

STAYING ORGANIZED — A Checklist for Patients and Families

Perhaps your loved one has been exhibiting changes; perhaps they have just been given a diagnosis of dementia. You may be wondering about what steps to take.

There are many issues that all of us should discuss with our families, whether we are ill or in good health. With some exceptions, dementia typically follows a gradual, yet progressive course. The better prepared you are, the more in charge you will most likely feel. With advancing dementia, it is expected that the person's ability to make decisions will falter. It is generally best to have these discussions with your loved one while they are able to carefully consider their values and future wishes. In this way, you can feel comfortable carrying out their desires when the time comes that they are no longer competent to make decisions like healthcare planning, financial planning, and surrogate decision-making. This is also true for end-of-life decisions such as treatment and autopsy. While it may be years before you encounter these situations, it is best to be prepared.

The following is meant to serve as a general guide of tasks to complete in order to ensure important decisions have been made.

EVALUATION

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 and history taking, tests of cognition, and blood work. A scan or image of the brain is often useful. Your healthcare provider (physician or nurse practitioner) may assist you in arranging such an evaluation. Specialty organizations such as The Alzheimer's Association offer information on where to turn for an evaluation.

EDUCATION

If you are given a diagnosis of dementia you should expect a description of the clinical course and prognosis. Features and prognosis varies with the different types of dementia. Alzheimer's disease is the most common cause of dementia; other causes include Frontotemporal dementia, Dementia with Lewy Bodies, and vascular dementia. There are also rapidly progressive dementias such as Creutzfeldt-Jakob disease. Refer to Internet sites and reading materials. Place yourself on mailing lists for relevant newsletters so that you will be informed of advances, announcements, classes and lectures.

TREATMENT

None of the degenerative dementias have a cure, however, there are medications that alter the progression and relieve some of the associated symptoms. For example, cholinesterase inhibitors may enhance memory abilities. A newer medication, Namenda (NMDA antagonist) appears to alter the functional and cognitive deficits in Alzheimer's disease. Selective serotonin reuptake inhibitors (SSRIs) can be helpful in managing certain behavioral symptoms. An antidepressant may be indicated if the person suffers from depression. Ask your healthcare provider which therapies might be indicated in your situation. Maintain a healthy lifestyle that incorporates regular exercise and good nutrition.

LEGAL AND FINANCIAL PLANNING

Some of the issues that you may need to consider include money management, protection of assets, and decisions about appropriate places to live as care needs change. It is recommended that you appoint a person who will know where your important papers are located and to have a plan for handling legal and financial matters in the event you are unable. It is best to consider these issues while the person with dementia is able to participate in discussions and planning.

Legal documents commonly used:

- **Durable Power of Attorney** appoints an agent (someone trusted) to make legal and financial decisions if the person is unable to make decisions themselves.
- **Living Trusts** manage assets and investments by an appointed agent.
- A **Will** documents an executor (person who will manage the estate) and the beneficiaries (those who receive the estate at the time of the person's death).

SAFETY

- **Safety Plan:** Behavioral and cognitive symptoms may impact safety. If getting lost or wandering is an issue, obtain a Safe Return bracelet from the Alzheimer's Association. Pay attention to potential hazards in your home that may include appliances, weapons and electrical devices. Information may be obtained from your health care provider, classes, support groups and reading material provided by the Alzheimer's Association and Family Caregiver Alliance.
- **Emergency Plan:** Have an emergency back-up plan in place. One can never anticipate when urgent needs will come up. Your health may suffer; other family emergencies make require your attention. Enlist the assistance of

family, friends, or neighbors to be available in case unexpected events occur. Appoint someone who will know where your important papers are located.

- **Driving:** Make a decision about driving or the need to have a driving evaluation. Physicians are required by law to report conditions that may affect safe driving. These conditions may include cognitive deficits and a dementia diagnoses. The report is sent to the Department of Public Health and the Department of Motor Vehicles (DMV). The DMV decides whether to reexamine the client or revoke a license.

CONSIDER YOUR LIVING SITUATION

Think about your current living situation with anticipation of future needs. Consider options such as Assisted Living, retirement facilities, Board and Care, and Nursing homes. Companions and aides may be hired to come to your home. Many patients participate in day programs that provide socialization and activities while giving the caregiver a respite from providing care. Long-term care is generally needed when care demands and functional dependence is too much to handle for the family caregiver.

MEDICAL PLANNING

- **Routine Visits with Physician**

Ensure routine follow-up and review of medications with the patient's healthcare provider. Co-existing medical conditions need to be monitored. Treatment decisions and health screening are decisions that should be individualized according to the patient's stated preferences, known values, while in considering the severity of the patient's dementia and the prognosis. Make sure you have a relationship with a physician that you trust and with whom you can communicate comfortably.

- **Documents Commonly Used:**

- Durable Power of Attorney for Health Care
- The Living Will

For information, [see Legal, Financial, and Planning](#).

- **Other Medical Issues**

Nutritional intake can be an issue for some people with dementia and a consultation with a nutrition specialist is sometimes helpful. Attend to safety issues if swallowing difficulties are present. An evaluation by a Speech Pathologist may identify types of swallowing difficulties and treatment strategies. Balance problems increase the chance of falls. An exercise program and/or physical therapy may help with strengthening and decrease the risk for a fall.

- **Autopsy Program**

Enroll in autopsy program if desired. Autopsy provides a definitive diagnosis

for the person's condition, which can be helpful for families and invaluable for future understanding of dementia conditions. Patients of our Memory and Aging Center may call the Autopsy Coordinator for information at (415) 476-6880.

- **Hospice**

Consider hospice when it is generally agreed that life expectancy is 6 months or less. Hospice care can be arranged in accordance with your living situation (e.g. it can be in your home, assisted living or long-term care facility).

- **Caregiver's Health and Well-being**

Regular exercise and time spent in activities that are enjoyable is critical to maintain your health and emotional well being. Organizations such as the Alzheimer's Association and the Family Caregiver Alliance offer support groups and classes to help with strategies and coping.