car keys.
- Replacing the car keys with a set that won't start the car.
- Disabling or selling the car.
- Moving the car out of sight.

## 10. THE 10 STEP PLAN FOR CARING

1. Get a baseline of information for making current and future care decisions.
2. Get a medical assessment and diagnosis.
3. Educate yourself and your family. Information is empowering.
4. Determine your loved one's needs.
5. Outline a home care plan.
6. Look at finances.
7. Review legal documents.
8. Safety-proof your home and keep your loved one safe.
9. Connect with others.
10. Take care of yourself.

## 11. COMMON CAREGIVER RESPONSES & HEALTH TIPS FOR THE CAREGIVER

**Grief.** You may feel that you have lost a companion, friend, or parent, and grieve for the way the person used to be.

**Guilt.** It is common to feel guilty for being embarrassed at the person's behavior.

**Anger.** It is important to distinguish between anger at the person's behavior – which is a result of the disease – and your anger with the person.

Caregivers should try to make sure they get adequate breaks from caregiving so that they are not worn down by demanding behavior. Use of adult day care centers, in-home respite, and regular residential respite are helpful ways to achieve breaks. Here are ten recommended steps for taking care of yourself:

1. Engage in mentally stimulating activities as they strengthen brain cells and the connections between them, and may even create new nerve cells.
2. Optimize memory by mental gymnastics (try one new cognitive endeavor every 5 – 10 years, e.g., a new sport, foreign language, card game, word puzzle).
3. Research suggests that high cholesterol may contribute to stroke and brain cell damage. A low fat, low cholesterol diet is advisable. A diet rich in dark

vegetables and fruits, which contain antioxidants, may help protect brain cells.

4. Get rid of stress – stress can make it hard to sleep, concentrate, learn and remember. Exercise, prayer and meditation are good stress relievers.
5. See your health care professional regularly – many health problems, such as high blood pressure, diabetes, depression, and cardiac illness can cause a predisposition for dementia.
6. Avoid medications that may make your memory worse, such as anticholinergics (antihistamines, tricyclic antidepressants, bladder medications) and benzodiazepines (psychotropic drugs, commonly known as minor tranquilizers, are prescribed mainly for anxiety and sleeping problems).
7. Remain socially active – social activity makes physical and mental activity more enjoyable and stimulates brain cells.
8. Stay connected and engaged with friends and family.
9. Avoid obesity – walk, dance, and tai-chi for balance and exercise. Exercise increases blood flow to the brain, which helps keep the brain healthy and may even help new brain cells grow.
10. Eat a diet that is low in saturated fat (avoid fried foods, butter, cheese, beef and pork), rich in fruits, vegetables and B vitamins.

## 12. RESOURCES IN THE COMMUNITY

Because of the intensity of care that may be required, it is often difficult for even a loving family to provide all the “around the clock” care that a relative with dementia may need. It is not uncommon for a spouse or children to feel that they have an impossible choice between being utterly overwhelmed (if they try to provide all the care) or feeling they are betraying their relative (if they send them to a nursing home). This often leads to the care provider becoming exhausted. Because of this it is often helpful to investigate local resources to help the caregiver.

- Placement Resource – Contact a local group/agency to assist you in finding a suitable placement for the patient.



- Respite Care – Publicly or privately paid temporary care (relieves primary care giver to do errands or just “get away for a while”). Friends and relatives often provide this even when they are unable or unwilling to share primary care responsibilities.
- Adult Day Care – Private programs that provide a safe, structured setting, with trained personnel, for several hours in a day.
- Adult Foster Care – Private individuals or non-profit organizations maintain houses and provide care for one or more patients.
- Home Delivered Meals – Contact a local agency who provides home delivered meals.
- Case Manager and Service Coordinator – In recent years a number of people, often social workers, assist the families of cognitively and/or physically impaired persons with identifying and coordinating needed services.
- Home Care Services – getting help from home care agencies, home health agencies and geriatric care managers for assistance with activities of daily living (i.e. like bathing, dressing, personal hygiene, toileting, eating) and handling difficult behaviors (i.e., repetitive questioning and wandering).

#### **WHERE TO LIVE – CHOOSING A FACILITY OR NURSING HOME**

A person with dementia may be moved to a facility or nursing home because his or her care needs or behaviors may exceed the abilities or resources of their family or friends to care for them at home.

The decision to move your loved one is often hard. The person with dementia may not wish to go or live elsewhere and may become outraged or frightened when the decision is mentioned. There is also quite a bit of variation in the quality of care in facilities and nursing homes. It is best to visit the prospective facility and ask about the number of staff members per resident, the qualifications of the staff (aides, nurses) the presence and frequency of services by support personnel (physician, activities therapist/coordinator, podiatrist). Observe how other residents are being treated (do they appear clean and groomed), does the staff seem overworked and impatient or pleasant and respectful toward residents. In general, the better staffed facilities and nursing homes cost more. This

may require the person to liquidate most of their assets or the person may have to rely on family or community resources to assist in paying the cost. Once someone with dementia has moved to a facility or nursing home, it is not uncommon for the person to take several weeks to get used to the new place.

- Assisted Living – care homes that specialize in providing some level of assistance with activities of daily living (bathing, dressing, grooming, eating, toileting, etc).
- Skilled Nursing Facilities (SNF; aka Nursing Home or Convalescent Hospital) – care homes intended for individuals who require an extremely high degree of ongoing personal care such as in moderate, late or final stage dementia.
- Special Dementia Care Units – facilities providing security to wanderers, staff trained to deal with behavioral difficulties and activities tailored to the needs and abilities of persons with dementia.
- Continuing Care Communities (CCC)/Life Care Communities (LCC) – facilities with independent, assisted and memory support wings can be very useful.
- Hospice and Palliative Care – programs considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury. Hospice and Palliative Care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the person’s needs and wishes. Support is also provided to the patient’s loved ones.

### **13. TREATMENT**

Talk to your doctor about what treatment may be right for the person in your care. A medication’s effectiveness, and the side effects it may cause, can vary from one person to the next. Treatments vary depending on the cause of dementia – hence accurate diagnosis is critical

#### **KNOWN MEDICAL TREATMENTS**

1. Drugs are not effective for everyone and effectiveness may be limited to early and middle stage dementia.
2. Commonly used drugs are – Aricept, Exelon, Reminyl and Namenda.

### **MEDICATIONS TO TREAT COMMON SYMPTOMS**

- Antidepressant medications for depression.
- Medications for anxiety, restlessness, verbally disruptive behavior, resistance, hallucinations, delusions, agitation, aggression, hostility and uncooperativeness.
- Medications to manage conditions like sleep and movement disorders.

### **COMMON QUESTIONS TO ASK THE PHYSICIAN WHILE DISCUSSING TREATMENTS OPTIONS**

- What kind of assessment will you use to determine if the drug is effective?
- How much time will pass before you will be able to assess the drug's effectiveness?
- How will you monitor for possible side effects and what effects should we watch for at home?
- Is one treatment option more likely than another to interfere with medications for other conditions?
- What are the concerns with stopping one drug treatment and beginning another?
- At what stage of the disease would you consider it appropriate to stop using the drug?

With the current aging of the population worldwide, the number of those with dementia and Alzheimer's is increasing rapidly, and along with it the impact of the disease on society. Research efforts are expanding to include drugs for the prevention or delay of the disease, the amelioration of its symptoms, and creation of strategies for managing the care of those afflicted.

Rita Ghatak, Ph.D.,  
Director, Aging Adult Services at Stanford  
e-mail: [rghatak@stanfordmed.org](mailto:rghatak@stanfordmed.org)  
[www.geriatric.stanfordhospital.com](http://www.geriatric.stanfordhospital.com)





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