



Planning for Alzheimer's Care

Four Steps in the Alzheimer's CarePlan

Step 1 - Advance Directives

Alzheimer's disease is a dementing illness. As it progresses, patients lose their memory, their ability to reason, and the ability to understand the consequences of their decisions. Once an individual with Alzheimer's disease has lost competence, it is too late to designate the person(s) he or she wants to make his or her health care, financial- and estate-planning decisions. Yet choosing a decision-maker in advance of incapacity can be critical to maintaining the quality of life for a loved one with Alzheimer's disease, as well as for his or her family. It is one of the best arguments supporting early diagnosis, since most people in the early stages of Alzheimer's disease can execute advance directives before their illness has progressed too far.

There are important documents and directives, such as a power of attorney, a durable health care power, and a will or trust, that must be in place prior to incapacity. For Alzheimer's patients, empowering family members or trusted friends to make health care decisions (health care power) and to do estate and financial planning (power of attorney) ensures that the caregiving effort won't freeze up due to a lack of resources or the absence of a decision maker. The proper execution of advance directives by Elder Law and Estate-Planning Attorneys is a critical component of any Alzheimer's care plan.

Step 2 - Estate Inventory

Before charting the course for a loved one's long-term care journey, we must first determine where we are. An estate inventory is a snapshot of the resources at one's disposal that may be needed to subsidize caregiving. There are six long-term care resources-1) health insurance, 2) income and assets, 3) community resources, 4) family and friends (themselves a resource for caregiving), 5) the home environment, and 6) the client's capacity for self-care. An estate inventory defines three of these resources-health insurance, income/assets, and community resource eligibility. The other three resources-family/friends, the home environment, and client capacity-are established by the CareNeeds Assessment, the third step in the care planning process (see below).

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We cannot efficiently plan or manage long-term care without knowing how much care we can pay for ourselves or how much can be subsidized by the community (local, state, federal programs). A clear snapshot of our income from fixed sources (social security, pension and other retirement income), of our assets (savings, investments, equity in the home, and so on), and what our health insurance will and won't cover (including long-term care insurance) must be done before we decide on caregiving arrangements for a loved one with Alzheimer's disease.

Step 3 - CareNeeds Assessment

Both the amount and the type of care needed by an Alzheimer's patient will change over time. In the early stages, periodic supervision and homemaking (shopping, cleaning, and laundry) may be all that's needed. Gradually, the level of care may increase to include higher levels of supervision, personal care assistance, behavior management, or even placement in a specialized dementia-care facility or nursing home.

A careneeds assessment for an Alzheimer's patient examines what the patient needs, how much care his or her family can provide, how the home is configured, and what the patient is capable of. The assessment is best performed by family members and/or loved ones working in consultation with mental health and health care professionals skilled in Alzheimer's care. Since many people with Alzheimer's disease are still living in their homes-either with spouses, with children or alone-the best place to turn for a careneeds assessment is often a home care agency.

A skilled assessment by a home care nurse, preferably with a dementia-care specialty, done in tandem with a home health care social worker, can often be ordered by a physician and paid for by Medicare. But if Medicare won't cover it, the patient or family may have to pay. Spending a few hundred dollars for the advice of a seasoned home care professional is nearly always money well spent in determining the feasibility of home care, how it will be paid for and in setting limits for patients and caregivers alike. Families may also call upon independent care managers or their local elder service agencies (Pikes Peak Area Agency on Aging) to perform the careneeds assessment.

Step 4 - Defining the Options

With advance directives in place, resources organized, and care needs assessed, the actual planning can begin. It is best to take a short-term/long-term approach to planning. Immediate need must be met while plans for likely future needs are constructed. And it is best not to confuse planning with wishful thinking. The best approach is to hope for the best-plan for the worst. Alzheimer's disease is progressively debilitating. Planning for the "worst" acknowledges that nursing home placement may be required at some point in time (costing as much as \$6,000 per month in some areas) and that home care could become even more expensive. Realistic planning for the potentially high cost of long-term care forces us to find the estate-planning and community-support solutions that can preserve the Alzheimer's patient's independence as well as his or her savings-for the caregiving effort, and for the needs of a well spouse or a family's future.



Most care-planning options turn on two primary factors—cost and living environment. Mapping out a care plan often requires that we compromise between competing priorities. Quality of care is usually the top priority and it is usually defined in terms of the venue of care. The home is most often preferred, but resource and caregiver limitations may force a compromise choice for placement in a more restrictive setting.

Today, there are many residential choices for people with Alzheimer's disease, the appropriateness of which is first determined by safety concerns. Safety is first measured by actual physical risk for injury and by behavioral and emotional stability second. These risks are reduced by incrementally higher levels of supervision, personal care assistance, and restrictions on freedom of movement. Home care for a person with Alzheimer's disease may not work if he or she cooks unsafely, smokes unsafely, or tends to wander. In such cases, the family may be forced to hire 24-hour supervision, or provide it themselves. And even if this is affordable, it may not be the best choice for all concerned.

The next least-restrictive setting may be an assisted living facility with some private-duty care. If a person's cognitive function and self-care ability has declined to where he or she requires more supervision, a rest home or specialized dementia-care facility may work—still less restrictive (and less expensive) than a nursing home, but possibly safer and often less costly than 24-hour home care. And community programs may also subsidize all of these options for income- and asset-eligible patients.

Behavior management often makes planning for Alzheimer's care particularly difficult. But at the end stage of the illness, behavior management may become less of a challenge than basic personal care and intermittent nursing services. Care planning must anticipate a sequence of living arrangements that may, ultimately, result in a return to the home. Many Alzheimer's patients become home care patients once again, for the final stage of the illness.

Conclusion

Long-term care can be likened to an expedition. As with all expeditions, planning is a prerequisite to success. For a plan to work it must be adaptable and it must be based on good information. The more knowledge one has about the nature and course of Alzheimer's disease, the better. Combining knowledge with the basics of long-term care planning greatly increases the likelihood that a loved one will receive the best care available and that's family's journey will be as smooth as possible.