

Aging Adult Services
Memory Support
Program



Stanford
HEALTH CARE
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Aging Adult Services Memory Support Program

The Memory Support Program provides evidence-based support for adults and families facing memory and cognitive impairment. Through one single point of contact, the Memory Support Program offers consultations, assessments, family meetings, home visits, and care coordination of medical and non-medical services. The program's team develops a comprehensive care plan customized to meet the adult's individualized needs. The care plan includes caregiver support, education, care approaches, and connections to community resources.

Overview

Growth of an at-risk population

In 1950, adults 65 and older were 5.2% of the population. By 2050, that percentage is expected to quadruple. As we age, our risk of developing dementia and Alzheimer's disease also increases: 5% of people 65 and older are afflicted by dementia. Caring for a person with dementia presents challenges that few understand until dementia becomes a reality for a family member or friend. Information about dementia and care strategies is an essential part of caring for your loved one with confidence and compassion.

Dementia

Dementia refers to an organically caused brain disorder that produces memory loss, personality changes, and overall loss of intellect or essential mental capacity. Dementia is usually caused by widespread destruction of cells in diverse areas of the brain, with subsequent loss of mental functions once provided by those cells. There are many kinds of dementia, Alzheimer's disease is the most common.

Mild Cognitive Impairment

- Mild cognitive impairment (MCI) is characterized by losses in memory, language, and other mental functions that are noticeable and show up on tests. Since these losses are not serious enough to interfere with daily activities, the person with MCI does not meet the criteria for a

dementia diagnosis. Common changes with MCI include forgetting important appointments or social engagements, losing a train of thought or the thread of conversations, feeling increasingly overwhelmed to accomplish a task. People with MCI have a significantly increased risk — but not a certainty — of developing dementia. Few risk factors for MCI are increasing age, diabetes, smoking, high blood pressure and cholesterol, depression, lack of physical exercise or mentally or socially stimulating activities, having a specific form of a gene known as APOE-e4, also linked to Alzheimer's disease — though having the gene does not guarantee that the person will experience cognitive decline.

Causes of Dementia

Reversible dementias can be caused by:

- **Reactions to medications.** Adverse drug reactions are one of the most common reasons older adults experience dementia-like symptoms. All medications, over-the-counter pills and herbal remedies should be monitored by a physician.
- **Endocrine abnormalities.** Low or high thyroid levels, parathyroid disturbances or adrenal abnormalities can cause confusion that mimic 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 lead to cognitive impairment.

Degenerative (irreversible) dementias:

Common degenerative dementias are:

- **Alzheimer's disease.** The most common cause of dementia in people over 65, although it can develop at a younger age. Alzheimer's affects approximately 50 % percent of those over 85. Researchers do not yet know what causes the disease, nor is there a cure. Although the speed of progression varies widely, Alzheimer's disease typically takes seven to ten years from the first signs of memory loss to severe dementia and death. Symptoms include loss of initiative, difficulty performing tasks, disorientation to time and place, unsettled behavior evident in the late afternoon or early evening, wandering and or pacing, poor or decreased judgment, problems with abstract thinking, misplacing things, problems with language, repeating things, difficulty with word finding, driving difficulties, and losing one's way in familiar territory. Other changes can be incontinence, neglect of self-care, inappropriate behaviors such as being flirtatious, suspicious, paranoid, withdrawn or apathetic; developing abnormal beliefs or hallucinations, irritability; becoming accusatory, tearful, combative, aggressive, mean, and clinging and shadowing the person caring for them.
- **Ischemic Vascular Dementia.** The second most common form of dementia is characterized by an abrupt loss of function or general slowing of cognitive abilities that are needed for planning and completing tasks. When symptoms appear suddenly, the person has usually experienced a stroke.
- **Dementia with Lewy Body.** A progressive degenerative disease that shares symptoms with Alzheimer's and Parkinson's. People afflicted by this disease have behavioral, motor and memory symptoms.
- **Frontotemporal Dementia.** A degenerative dementia which affects the front part of the brain. It typically occurs after age 40 and before age 65. Symptoms appear in two seemingly opposite ways: Some individuals are overactive, restless, distracted and disinhibited (showing poor social judgment). Other people with this condition are apathetic, inert and emotionally blunted.

- **Creutzfeldt-Jakob Disease.** A rapidly progressive fatal brain disease that can be very difficult to diagnose due to many different symptoms which can be confused with other medical conditions. Symptoms include behavioral, movement and cognitive changes, sleep problems, loss of appetite and headaches.
- **Parkinson's Dementia.** This condition implies a collection of symptoms and signs that include tremor, stiffness, slowness of movement and unsteady gait. Many neurological disorders have features of Parkinsonism, including many of the dementias.
- **Primary Progressive Aphasia.** A form of aphasia that involves a progressive loss of language function.
- **Progressive Supranuclear Palsy.** A condition which involves the gradual loss of balance, trouble walking, loss of control of voluntary eye movements, dementia and is frequently misdiagnosed as Parkinson's disease.
- **Normal Pressure Hydrocephalus.** A disorder characterized by gait instability, urinary incontinence and dementia. Traditionally, treatment is surgical implantation of a shunt to reduce the pressure caused by the buildup of cerebrospinal fluid.
- **Huntington's disease.** A genetically transmitted fatal disease typically characterized by involuntary movements (chorea) and cognitive decline.
- **Mixed Dementias.** At times, two of these conditions can overlap.

Symptoms Not Typical of Normal Aging

1. Forgetting things more often
2. Forgetting how to do things done before
3. Trouble learning new things
4. Repeating phrases in the same conversation
5. Trouble making choices or handling money
6. Not being able to keep track of what happens each day

Diagnosing Dementia

Memory loss in dementia is often first noticed by relatives and friends. Dementia can be diagnosed by a specialist — a neurologist, geriatrician, or psychiatrist. The diagnosis may include the following: medical examination, extensive history taking, neuro-psychological testing, blood work (including thyroid function, B12, folate, Lyme titer, and serum protein electrophoresis), lumbar puncture, 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. Special focus organizations such as the Alzheimer's Association offer information on where to turn for an evaluation.

Importance of Early Diagnosis

Receiving a diagnosis earlier rather than later offers adults and families more time and opportunity to plan, increases the chances of participating in clinical drug trials, and may slow the progression by allowing the person to benefit from available services. Early planning is essential for end-of life decisions.

Treatment

Pharmacologic Treatment

Treatments vary depending on the cause of dementia which makes accurate diagnosis so critical. People with dementia require considerable medical attention as they may have other concurrent health conditions that require attention and treatment. Treatment decisions should be based on the patient's stated preferences, known values, and a consideration of the severity of the patient's dementia.

Known Medical Treatments

1. Medications are not effective for everyone and their effectiveness may be limited to early and middle stage dementia. Inquire about commonly used medications.
2. Antidepressant medications can be prescribed for depression.
3. Other medications may relieve anxiety, restlessness, verbally disruptive behavior, resistance, hallucinations, delusions, agitation, aggression, hostility, and uncooperativeness.

4. Medications can also be used to manage poor sleep conditions and movement disorders.

Handling Difficult Behaviors

Individuals who suffer from dementia can often be difficult to care for, which is why many caregivers turn to assistance outside of the home. Areas of difficulty for the patient can be losing the right to drive, knowing something is wrong, losing friends, becoming isolated, all of which can be triggers for anger, sadness or frustration. The following are few suggestions to help manage difficult behaviors:

- The person you are caring for has a brain disorder that shapes who they become. Maintain a positive attitude and remember the worth of the person. Accommodate the behavior, try not to control it.
- Do not argue or try to persuade. Instead, try to distract or redirect the person by offering the person something they like to eat or drink, by watching a television show or listening to music, asking the person for their help with a simple activity, or leading the person to a different room.
- Affirm the person's feelings if they are upset. You don't have to agree with why they feel that way but acknowledging their feelings can be validating.
- Structure the day: routines are reassuring. Help the person to look forward to milestones of the day, such as bathing, dressing, meal preparation or getting ready for bed. Enlist the person in accomplishing small tasks around the house or yard.
- Keep the environment familiar by putting things in expected places. Label drawers, cabinets and commonly used objects. Provide consistent environmental cues about time of day and date.
- Identify triggers that cause the person to have behavior outbursts, keep a diary.
- Be near the person and hold their hand while you talk. Many people with dementia feel most comfortable if their caregiver is nearby.
- Get help for activities of daily living including bathing, dressing, personal hygiene, toileting and eating.

- Manage expectations of family and close friends. If needed, describe the diagnosis as a memory problem.

Driving and Dementia

A diagnosis of dementia may not immediately mean that the person can no longer drive safely.

In the early stages of dementia, some people may still possess skills necessary for safe driving.

Most dementias are progressive: Symptoms such as memory loss, visual-spatial disorientation, and decreased cognitive function will worsen over time.

These changes decrease a person's driving skills and eventually the person will need to give up driving. Physicians will alert authorities if the person has a diagnosis of dementia.

Arrange for alternative transportation by asking family and friends to help and take advantage of public and senior transportation services. As a last resort, you may have to prevent access to a car.

Caregiver Support

Common Caregiver Responses and Health Tips for the Caregiver

Grief. You may feel loss and grief for the person you knew as a companion, friend, or parent.

Guilt. It is common to feel guilty for being embarrassed at the person's behavior or not being by the person's side always.

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

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 residential respite, are helpful ways to take breaks. Here are recommended steps for taking care of yourself:

1. Engage in activities that are mentally and physically stimulating.
2. Optimize your brain health by trying new cognitive endeavors including learning a new sport, musical instrument, foreign language or any skill that's outside what's been familiar.

3. Research suggests that high cholesterol may contribute to stroke and brain cell damage. Eat a diet low in saturated fat (avoid fried foods, butter, cheese, beef and pork), rich in dark fruits and vegetables, high in antioxidants and B vitamins.

4. Learn how to manage stress. Stress can cause poor sleep, concentration and impact your health. Exercise and meditation are good stress relievers.

5. Visit 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. Talk with your doctor about alternatives for the medications that may make your memory worse including anticholinergics (antihistamines, tricyclic antidepressants, bladder medications) and benzodiazepines (psychotropic drugs commonly known as minor tranquilizers prescribed mainly for anxiety and sleeping problems).

7. Remain socially active. Social activity stimulates brain cells and makes physical and mental activity more enjoyable.

8. Stay connected and engaged with friends and family.

9. Exercise, walking, dancing and tai-chi are good choices that can help maintain a healthy weight, improve balance and increase blood flow to the brain.

Legal and Financial Planning

The cost of providing long-term care for the person with dementia can be very high. Family members assume that government programs such as Medicare and other health insurance plans will cover the cost. Reducing the financial burden of needed care requires legal, financial, and medical planning. It is best to consider life-planning decisions while the person with dementia can still thoughtfully consider options and voice their wishes.

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, memory care, and skilled nursing facilities

Legal Planning

Advance Directives

- A **living will** allows you to document wishes concerning medical treatments at the end of life. A living will, which can also be called an advance directive or physician orders of life sustaining treatment (POLST), outlines the way an individual wish to be treated for end-of-life medical care. This is quite helpful for a patient with a progressive disease, like Alzheimer’s, who may eventually need life-sustaining treatment. Before the living will can guide medical decision-making, the person must be able to make medical decisions.
- A **medical power of attorney** (or healthcare proxy) allows you to appoint a person you trust as your healthcare agent (or surrogate decision maker), who is authorized to make medical decisions on your behalf. Before a medical power of attorney goes into effect a person’s physician must conclude that they are unable to make their own medical decisions.
- Conservatorship names a court-appointed individual to make decisions for the person who is not able to make decisions for themselves.

Financial Planning

It is important to create a file of the following financial records and documents:

- Bank and brokerage accounts. Professional financial advisers and banks can help identify potential financial resources such as bank accounts, stocks, bonds, CDs, major debts, real estate, jewelry, insurance, etc.
- All documents of title such as mortgage papers, ownership statements, deeds, certificates, loan papers, legally binding documents.
- Pension, retirement benefit summaries, social security payment information, and monthly or outstanding bills.

- All insurance coverage for health, long-term care or custodial care, private insurance or government benefit programs for long-term care at home/assisted living/skilled nursing facilities.

Other resources that may help cover costs:

- Government insurance programs such as Medicare and Medicaid (Medi-Cal in California); 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 services at low or no cost such as respite care, support groups, transportation and meal delivery.

Caregivers may need to step in by:

- 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

Resources

Because of the intensity of care that may be required, it is often difficult for even a loving family to be able to provide “around the clock” care. It is not uncommon for a spouse or adult children to feel they have an impossible choice between being overwhelmed (if they try to provide all the care) or feeling they are betraying the person (if they send them to a care facility). This strife often leads to the care provider becoming exhausted.

Resources in the Community

- Placement Agencies: There are agencies and professionals that can assist in finding suitable placement for the person with dementia, such as assisted living facilities, board and care homes, long term care facilities, etc.
- Respite Care: Publicly or privately paid temporary care that enables the primary

caregiver to be able 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 or cost.

- **Adult Day Care:** Programs that provide a safe, structured setting with trained personnel for several hours a day.
- **Adult Foster Care:** Private individuals or nonprofit organizations maintain houses and provide care for one or more adults.
- **Home Delivered Meals:** Local business or community agencies that provide and deliver meals.
- **Case Manager/Service Coordinator:** Assist the families with identifying and coordinating needed services.
- **Home Care Services:** Home care agencies, home health agencies and geriatric care managers assisting with activities of daily living (bathing, dressing, personal hygiene, toileting, eating) and handling difficult behaviors (repetitive questioning and wandering).

Where to Live (Choosing A Facility)

A person with dementia may need to move to Assisted Living, Memory Care, or a Skilled Nursing Facility because his or her care needs, or behaviors may exceed the abilities or resources of their family or friends who care for them at home. The decision to move your loved one is very hard. The person with dementia may not wish to go or live elsewhere and may become outraged or frightened when the topic is mentioned. There is quite a bit of variation in the quality of care in facilities, so it is important to consider the following:

- 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).
- 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 cost more. Once someone with dementia has moved to a facility, it is not uncommon for the person to take several weeks to get adjusted to the new place. A good practice will be to continue working with the facility for ideas to help the person slowly get used to the new environment.

Types of Facilities:

- **Assisted Living:** Community living that specializes in providing some level of assistance with activities of daily living (bathing, dressing, grooming, eating, toileting, etc.).
- **Skilled Nursing Facilities (SNF),** used to be known as Nursing Home or Convalescent Hospital: This type of facility is intended for individuals who require an extremely high degree of ongoing personal care which can be needed in late or final stages of dementia.
- **Memory Care Communities:** Community living that assist with activities of daily living, security to wanderers, staff trained to deal with behavioral difficulties, and activities tailored to the needs and ability of the person with dementia.
- **Continuing Care Retirement Communities (CCRC)/Life Care Communities (LCC):** Community living with independent, assisted, memory and skilled units.
- **Hospice and Palliative Care:** Each program is the model for quality, compassionate care for people facing a life-limiting illness or injury. Hospice and Palliative care involve a team-oriented approach for expert medical care, pain management, and emotional and spiritual support tailored to a person’s needs and wishes. Support is also provided to the patient’s loved ones.

Summary

The 9 Step Plan for Caring

1. Get a baseline of information for making current and future care decisions.
2. Get a medical assessment and diagnosis, learn about clinical trials.
3. Educate yourself and your family. Organize a family meeting - information is empowering. Share the diagnosis with others if the person feels comfortable doing so.

4. Work on creating Advance Directives, Durable Power of Attorney as needed.
5. Outline a home care plan, safety-proof the home to keep your loved one safe. Find and use local resources- respite care, caregiver support groups, education and training programs
6. Make legal, financial, and other life plans while the person is able.
8. Connect with others.
9. Take care of yourself.

Aging Adult Services Program

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Transitions of Care

Consultations, access to community resources and health education, assistance to patients and families with transitional care from hospital to home and care facilities 650-723-1303

Memory Support Program

Consultations, care coordination, and support to patients and families coping with memory loss 650-723-1303

Community Programs

Strong for Life

Free muscle-strengthening exercise program for older adults 650-723-1303

Other Resources

Stanford Neurology **650-723-6469**

Stanford Senior Care Clinic **650-725-5222**

Farewell to Falls **650-724-9369**

Stanford Health Library **650-725-8400**

NIH Stanford Alzheimer's Disease Research Center (ADRC) **650-721-2409**

Stanford Neuroscience Supportive Care Program **650-721-8500**

Collaboration

The Memory Support Program works closely with the NIH Stanford Alzheimer's Disease Research Center (ADRC). The ADRC is working to translate research advances into improved diagnosis and care for people with Alzheimer's disease and related brain disorders. med.stanford.edu/adrc.html

Material written by staff and adapted from few sites