

## Chapter 7

# Caring for the Caregiver

We have a special message for caregivers: *Your loved one will only do as well as you are doing.*

A caregiver has to take care of himself or herself first in order to be ready, available, and healthy enough to assist another. If the caregiver's mental or physical health worsens, he or she may become unable to care for himself or herself, let alone the patient. So, if you're a caregiver, take care of yourself. This means seeing a primary care doctor and any other specialists necessary to ensure your overall health, educating yourself, and enlisting assistance when you need it. If you are overwhelmed, need some days off, or want a housekeeper, then by all means bring in help. This may include other relatives, friends, and/or professionals (medical and other). It also may mean going outside the home for planned respite care, in which your loved one might attend an adult day program or stay overnight (or longer) in a memory care unit or similar facility.

None of us want the caregiver to burn out. You don't need to act alone and it's actually much better not to try to fly solo. Remember that socialization benefits both patient and caregiver. Furthermore, working as part of a team also usually optimizes medical care. Speaking of which, even experienced and/or professional caregivers need to take heed of this advice. The more we mature in our caregiving skills, the greater our tolerance, but the lesser our awareness, of stress. If you are even contemplating whether you might need a hand, then it is worth at least looking into or inquiring about additional assistance. As long as financial considerations were taken into account, we have never heard of a caregiver who got help "too soon."

**Common sense rule: A patient will only do as well as his or her caregiver does.**

### Family Members of Caregivers

This section is directed mainly to adult children of parents dealing with dementia, but other relatives and caregivers may certainly find it applicable as well.

Physicians learn early in their training that an abnormal finding might be missed without thoroughly checking for it. This principle explains why we perform a history and physical in the methodical fashion outlined in Chap. 5. Such careful assessments are especially important for a slow-moving disease like dementia, which tends to sneak up on a patient (and family) little by little.

If you have one parent with dementia and one who is the primary caregiver, you need to monitor the situation, too. This is not only true for parental caregivers who have expressed problems but also for those who haven't. Caregivers may become so hopeless that they give up on any help or solution. They may feel too tired or overwhelmed to pick up the phone or converse in detail about what they are going through. They may also consider it a failing or find it embarrassing to mention such problems to others, especially their children. Therefore, you need to ask questions and also see how things are going with your own eyes.

Find out how your caregiver parent is doing, feeling, and coping. Learn about any particular issues that have emerged in caring for your family member with dementia in any of the "ABCs": Activities of Daily Living (ADLs), Behaviors, or Cognition. Ask about any depressed mood and any problems with sleep or appetite, which can be signs of depression. It's important to know about these issues in the caregiver as well as for the patient. Caregivers of patients with dementia suffer from depression at high rates, especially if the patient has depression and/or behavioral problems [1]. On a happier note, a variety of strategies, including caregiver education and support may be helpful [2] and even delay the placement of a patient into a nursing home [3, 4]. Physicians typically focus office assessments on cognition, but problems with ADLs and behaviors can impose significant daily difficulty for a family caregiver and, along with the caregiver's health, are major reasons for institutionalizing a loved one with dementia [5].

### **Common sense rule: Care for the primary caregiver.**

If your caregiver parent hasn't asked you for help, ask your parent. If your parent declines your assistance, but you suspect it may be needed, express your interest in making life easier for them as subtly and unobtrusively as possible. Parents may be leery of getting help from their grown children, so it is often best to make it about you, rather than them. For example, if you would like to attend a doctor's visit, you might say that you have some questions that you would like to ask the physician and inquire as to whether you could go with them to the clinic to do so.

Make specific proposals of help, especially in ways in which you may be well-suited, such as making doctor appointments and/or driving your parents to these. For parents who are not as adept with computers, offer to convert ordering medications to online and manage these for them. Depending on the circumstances, it may also be helpful to do this with banking or other financial transactions.

Specific times and types of help work best. They are often more practical, easier to receive, and more likely to be accepted, while still offering flexibility. ("Mom, I have Thursdays off and I could take Dad out golfing that day. I could also take him out on the weekend.") This honors and respects an individual's ability to choose between a couple of good choices (or accept them all!). It usually works best to find

nonthreatening approaches of assistance and avoiding blatant interference or injury to anyone's pride and dignity. If offers for help are declined despite an apparent obvious need, your options may include stepping in more assertively, enlisting other family members or friends, and/or consulting with your parents' doctors or other medical professionals.

**Common sense rule: Make specific offers of help.**

Adult children need to keep a close eye on a parent who is a caregiver to make sure Mom is taking care of herself or Dad has some help with the cooking or whatever the case may be. Our experience is that parents often minimize their caregiver burden to and decline offers of assistance from their grown children. Such spousal caregivers often express to us that they don't wish to "bother" their offspring and conceal their real level of distress. We therefore find it helpful to include the adult children (or at least one) at the clinic visit whenever possible.

You might spend a few days and nights staying with your parents quietly and unobtrusively observing how they do from day-to-day. If family members do not live close by or this is otherwise not feasible, consider hiring a geriatric care manager to perform an in-home assessment. It may work best to enjoy a social visit and avoid critiquing or intervening (unless a situation poses a basic health or safety risk), so that you can how things go when you're not there. Obviously, it is important to pitch in as needed, but it is also essential to observe the daily routine (or lack thereof) as it occurs when you're not present, so that you can see what works, what doesn't, and what might be improved.

You may be very surprised by what you find, so prepare yourself. For example, you might schedule a family meeting with your sibling or siblings, by phone or in person, to occur before and/or after the visit, so that you can talk things over. You might also need some time after your visit for reflection, research, or even just some relaxation.

Once you have assessed the situation in your parents' home, then you might develop a plan of action by meeting with your caregiver parent and/or other family. Of course, if you do perceive health or safety risks, these need to be addressed immediately as well as for the long-haul. If you conclude that your caregiver parent is struggling, intervene. The decline we see in a patient sometimes corresponds more to the caregiver's decline than due to the patient's underlying dementia. And, remember, sometimes the spouses of our elderly patients develop dementia, too. In fact, the spousal caregivers of patients with dementia have been shown to experience dementia at a rate six times higher than their age-matched peers [6], perhaps due to the difficult demands of caregiving for a loved one with a dementing illness.

Just because you aren't aware of a problem, doesn't mean it's not there. Look, listen, and dig deeper. Patients have regular examinations. Make sure to check the caregiver, too. Preventive care is always best. If a problem can't be completely avoided, perhaps it can be minimized.

**Common sense rule: Live a day (or more) in a primary caregiver's shoes.**

## Caregiver and Family Dynamics

We conclude this chapter by pointing out problematic caregiver and family issues that we see regularly in caring for patients with dementia. We suspect that some of these difficulties reflect the underlying personality organization of the individual or a family member's internal struggles. Others represent family dynamics that eventually manifest in problematic caregiving behavior. No easy solutions exist for predicaments stemming from ingrained personality types and family dynamics. However, individual or group psychotherapy may sometimes help deal with these issues.

If any of these apply to you or your family, the first step is recognition. The second step is contemplation. Consider how you and your family might avoid or minimize conflict and counterproductive behaviors. Such measures might include counseling. It is unlikely that long-standing family or personality problems will be resolved. Stress and illness usually exacerbate these troubles rather than resolving them. Keep in mind as you read this section that each of us has flaws and almost every family has some level of dysfunction, but most caregivers that we encounter (especially unpaid family members) are good, well-intentioned, and altruistic individuals doing the best they can in a very sad, difficult, and challenging situation. So, caregiver, know thyself. But remember, the most likely answer to the question, "What kind of caregiver am I?" is "A good one."

## Some Caregiver Types and Traits

We all have personality traits that can work to our advantage or disadvantage. For example, you probably want your doctor to be attentive to detail, and most doctors are, although you might also become frustrated by how long you must wait for one who takes his or her time. Such traits can influence what types of caregivers we are. Awareness of these can help you capitalize on your strengths—and minimize pitfalls.

*The Inflexible Caregiver.* This is someone who cannot adjust to the changes in a loved one (or life in general). The inflexible caregiver lives in a world of black and white. Instead of letting things slide, he or she feels compelled to correct each misstatement a patient with dementia utters. The inflexible caregiver doesn't appear to know what the term "roll with it" means. He or she would never even consider bending the truth for the greater good. Since flexibility is one of the main keys in living with a patient with dementia, this caregiver will be traveling a hard road.

**Common sense rule: It is better to bend than to break.**

*The Micromanager.* Often we see micromanaging as a way of dealing with the depression, anxiety, anger and/or guilt that caregivers experience. The Micromanager channels these feelings into creating documents and lists. He or she looks over the

shoulders of all other caregivers, which might include the staff of a facility where a patient resides. The Micromanager calls the physician's office so often that the receptionist can identify his or her voice. We, as physicians, are often impressed by the thoroughness of the Micromanager. However, the Micromanager tends to take on too much alone and may lose the forest for the trees, rather than letting some things go in favor of more pressing issues. From a psychiatric standpoint, we want to make sure the micromanaging is not being used as a diversion to avoid experiencing the strong emotions that this disease can elicit.

A Micromanager needs to learn to delegate what, when, and where needed and have time and an outlet for diversion and relaxation.

A woman in her 70s with moderate-to-severe Alzheimer's disease required 24/7 care, including assistance with dressing and bathing. They had no relatives nearby and her husband gave up his long-standing weekly tennis game despite repeated recommendations by her dementia specialist to obtain outside help (including professional help covered by long-term care insurance), so that he could resume this. He tried a couple of professional in-home caregivers but rejected each after one visit as he said that his wife didn't want anyone else but him to take care of her and that none of the aides lived up to his exacting standards. At each visit, the patient's husband provided a typed list of her medications and a detailed update on her condition, which was also typed out. She participated in a clinical research trial in which the study medication her husband administered to her was checked and counted at regular intervals, always with 100 % compliance. After several years, the patient's husband finally relented to having a part-time in-home professional caregiver (paid for by their insurance) and this appeared to be a good solution for both of them. The patient had always interacted well with all of our office staff and got along well with this companion from an outside agency, too. Her husband enjoyed going back to playing tennis regularly with his friends. He appeared more rested and relaxed and both seemed happier at clinic visits.

### **Common sense rule: Sometimes the patient needs a break from the caregiver!**

*The "I just want to make them happy" Caregiver.* On the surface, there is nothing wrong with this attitude. However, it is concerning when taken to the extreme. It is relatively easy for a doctor to spot a patient that is hard (or impossible) to please. So, when we see a caregiver of such a patient jumping through hoops for naught, we will ask the caregiver about the fervor behind their efforts. Often the explanation given is to make the patient "happy." Typically, we ask the caregiver whether the patient has ever been happy. When the caregiver's response is to laugh at this notion, it becomes evident that even taking great pains to do so will remain futile. It is important to realize that ingrained personality traits are unlikely to change and may become even more pronounced in the case of dementia. In these types of cases, we do not want to see the caregivers set themselves up to fail.

### **Common sense rule: Don't bend over backwards for naught.**

*The Martyr.* We recognize the significant sacrifices that all caregivers must make. However, the Martyr caregiver may dominate a doctor's visit or support group in talking about how overwhelmed he or she is, while categorically rejecting all recommendations and offers of assistance. Extreme sacrifice of one's interests for

another (or others) may represent a long-standing role or personality trait. The Martyr caregiver may have built his or her life around the caregiving role, and this may comprise a significant part of his or her identity. Therefore, there may be considerable backlash against the intrusiveness of others, even if such action is required for the patient's (and caregiver's) well-being. We have seen success when other family members step in and put assistance in place (despite reluctance from the primary caregiver), while acknowledging the importance of the primary caregiver, preserving his or her sense of purpose, and involving him or her prominently in the patient's continuing care. The best strategy for dealing with dementia is a team approach. It serves no purpose to add to the suffering of this disease by rejecting help and trying to go it alone.

A woman participated for the first time in a caregiver support group moderated by two dementia specialists. Her husband, who was 68 years old, had been diagnosed with "dementia" by the patient's general practitioner. She spoke about problems she was having caring for him, including some that posed risks to the patient and others. These included driving against medical advice and carrying around a loaded gun in his pocket (which had accidentally discharged into their refrigerator, but fortunately had not harmed the patient or any other person). This support group represented her first attempt to reach out for help beyond the patient's primary care doctor. During the rest of that day's session, all members of the group offered support to this caregiver and a variety of suggestions, all of which were rejected. Soon thereafter, other relatives of this patient stepped in to arrange his placement in a memory care unit where he stayed social and active.

**Common sense rule: If it's broke, fix it.**

## Family and Caregiver Issues

Although we often see the following issues in the context of family dynamics, they certainly may apply to the individual caregiver as well.

*Families Paralyzed with Indecision.* We sometimes work with families who will discuss something to death, but never make a decision. We may be amazed to look back in the medical record and see that we've been discussing a particular topic for over a year without any progress. This may reflect underlying family dynamics. We have also witnessed some families so paralyzed that they actually try to defer all decisions to the person with advancing dementia. Calling a family meeting is a first step in addressing this problem. Depending on the patient's cognitive abilities, it may be necessary to have the family meet without the patient. If you have any questions about this, check with the patient's dementia specialist. Follow-up or regularly scheduled family meetings may be required, but if you have had a couple of such get-togethers without resolution of major issues, then consider scheduling a family appointment with a therapist and/or the patient's physician. Regularly scheduled doctor's visits (rather than just calling the clinic for help and/or making an appointment when a crisis arises) and following our tips to make the most of medical help, as outlined in the preceding chapters, can also be beneficial.

**Common sense rule: Make decisions and follow through.**

*Family Members Trying to Settle Old Debts.* Family relationships can be hard. Sometimes a spouse or a parent fell quite short of the ideal. What if Mom withheld love and approval or drank her way through your formative years? Maybe Dad was absent. Perhaps your spouse was unfaithful. Sometimes we work with families mired in the history of their relationship. One of the more common scenarios we see is an adult child seeking the love and approval of a parent who long withheld both. Even as a rational, high-functioning adult, it's difficult to resist the chance to finally meet that need. The idea is as follows: If I take good care of Mom during her decline, she will love and accept me. Mom will be thankful and acknowledge my contributions. Unfortunately most of these situations end in disappointment. If Mom did not have insight into the situation when her brain was at its best, she will certainly not at its worst. Be mindful that childhood losses and longings may rise up in full force when you become a caregiver for the one who didn't adequately care for you. Some see an opportunity to right a wrong. In these situations, we strongly suggest an individual therapist for the caregiver. Even if you have no interest in dredging up the past, you need support during this time.

We also commonly see conflict between two or more family caregivers which may include sibling conflict and/or other issues. Therapy is much more sensible (and usually cheaper) than legal alternatives. Maintaining rapport is often the best way to avoid another party from engaging in legal action. Another option is to hire a geriatric care manager to serve as the point person in Dad's care. The care manager not only ensures Dad's needs are met, but can moderate between various family members who may have varying opinions on what is going on and what should be done about it.

If you are a patient's primary caregiver, reach out to and maintain lines of communication with other relatives. This might be through regular family meetings, phone calls, and/or email. Notify and invite immediate family to doctor's appointments. Find ways of engaging family members that wish to be involved (sometimes people are flattered just to be asked and certainly if you ask their input into how they might help). If you have any specific needs that you know would be aligned with their time, interest, and abilities, you might ask if they could help with those (such as asking your sister, who works with computers, if she could help your with ordering your mom's medications online).

We suggest that if you find yourself in a situation involving persistent unresolved conflict that you see a therapist—even if the other party won't.

**Common sense rule: Don't use illness to settle old debts.**

*Denial.* Denial is a part of life. We all regularly use some form of denial when assessing our beauty or golf game. However, in this case we're not talking about not being on the same page, we're talking about not being in the same book. Some families, even in advanced dementia, question whether their spouse or parent has dementia at all. This type of denial hinders families from moving forward and may even

paralyze them into inaction. This is one of the most challenging parts of our work as dementia specialists. It is very hard to penetrate this defense mechanism and sometimes counterproductive to try. Fortunately, if you are reading this book, you are probably past this point.

If you are dealing with relatives who are in denial about a loved one with dementia, it probably won't work to "talk them out of it." You may wish to include them at visits with specialists or spend time with the patient, observing difficulties in performing daily activities, etc. Sometimes prolonged periods of time and/or significant crises may finally trigger a fuller realization of a dementia. Even in the face of forceful facts, denial is a powerful and often intractable defense mechanism. Most of our patients come to initial dementia evaluation after 2–3 years of decline in cognition, behavior, and daily function. In some cases, relatives only made appointment for their loved ones after a crisis (or repeated crisis) situation, such as being brought home by police after becoming lost or even jailed for disorderly conduct.

We are often asked about denial in patients with dementia. ("I think Dad is in denial about his memory problems.") This usually does not represent denial per se. Rather, it is very common for patients with mild dementia to have poor insight or awareness of their memory or other deficits rather than true denial.

**Common sense rule: The first step towards a solution is acknowledging the problem.**

## Summary

Caregivers should consider their own mental and physical health and work as part of a team to optimize care for a patient with dementia. Family members should regularly monitor and check on loved ones with dementia and their primary family caregivers for stress and other quality of life issues and offer help. Personality types, defense mechanisms, and family history and dynamics may determine caregiving issues. These should be addressed if it is necessary and feasible to do so. Professional assistance, such as psychotherapy, may be indicated in some cases.

## Common Sense Rules

- A patient will only do as well as his or her caregiver does.
- Make specific offers of help.
- Live a day (or more) in a primary caregiver's shoes.
- It is better to bend than to break.
- Sometimes the patient needs a break from the caregiver!
- Don't bend over backwards for naught.



- If it's broke, fix it.
- Make decisions and follow through.
- Don't use illness to settle old debts.
- The first step towards a solution is acknowledging the problem.

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