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Assessing Your Situation

Imagine 50-year-old James flying into a panic after learning that Frank, his 78-year-old father, has had a stroke and is in intensive care. Rushing to the hospital, James remembers he promised his dying mother he would always look out for Dad. A decade later he realizes the time has come for him to keep his promise and demonstrate he is capable of being his father's caregiver.

Sounds admirable, yes? Like so many family members who become caregivers, James feels a calling and is determined to do the right thing. But he rushes headlong into caregiving, pressing hospital and, weeks later, the rehab staff to help his father more and pressuring the doctors to address his father's muscle pains. When James's wife suggests he use a calmer tone with his father's treating professionals, he says his father needs all the care he can get right now to quickly regain his independence. At one point he snaps at Frank for not working harder during his physical therapy sessions.

James's dedication is unquestionable, but his understandable high emotion seems to be getting in the way of thoughtful planning. He knows Frank's recovery will take months, but his impatient and impulsive behavior is pushing away the professionals and even his wife, with whom he should be joining forces. He has not begun to consider how he will care for his father after rehab or who will help him or how he will balance caregiving with working. When his wife tries to talk with him about these matters, he brushes her aside.

Good intentions, abundant energy, and strong will are necessary but not sufficient for being an effective caregiver. James may declare to anyone who will listen that he will do "whatever it takes" to help Frank, but he does not yet understand the knowledge, skills, and relationships he will need to accomplish that. Before he dives into caregiving, he'd benefit from slowing down to step back and reflect.

Whether you're caring for a parent, spouse, or other relative or close friend—and whether the disability has been caused by stroke, cancer, dementia, Parkinson's disease, chronic obstructive pulmonary disease, diabetic complications, or some other disabling condition—it's important to proceed deliberately and strategically. Start by grounding all caregiving plans in a thorough understanding of the situation at hand—your care receiver's health condition, current and likely future needs, preferences, and wishes. Only then can you accurately determine your role as a caregiver. And once you know what your care receiver may need going forward, you can evaluate your own readiness to provide it.

ASSESSING THE CARE RECEIVER'S NEEDS

● I listen carefully to what the doctor says about my father, but I don't always understand everything. How can I learn more?

Learning about your father's condition is the right place to start in preparing yourself to provide care. Ideally, understanding four aspects of a care receiver's condition will help you figure out how much caregiving is likely to be needed, for which tasks (like dressing, driving, grocery shopping), and for how long:

- Your relative's **diagnosis**, what the condition is called, based on internationally recognized criteria.
- The condition's **severity**, usually described as *mild*, *moderate*, or *severe*.
- Your relative's **functional status** due to the condition and its impact on their ability to take care of themselves. Functional status is usually measured in their capacities to perform what are called *activities of daily living*, such as eating, bathing, and mobility, and *instrumental activities of daily living*, such as financial management and meal preparation and clean-up.
- Your relative's **prognosis**, the predicted future outcome of their condition, often described in terms such as *good*, *fair*, *guarded*, and *poor*.

For example, if James, introduced previously, asked the physicians about his father's diagnosis, severity, functional status, and prognosis, he would learn that Frank:

- Suffered an ischemic right-brain stroke due to a blood clot that lodged in an artery in the right half of his brain, cutting off the blood supply carrying oxygen and nutrients to the nerve cells fed by that artery.
- Had a stroke of mild to moderate severity, causing him to have some left-sided weakness and making it difficult for him to walk on his left leg or do fine-motor activities with his left hand.
- Currently needs some assistance with his activities of daily living, including dressing himself, but needs no help with his instrumental activities of daily living, such as balancing his checkbook or taking medications as prescribed.
- Has a fair prognosis. He is expected to make good, if not complete, recovery of all functioning within the next three to six months unless he has another medical setback.

This information would help James understand how he might assist his father in the short term (helping him with dressing and getting around), intermediate term (providing some help for at least several months), and long term (possibly assisting his father indefinitely with some activities, such as walking long distances and mowing his lawn, if he doesn't recover fully). With this information in hand, James can more knowledgably plan with Frank, his wife, and his employer about how he will handle his new caregiving responsibilities and still address other family and work responsibilities.

Why haven't I already been given information about my dad's condition?

Doctors draw conclusions, to the best of their abilities, as they learn more about the patient's condition, so they can develop the best possible treatment plan. But if your relative's doctor hasn't provided it, it could be because pinning down a diagnosis sometimes takes time. With stroke and some other conditions, the evaluating physician may realize quickly what the right diagnosis is and can share that information with you. But with other conditions, such as Parkinson's disease and multiple sclerosis, the diagnosis may not be immediately clear. In those instances doctors have been trained to develop what is called a *differential diagnosis*, a list of possible diagnoses based on the patient's symptoms, medical history, physical examination, blood tests, CT scans and other imaging, and so on. Doctors continue to gather information about the patient to rule out different diagnoses through a process of elimination before zeroing in on what they deem to be the correct one. This process can take weeks or even months, which can be very frustrating for you.

- **The provider for the person I'm caring for does not give me much information about the condition. Where else can I go to learn about it?**

Many people go to their favorite health-related websites to read short, clearly written, and easily understandable articles about the essentials of a disease and its treatments. We often refer people to the Mayo Clinic website and WebMD because their informational articles are well vetted by physicians and other healthcare professionals. We also suggest visiting the websites for the disease-specific organization of pertinence to your relative's diagnosis, such as the Alzheimer's Association, Parkinson's Foundation, American Heart Association, American Lung Association, and American Cancer Society.

Remember, however, that all information online is going to be general; you would still need your care receiver's physician to provide more specific details about their diagnosis, severity, functional status, and prognosis.

- **My mother has assessed her own condition and says it's nothing to worry about. She refuses to believe she has heart failure as her physicians says. Who has the final word?**

The principle of person-centered care, a foundation of today's healthcare, ensures each person has the right to run their own life, including whether they accept any healthcare treatment or which treatments they agree to. (The exception is if the person lacks the capacity to make decisions because of dementia or some other cognitive impairment and someone else has been identified through a legal process to make healthcare decisions for them.) That means, regardless of what her physicians say about her condition or necessary treatments, your mother has the final say over her treatment plan.

But honoring each person's right of self-determination is not the same as saying they can or should diagnose themselves. In our work we have met many people with health conditions who deny them or their importance.

We understand this behavior psychologically as a way for them to manage their own emotions and maintain a sense of control over their lives. But a broken leg is a broken leg. Heart failure is usually just that. Your mother will decide whether she takes the usual medications for treating heart failure (diuretics to cause her to urinate more and reduce the fluid that has built up in her body) and whether she will or won't eat a low-salt diet (also a vital part of managing heart failure), but we would put stock in her providers' diagnosis, not her self-diagnosis.

If you think your mother is denying a health condition she should be taking seriously, you could gently try to help her come to terms with it by asking her more about what she thinks of the specific concerns her doctors have raised. However, we do not suggest confronting her aggressively to try to persuade her. Your efforts could backfire and cause her to dig her heels in more.

- **My father believes he has diabetes just like the doctors said, but he doesn't think he has to do anything about it because his father and uncle also had diabetes, didn't do anything to address it, and died of other causes. How do I convince him to listen to the doctors?**

Minimizing the importance of a health condition is another way people cope with news they don't want to hear and then convince themselves they don't have to make any lifestyle changes. As we said previously, it's your father's right to decide how he'll take care of a health condition, if at all. However, he is taking a risk. The consequences of diabetes can be severe. He should have that information, not to scare him, but to help him make the most informed decision he can.

ASSESSING YOUR OWN READINESS

- **How can I assess whether I have what it takes to do a good job as a caregiver? I have never done caregiving before, and I'm afraid I will mess it up.**

Every caregiver initially worries about their capabilities. No one wants to let a relative down and fail. Before making the commitment to being a caregiver, we recommend you sit down and seriously ask yourself whether you are willing, able, and available to be a caregiver for someone you care about. We spoke in general terms in Chapter 1 about what willingness, ability, and availability mean. Here you can consider where you stand on these three factors:

1. WILLINGNESS

Caregiving requires sacrifices. Time and energy you would ordinarily put into cherished activities, such as socializing, working out at a gym, or reading, would now need to be devoted to supporting a care receiver. This is not a minor commitment idly undertaken. Caregiving often goes on for months and years and becomes progressively harder if the care receiver declines over time and needs more assistance. It works best when the caregiver is willing to make these sacrifices for these extended lengths of time. If you feel you have no choice about stepping into this role because of family pressures or a sense of obligation, caregiving may feel more arduous to you.

This is the most complicated factor affecting an individual's choice to become a caregiver but often receives the least attention by caregivers themselves or healthcare and social service professionals. Your history with the family member or friend who needs care will probably come into play. Usually, the better the previous relationship you had with that person, the more willing you may be to provide care.

Willingness is not a simple yes-or-no proposition. Many family members are willing to pitch in to take on certain tasks—picking up groceries or driving the care receiver to physical therapy appointments, for example—but are reluctant or outright refuse to do other things, like helping with bathing and grooming or taking time off from work to attend a care receiver's medical appointments. As you reflect on your willingness to be a caregiver, try to also think through exactly which activities you're willing to sign up for and for how long.

2. ABILITY

This is a broad term that covers a multitude of talents, including physical strength, emotional resilience, patience, kindness, intelligence, common sense, humor, and financial acumen. Each of us has stronger abilities in some areas versus others. For example, a caregiver may be an excellent problem solver and an empathetic listener but has a bad back that makes it impossible for him to pick up a relative who has fallen. Another caregiver may be superb at shaving, showering, and dressing a relative but has trouble comprehending the doctor's explanations of the relative's condition. Ask yourself which abilities you have. Do your abilities realistically match your relative's needs, or does that care receiver have more physical or emotional needs than you can provide for?

Another aspect of ability you should consider: Can you handle the stress of the job? Caregivers are prone to burnout and depression if they do not carefully manage their responses to the uncertainty and sudden emergencies that are common during caregiving. To gauge how stressed you are or how vulnerable you are to being stressed, you can fill out any of several self-assessment questionnaires online. For instance, the Caregiver Self-Assessment Questionnaire was originally developed by the American Medical Association and is now available through the Health in Aging Foundation's *HealthinAging.org* portal. It has 18 questions and a scoring key for easy interpretation of your ability to withstand caregiver stress.

3. AVAILABILITY

This one is straightforward. Can you be there in the moment when the care receiver needs help? Can you be there at the times of day when the care receiver most needs assistance? First thing in the morning when needing to get out of bed? When needing to go to the bathroom? While assessing yourself, please be honest. Overestimating your availability to be a caregiver will only cause conflicts in your schedule and make someone—or everyone—unhappy if you do not meet their expectations and potentially leave dangerous gaps in care. Sometimes noncaregiving responsibilities prevent a family member from being available as a caregiver. For example, Gretchen and her husband, Ralph, still depend on her income and health insurance as a teacher. Until she works enough years to retire and get her full teacher's pension, she can't afford to be available 24/7 to her mother. If Ralph or one of their adolescent children becomes ill, Gretchen will have an even harder time also taking care of her mom.

● I love my mother and am willing and able to take care of her. But I can't be available all the time because my partner and teenage daughters need my time and attention, too. What should I do?

It sounds like you're very good to your mother, and you have other important family duties. Unfortunately, you can't clone yourself. *Please keep in* *mind that caregivers are not responsible for attending to the care receiver's every need on their own; their commitment should be to ensure that their care receiver is well cared for, even if that means delegating some of the care tasks to someone else.* Are there other family members or people in your social circle who are willing, able, and available to be there for your mother whenever you're not available? Do your family members and/or others have the means to hire personal care aides to be there in your stead?

- **Because I'm the daughter who never married or had kids, my siblings assume I'm most available to take care of our father. That doesn't seem fair. I have my own life, too. I'm not always available, and I'm not always willing. Dad never treated me very well, and I have mixed feelings about taking care of him now. What should I do?**

We discuss sibling situations like this one at greater length in Chapter 11. What is important here is that no one else gets to decide whether you're willing, able, and available. That's entirely your decision, based on your assessment of yourself and your capabilities. Your siblings and father cannot subtly or overtly force you into the caregiver role. Tell them what you're willing, able, and available to do and negotiate a fairer caregiving plan with them.

- **What if Dad or other family members get mad at me because I don't agree to do what they think I should do?**

Again, you know best what you're willing, able, and available to do. If that reality is not expedient for them or violates their impressions of what your family role should be, we still recommend holding your ground by calmly and firmly explaining what you can and cannot do. There are many ways of providing adequate care; it does not rest entirely on your shoulders.

- **I am willing, able, and available to be a caregiver for my spouse and want to do the best job I can. I don't know, though, what I don't know going into this. How do I figure out what I need?**

Most caregivers need education and training, practical guidance, social and emotional support, and financial support to provide the best care they can for as long as a care receiver needs it. It's important to feel free to access all the support available to you as you encounter new caregiving challenges.

EDUCATION AND TRAINING

- **I have no experience in providing any level of healthcare. How do I learn how to do things for my sister that I've never had to do before?**

We have already discussed the importance of learning about your care receiver's health condition, which will equip you with some sense of what kinds of daily help your sister might need. As to how to provide that help, short videos by AARP, Caregiver Action Network, UCLA +Health, and other advocacy organizations and academic institutions provide training on specific caregiving techniques, such as safely giving a care receiver a bath, managing medications, and dealing with the agitated behavior of a care receiver with dementia. See the box below for these and other sources of education and training.

Where to Find Caregiver Education/Training

Informative books and websites (AARP, Family Caregiver Alliance, Caregiver Action Network, and others)

Disease-specific organizations (such as Alzheimer's Association, National Multiple Sclerosis Society)

Local lectures and short courses (try Area Agencies on Aging, senior centers, skilled nursing facilities)

Hospitals/health systems

Health insurance plans (especially Medicare Advantage, Dual Eligible Special Needs Plans [D-SNPs])

- **What if I don't want to learn too much about my mom's condition? Whenever I hear that it's going to get worse, I feel upset and overwhelmed.**

Yes, it can be emotionally overwhelming if your relative or friend is diagnosed with a progressive disease such as dementia or Parkinson's disease and you imagine terrible things happening to them one day. We also understand that people vary in their reactions to adversity: Some want to know every detail about what is going to happen, and others, like you, want to know as little as possible to help protect themselves from being demoralized and overwhelmed. There is no standard for how much education and training you should receive. But we also have seen that caregivers who have learned at least the basics of a disease are better equipped to ask the right questions, reach for the right resources and supports, and do the best caregiving job they can.

PRACTICAL GUIDANCE

- **I now know how to help my sister with her medications, with bathing, and with getting ready for bed. But now I feel like she's not stable enough to walk safely to the bathroom by herself. What can I do to protect her?**

Having someone who can help you navigate our complex healthcare system, explain confusing health insurance forms and processes, or direct you to crucial community resources, such as home-delivered meals, home renovation contractors, and caregiver support groups, can greatly reduce caregiver distress. Family members, friends, and acquaintances with their own experiences as caregivers can sometimes provide this information by sharing whatever worked for them.

Different types of healthcare and social service professionals, including caregiving-savvy social workers, discharge planners, care managers, and care navigators from hospitals, health systems, health insurance companies, and community-based organizations, such as Area Agencies on Aging, also offer guidance about what you may need and where you can find it.

You can also hire aging life care professionals—previously known as *geriatric care managers* and usually trained as social workers or nurses—who live in local communities and are familiar with the local resources, including home-based services and facilities.

The Caregiver Action Network has a dedicated toll-free phone number you can call during business hours to ask general questions about caregiving and receive guidance for free from caregiving experts. AARP has a dedicated toll-free number that can suggest caregiving resources on a variety of topics.

SOCIAL AND EMOTIONAL SUPPORT

- **My husband doesn't want help from anyone but me. He says he would feel ashamed accepting help from others, even other family members. What should I say to him?**

It's understandable to want to spare your husband's feelings. It would compound the hurt he is already feeling if you simply overrode his judgment and began bringing social supporters into your home to care for him without his okay. We suggest you ask him for his permission and cooperation by saying, "I love you and want to be here for you. Having some support from others would help me do that. Can you do this for me as your wife? Can you help me help you by accepting outside help?"

There is often overlap between social and emotional support. The family, friends, and others who will pick up the care receiver's medications and do some driving for you are often the same folks who will take you to lunch, provide you with a willing ear so that you can vent, and offer encouragement. But you may also have separate groups of social and emotional supporters—those who do caregiving tasks and those who do not but instead listen well and provide empathy. Both make a positive difference. You can also receive emotional support through in-person or online caregiver support groups, online Facebook groups and other chat rooms, and mental health counseling for those caregivers who are suffering from depression and/or anxiety in response to caregiving distress.

Humans are social beings. When stressed we perform better with other people rooting for us and pitching in to help. When socially isolated and lonely, we become more prone to developing both mental and physical health disorders and dying sooner than more socially connected people do. As a caregiver you need other people's support.

Caregiving is ideally a team sport for which the primary caregiver has family members, friends, neighbors, fellow church congregants, and others who become part of the team to complete needed caregiving tasks. Though not every caregiver has a family—or at least one willing, able, and available to help—every caregiver should reach out for assistance to others who care about the care receiver. Requests for social support should be concrete and specific. For example, ask a sibling or friend, "Would you pick up the medications that will be ready after 2:00 at the pharmacy for my mom and drop them off at my house?" or "Would you please drive Dad to his physical therapy appointment this Thursday?" rather than saying "I know you're busy, but I can use your help" or "Will you have time one of these days to stop by and say hello to Dad?"

- **My husband doesn't want me to share my feelings with anyone else. He said we should keep our problems within the family. Should I do what he wants?**

He sounds afraid that he's the problem and that you're complaining about him to others. If that belief proves true, he would feel even more ashamed than he already feels about having a condition that has left him needing assistance. You could tell him that dealing with illness is a family, not an individual, challenge. You are battling the disease together. Receiving others' emotional support will strengthen your resolve as a caregiver and better enable you to stand with him, not against him, during these difficult times.

FINANCIAL SUPPORT

- **I'm happy that I can provide the care that Mom needs—but how long will that last? What if I need to hire help or move her to an assisted-living facility?**

Caregiving is expensive. A 2021 AARP study found that caregivers spend $7,242 per year on average on out-of-pocket costs, such as medical and pharmacy co-pays, paying for home modifications, hiring home health aides, and so on. While incurring these costs, some caregivers will also lose income by cutting back on their work hours or quitting their jobs entirely to attend to a care receiver's needs. Many caregivers suffer financial strain.

It is never easy asking anyone, even family members, for money. But the caregiving costs usually cannot be borne indefinitely by the primary caregiver alone. It should be understood by all caregiving team members that they contribute time or money and hopefully both. For example, the siblings of Maria, an older woman with dementia, offered to pay for additional nursing assistant care in the memory care center where she resided. They also visited her whenever they could. Maria's caregiving children were extremely grateful for the money and this tangible gesture of support from their aunts and uncles. The financial aspect of caregiving is covered in more depth in Chapter 10.

● I don't want to ask anyone in my family for financial support. They will probably say no and resent me for asking. How can I get paid for the caregiving I do?

There are three possibilities to explore depending on the age and finances of the person you are caring for and the regulations in the state where that person lives.

The first is the easiest. If your care receiver has the means to pay you even a nominal salary for the work you are doing for them, that would help defray your costs and loss of income. It's best to have a written agreement, usually called a Personal Care Agreement and drawn up by an attorney, to document the terms of this financial arrangement so that other family members do not jump to the awful conclusion that you are pilfering from the care receiver's bank account.

The second is called *self-directed*, *consumer-directed*, or *participant-directed care*, depending on the terminology used by the state where the care receiver lives. A care receiver who has low income, few financial assets, and receives Medicaid health insurance is eligible in all states to choose who can be hired to provide any personal care needed. If you're chosen, you can receive hourly wages set by your relative's state. Please check the website of your state's agencies in charge of Medicaid or aging- and disability-related services (which go by different names in different states) for details on the state's self-direction program.

The third is a helpful financial stipend, not a regular salary. If your care receiver is old enough to receive services according to the threshold established by the state (such as age 60) and is deemed to have limited enough income to qualify for services, their local Area Agency on Aging will sometimes pay up to a set amount per month for caregiving-related costs, such as home modifications, diapers, cans of nutritional supplements, and so on.

● I think we have enough money and long-term care insurance to pay for whatever my husband needs, but I'm not sure. How can I figure this out?

We are not experts in financial management and cannot give you advice on this question. We do, however, offer information in Chapter 10 on the kinds of experts who can help. No one has a crystal ball, but a financial manager can probably provide you with a general idea of how long your money will last with the ongoing need for paying for support services for your husband.

We do not advise any caregiver to wing it. Assessing all the factors you can will decrease at least some of caregiving's inherent uncertainty and leave you as well prepared as possible. We believe that love and determination plus due consideration of all factors plus careful planning most often lead to caregiver success.