

10 Things

Every Dementia Caregiver
Needs to Know



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You are not alone. There are more than 15 million Americans providing unpaid, informal care for people with dementia. On the days you feel particularly lonely, isolated, or discouraged as a caregiver, remember this: 15 million other Americans are walking the same difficult path as yourself.

The following 10 practical tips can help you move forward, one step at a time, on your journey as a dementia caregiver.

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Dementia Care Central

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#1: Know How and When to Communicate the Diagnosis to Family and Friends

Just as acquiring an accurate diagnosis can take time, don't feel rushed in sharing the news with others. Process it as a family first. Talk through your concerns and fears, and establish plans and goals as a caregiver and caree/person with dementia.



Discuss how you wish to present the diagnosis, to whom, and in what order. Keep it simple: the diagnosis is scary and overwhelming for the individual with dementia, for you as the caregiver, and for those to whom you are communicating the news. It's probably not necessary to provide all the details of what's to come, particularly since much of the dementia journey is unpredictable and constantly changing. Write down what information you both (caregiver and caree) agree is most

important to share. You also may want to stage the details of the communication, perhaps sharing the diagnosis and its implications in multiple sessions. Another piece of information that is important to cover? Reminding friends and family that no matter how much memory loss occurs, the person with dementia is still the same person.

From there, develop a communication strategy. Will you, as the caregiver, be responsible for sharing the news? Will your caree draft a letter that can be mailed, emailed, or posted on a personal blog? Do you want to share your story on social media? If considering this option, carefully consider the implications of publically sharing your story and experience, and be certain to communicate the news to close friends and relatives before doing so publicly. Whatever is decided, be sure the person with dementia has a say in the decision process, letting your loved one have as much control over the situation as possible.

#2: Get the Family Involved in Providing Care

Dementia caregiving is not for the faint of heart. Therefore, it's vital to start building your village of support early on. Siblings, spouses, grandchildren, and children all can contribute in big and small ways. Create a list of tasks you'll need help with, such as housecleaning, errand-running, medical appointment transportation, meal prep, and respite care. (Caregivers must make time for self-care and regularly scheduled breaks, so respite care is a must!) Use online tools, like Google Calendar or Lotsa Helping Hands to delegate and manage these tasks and timetables. Beyond doctor's appointments, schedule weekly visits with grandchildren, trips to the barber or hairdresser, and other regular activities to keep both you and your loved one engaged and fulfilled. This also helps in maintaining a sense of normalcy despite the sweeping life changes to come.



Remember: Help comes in a variety of forms. Some family members may feel more comfortable assisting financially, such as paying for monthly respite care. Others may be willing to do the grocery shopping when they go shopping for their own family. Everyone can do something, and every contribution makes a difference. As the caregiver, you will know best when, where, and how you need the most support. Find ways to delegate effectively so you don't find yourself feeling resentful or angry when others are not helping the way you feel they should.

#3: Make Your Living Space Friendly & Safe

In the early stages, your loved one will probably be able to continue with daily interests and hobbies without much disruption. If certain preferred activities become difficult, make adjustments. For example, if your mother enjoys gardening, but seems to get distracted or confused outside, get a few window boxes that she can tend indoors. Perhaps your husband loved spending time in his workshop, but is struggling to use the tools and equipment safely. In this situation, find a tinkering project that he can work on inside where you can supervise and support him when he seems lost or frustrated with the next step.

It is helpful to post photos of regularly used items and clothing (toothbrush, hairbrush, belts, socks) indicating their locations. This saves the individual with dementia the frustration of searching through closets, drawers, and cabinets, and in the process, sometimes forgetting the item for which they were looking. Provide simple step-by-step lists for morning, afternoon, and evening routines. In later stages of dementia, photo cards may also foster choice and independence when communication is limited. Keep these guides age-appropriate in order to empower, rather than degrade. As a caregiver, it's important to never make your loved one feel like a child. As long as your loved one is able to communicate, ask what would be most helpful to him or her.



Approximately 6 out of 10 people with dementia will wander at some point. Therefore, if your loved one is mobile, they are at risk of wandering. Consider an alarm system, even just a simple bell on all home exits and entrances, to alert you to a potential egress. Should your loved one wander, there are many simple, wearable trackers, such as watches, pendants, jewelry, and even shoe inserts. Use a program like the Alzheimer's Association's Safe Return to ensure a speedy, safe recovery of your loved one should they wander from your home or become separated from you in the community, say, at the grocery store or at church.



As Alzheimer's advances, some individuals will lose partial mobility and coordination. Some may have vision deficits (depth perception and spatial awareness issues are common) that affect the safe navigation of one's environment. To help keep your loved one safe and unharmed, clear clutter and create barrier-free paths throughout your home. Also, remove throw rugs that can

present a trip/fall hazard, install grab bars in the bathroom, and keep dangerous household items (sharp knives, toxic cleaning products, etc.) locked away.

#4: Learn How to Communicate Effectively as Dementia Advances

Dementia drastically changes one's ability to communicate. In fact, often with memory loss comes the loss of language. This reality is a wearisome one for both the person with dementia and the caregiver.



Repetitive questions from those with dementia are quite common. Repetition results from short-term memory loss. (You can tell your loved one something 10 times or 100 times, but if her brain cannot physically retain the information, she will ask again).

However, repetitive questions may also be indicative of an underlying stress or anxiety, which the person cannot effectively communicate. Redirecting

the question might help for a time, but if the person is anxious about something, you may find yourself redirecting again and again. Try to get to the root of his concern or understand why she keeps asking what time it is. If he's pacing, perhaps suggest going for a walk. If she seems fearful, remind her she's safe. She may be worried about missing a date with a friend or he might be afraid he's forgotten to check in at work. Reality orientation can sometimes be helpful: i.e., "Today is Tuesday, and it's 11:30 a.m. The next thing we're going to do is prepare and eat lunch." Writing down the day's plans on a whiteboard may also be helpful, as you can direct the person to this board when questions about what's next arises.

When talking to a person with dementia, keep your language simple and direct. Do not talk down to the person or speak to your loved one as you would a child. Instead, focus on shorter sentences that require a simple

yes or no answer. For example, if you ask, “Would you like chicken for dinner?”, this only requires a simple yes or no or a nod or shake of the head. In contrast, if you asked, “What do you want for dinner?”, it requires remembering, finding, and saying the right word—a process that is extremely difficult when memory loss is continually occurring.

Also, do not ask questions they cannot answer (i.e. “What’s my name?” or “Do you remember your grandchild’s name?”), as it will only lead to unnecessary frustration and stress. Don’t take memory loss personally either. Keep this in mind; if your loved one could remember your name, he/she would say it.

Make sure to speak calmly and clearly. Don’t speak loudly, as if the individual is hearing-impaired. Use simple hand gestures or other means of non-verbal communication when words are not enough. It’s also important to try to read their body language for signs of anxiety, stress, or distress.



#5: Understand and Accept the Highs and Lows

How your loved one's disease will advance is unpredictable, and everyone's experience with dementia will be different. Do your best not to compare your loved one to someone else despite taking solace in their experience. Over the course of the disease, people with dementia can have moments of complete clarity sandwiched between moments of utter confusion. Some experience extreme mood swings or become aggressive. Personality changes and mood disorders are normal, and many lose their "filter" or become uninhibited after a lifetime of being reserved and modest.



When you're having a good day as a caregiver and care recipient, celebrate it. When you're having a rough week, be thankful for that moment in the middle of it when you saw recognition in your loved one's eyes or a smile on his face after days without seeing it. It may be helpful to keep a simple journal

with a record of these highs and lows. On hard days, reading back through your victories might give you the boost you need or remind you that this experience has brought joy, even as it has brought challenges.

Many individuals with Alzheimer's will also experience what experts call a "plateau," where the individual maintains a certain level of function and doesn't seem to be getting better or worse for a sustained period of time. However, it is also possible that your loved one will experience a serious plummet or decline seemingly overnight.

When you need to vent, which is healthy and necessary, always remember it is the DISEASE, not the PERSON, causing the challenges. Direct your frustrations at the disease, not the person. In your journal, record your loved one's victories, and write out your frustrations. Don't keep them bottled up, as these negative feelings (which are normal and justifiable) can lead to burnout, resentment, anger, or even abuse.

#6: Know the Types of Care that are Available

There may come a time when you need more help or when it's no longer safe for you to provide care at home. From residential memory care communities to medical/non-medical home care, adult day programs to respite/short-term stays, know what these services offer, how much they cost, and which are most appropriate for your situation. Even if you don't use these supports, simply knowing they exist and how to access them, especially should a care crisis occur, can provide peace of mind and prevent caregiver burnout.



- **Home Care (Medical vs. Non-Medical):** If the services of a skilled medical professional are needed (say, to administer medication or an IV, or to change a colostomy bag or wound dressings), it is considered home health care, or said another way, medical home care. If you need someone to visit on account of your loved one feeling lonely, companion/custodial home care is an option. Non-medical home care workers can also assist with basic ADLs (activities of daily living), like bathing, grooming, toileting, and feeding/eating. They may also help with housekeeping tasks or with

transportation to medical appointments. Some choose home care for overnight assistance if the caree tends to wake several times during the night and is prone to wander.

- **Adult Day Care (Medical vs. Non-Medical):** Adult day services can be medical and non-medical, much like the two types of home care. An adult day program happens in the community, at a senior center or in a freestanding adult day facility. Adult day programs offer meaningful activities and meals. For this reason, many choose adult day care to

prevent loneliness and isolation, as well as offer socialization for your caree. Sometimes the phrase “adult day social care” is used to emphasize that medical care is not provided. Alzheimer’s Day Care is simply a center that specializes in dementia care.

- **Respite Care:** Respite care can include short-term stays at assisted living facilities, nursing homes, adult day care centers, or in-home, so you, the caregiver, can take a break. The type of care is no different, but the objective of the care is to provide caregiver relief.

- **Assisted Living & Memory Care:** Assisted living provides non-medical assistance with the activities of daily living in a residential environment. Memory care units offer the same thing, but with increased security and staff trained specifically to assist persons with dementia. Sometimes memory care is offered in a secured area within an assisted living residence, and other times, it is a standalone residence.

- **Nursing Home Care:** Provides the highest form of care, short of hospitalization, providing 24 hours, 7 days / week medical and non-medical assistance. Less recreational activities and socialization are offered in nursing homes when compared to assisted living or specialized memory care residences.

- **Hospice:** This type of care is also called end-of-life care. In hospice, care is provided to make an individual comfortable, but doctors are no longer treating the disease itself. Hospice can be provided in a variety of locations, including at home, in a hospital, or in a specialized center.



#7: Assemble a Team of Trusted Medical Professionals

Occupational therapists. Home care workers. Neurologists. Family physicians. Geriatricians. Nurses. Pharmacists. There are many medical professionals involved in each patient's care.

Due to insurance related logistics, it can be a challenge assembling a team with whom you are comfortable. However, a care team that understands your loved one's unique needs and knows how best to support you, is an invaluable asset when the going gets tough. While it may take time to find the best care providers, it's well worth the return on your investment. Not sure where to find new providers? Find a local Alzheimer's caregiving support group and ask for word-of-mouth referrals and recommendations.



As you're assembling a team, make sure each member of the team knows the other members of the team and can communicate with them directly. Take it upon yourself to understand how each team member likes to communicate, and share their contact information with each other and your family members.

If you decide to hire in-home care, it may take time to find a person who is the right fit for the needs of your family. Be patient with the process. Sometimes it's a matter of trial and error, but finding a match will eventually offer more relief instead of continual stress for you, the caregiver, which will only lead to burnout.

#8: Plan for the Costs of Care

Know this first: Alzheimer's care is expensive. Medicare and Medigap plans pay very little toward long-term nursing home care, and they provide zero help for assisted living and non-medical, home care. Plan ahead for the possibility of long-term care in a nursing home or memory care community even if you envision yourself as the primary caregiver for the duration. It's important to note, the majority of persons with dementia will require nursing home care at some point, and nursing home care is approaching \$100,000 per year.

Fortunately, the slow progression of Alzheimer's affords families the opportunity to plan for the costs of care. Financial assistance is available, but eligibility criteria are complex, and wait lists are common. Furthermore, creating a financial plan and putting that plan into action are two separate challenges that run on different timelines. Financial experts strongly suggest starting to plan financially for care as soon as you receive the diagnosis. While it is understandable to wait a few months when dealing with the challenges of a recent diagnosis, do not delay a care plan any longer. It is also recommended that one consult with an Alzheimer's financial planning expert.



#9: Get Decision-Making Affairs & Legal Documents in Order

What if you pass away before your loved one with dementia does? What if you are unable to provide care during a crisis? It is critical to record your loved one's wishes and execute the vital legal documents listed below before the disease advances, i.e. before your loved one loses what the law defines as "competency." While one is not required to do so, consider working with an elder law attorney or geriatric care manager to help you create, maintain, and distribute the documents that follow.

- ***Last Will and Testament:*** Controls the distribution of one's property upon their death. Only property that is solely in the name of the individual can be covered by the will. It cannot designate jointly owned property, life insurance, or assets in trusts.
- ***Financial Power of Attorney:*** Allows an individual to appoint another person to act for them in financial matters.



- ***Healthcare Power of Attorney:*** Allows individuals to appoint another person to make healthcare decisions on their behalf. It cannot be used to allow someone to make financial decisions.

- ***Do Not Resuscitate (DNR):*** Informs medical professionals that they should not provide CPR or advanced cardiac life support if the individual stops breathing or if their heart stops. There are variations on this concept, such as Do Not Intubate.

- ***Advance Health Care Directive:*** Gives specific instructions regarding what health care decisions to make should one not be able to communicate their desires.

#10: Connect with Other Dementia Caregivers

As the caregiver for a person with dementia, there is a lot on your plate, and it can be very intense. You're coordinating, organizing, scheduling, redirecting, and prompting. You're doing many things behind the scenes even as you're making a meal for someone who used to make her own meals or feeding someone who used to feed himself. You're helping your husband get dressed in the mornings. You're losing sleep because you're worried that your mother may wander away at night. You're watching the person you love lose memories and the ability to function the way he/she used to in the past. Your relationship has changed as a result. Your free time is limited. You're not able to get together with friends as regularly or at least not without much effort. Your world has been turned upside down by this diagnosis. Dementia affects more than just the diagnosed individual.

Sometimes you'll just want to talk to someone who understands what you're going through, as caregiving can be isolating. When you're spending your days with a loved one and meeting many, or all of his/her daily care needs, it's easy to become drained emotionally, physically, and mentally. It's easy to feel alone. [Find a local support group, or join one online](#), if attending in person is uncomfortable or logistically challenging. You need to hear the stories of others in similar shoes. You need the

encouragement of people who have been there, or are there, in the trenches with you. You need advice from people who are going through the daily losses of dementia as you and your loved one are. It may be hard to open up, and it may feel uncomfortable to be vulnerable among strangers. However, for the sake of your sanity, and to provide better care to your loved one, a solid support group can make a life-changing difference.

