



Preparing for Dementia

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Dementia is on the rise with the aging of baby boomers. Nearly six million individuals in the U.S. have Alzheimer's, while others deal with cognitive decline related to Parkinson's disease, stroke, Downs Syndrome or other medical conditions. The changes are often wrenching, as parents become vulnerable and adult children grieve for what has been lost. But since dementia is often a gradual process, making early preparations can reduce future turmoil.

Legal Documents

At the onset, legal counsel must always ask, "Who is my client?" and "Does my client have mental capacity to make their own decisions?" In general, I consider it a red flag if, during a meeting, children do most of the talking on behalf of an elderly parent. Moreover, legal standards differ for determining mental capacity when entering contracts, signing estate planning documents and making healthcare decisions. Always arrange for a private one-on-one meeting with the client to help you answer these vexing questions.

Important documents include:

- A **will**, which establishes how the individual wants to dispose of their assets, can prevent family disagreements concerning property having either financial or sentimental value.
- A **power of attorney** authorizes one or more trusted persons to make financial choices on behalf of the grantor of the power. It doesn't replace them as an autonomous decision-maker, it simply empowers others to deal with economic matters when and if the grantor is unable to do so. This is a good time for named agents to have discussions with the grantor about how they'd like their affairs handled and to inventory their assets, liabilities and important documents. They should also share any passwords that will be needed in order to access digital records and accounts.
- In certain cases, creating a **living trust** is helpful to hold some or all of the individual's assets, with instructions to a designated trustee for their management. Most often both a living trust and a power of attorney are needed when, for instance, individuals want their investments held in the trust, but not their checking account

or car. In that case, the agent designated under the power of attorney would manage the car and checking account, while the trustee managed the assets held in the trust. Note that assets in a living trust are “countable” for the purpose of establishing Medicaid eligibility—a consideration if the individual may eventually need long-term care.

- A **healthcare proxy** designates someone to make healthcare decisions for the grantor of the proxy if they are unable to do so. It can be drafted to specify communication among family members with regard to healthcare decision-making and to define precisely the authority of the healthcare agent.
- [A living will/advance directive can provide critical guidance](#) to family members and medical providers by stipulating how aggressive end-of-life treatment should be. Perhaps more effective, though, especially in difficult cases, is a **Medical Order for Life-Sustaining Treatment (MOLST)**. A MOLST is a physician’s order and is created through a discussion with one’s physician about their current health and treatment options. It needn’t be exclusively about end-of-life care, but since it can’t possibly foresee all possibilities, a surrogate should also be named in the MOLST. In coordinated cases, the MOLST surrogate also serves as the agent under the healthcare proxy. Because a MOLST becomes part of the individual’s medical record, it’s less likely to be overlooked by health professionals during an emergency.

Creating some or all of these documents can avoid the need to establish **guardianship** of someone who has become unable to care for themselves. Guardianship is a court-ordered process, which invests broad, albeit court-monitored, decision-making responsibility in the appointed guardian. It’s an expensive, time-consuming and often emotionally draining process that, in most cases, could have been avoided if the individual had engaged in prior planning. In addition, the court has wide latitude for determining who should be appointed guardian. Often, if the judge suspects even minor conflict within the family, there’s a possibility that an outside party, rather than a family member, will be named as guardian.

Financial Planning

It’s also important to evaluate the potential costs of future treatment and to consider consulting a financial advisor. Will your family member be cared for at home by family members, require an aide, participate in adult daycare, need care in a personal care facility, or, perhaps eventually, in a skilled nursing facility?

If they have long-term care insurance, read the fine print. Policies differ significantly in how they define compensable coverage, at what amount, and for how long. Medicare won’t pay for long-term “custodial care” –help with tasks of daily living, such as showering and

dressing. And, in general, it will only cover care in a skilled nursing facility for limited periods following discharge from a qualifying hospital stay. While Medicaid covers both long-term custodial and medical care—sometimes at home—details vary by state, and there are stringent financial requirements. Make sure the financial advisor and legal counsel communicate with each other.

Caregiving Challenges

While caring for someone with dementia, or other memory impairments, can be difficult, remember that troubling behaviors often result from the dementia. Sometimes individuals with dementia become **argumentative or threatening** in ways that were previously atypical. They may be **uncooperative** about bathing, dressing or even eating. Or they may **wander** from home or a nursing facility. In some cases, pain or side effects from medication may be the cause, so check with their treating doctor.

Try to identify triggers and, rather than attempting to control the individual— which will probably be unsuccessful— endeavor to accommodate or redirect them. Alert neighbors to wandering and consider having the individual carry explanatory materials in their wallet or wear a digital device with GPS capability to prevent their becoming lost.

As dementia progresses, communication with the individual will become more difficult. Express your support through tone of voice, facial expression and appropriate physical touch, as well as words. Respect their personal space and don't stand too close to them or raise your voice.

Care for the Caregiver

With all the demands of caregiving, it's normal to have conflicting emotions. Anger and guilt may coexist with love and compassion. Give yourself credit for the difference that you're making and recognize that, while your relationship with your loved one has changed, it remains valuable.

Take "time off" in order to revitalize. You can't help your loved one if you become exhausted and ill. Are there family members or friends who could help? Look at support services available in the community.

You may want to consider hiring a home aide, especially for help with daily living tasks. While it's possible to receive medical services in the home, as well, there are often logistical problems. There's a shortage of visiting nurse practitioners and quality home health aides, and it can take months to get an approved care plan in place—too long for many families to wait, with the result that placement in a facility occurs. Depending on the

individual's diagnosis and financial situation, there may be public programs, including veterans' benefits, to assist with the expense.

In certain cases, it may make sense to pay a family member for their caregiving duties, especially if they have interrupted their career in order to help out. There are legal issues to consider, though, if you aren't hiring an aide through an agency. For more information on this topic, read "[The Pitfalls of Caregiver Employment: Paying, Withholding, and Reporting Requirements.](#)"

Special Needs Attorneys

Special needs attorneys help their clients navigate these emotional waters daily, and they have more to offer than the drafting of legal documents. They can help families understand the likely trajectory of dementia and other memory impairments as they plan for the future. When there are conflicts, they can assist by presenting options and ways of sharing of responsibility. They have a wealth of contacts with local service providers and a deep understanding of public benefits.

Teepa Snow is an authority on dementia and Alzheimer's care, and her website, <https://teepasnow.com/>, offers many helpful resources. Books I recommend for families navigating these issues are [Still Alice](#) and [Inside the O'Briens](#), by Lisa Genova.

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