



Caring for the Caregiver

When a loved one becomes ill, it's natural to want to step in and help. But, when the diagnosis is chronic and long-term, those thrust into the role of caregiver will need adequate resources and support to ensure they avoid becoming patients themselves.

By Trudie Mitschang

CAREGIVING RESPONSIBILITIES often sneak up on people. When a loved one is diagnosed with a chronic illness, seemingly overnight, caregivers' time is no longer their own. It may begin with an extended hospital stay (and the hope that things will eventually "get back to normal.") But, over time, there are follow-up doctor appointments, prescriptions to fill and errands to run, and gradually, caregivers realize they have inherited an ongoing commitment with no end in sight. The result? Life as they knew it becomes a thing of the past, and they enter a new normal that is anything but.

Defining the Role of Caregiver

Caregivers can be spouses, partners, adult children, parents, other relatives (siblings, aunts, nieces/nephews, in-laws, grandchildren), friends or even neighbors. Whatever the relationship with the person they are caring for, it's important to add the title caregiver to the list of titles they embrace. While caregivers may be hesitant to formally label their new role, it is important to begin identifying themselves as caregivers so they can begin to search for resources to help navigate this new role.

Realistically, things can quickly get complicated as no one is solely a caregiver; individuals step into this role with other responsibilities already in place. They may be employed full- or part-time. When caring for a sick child, they may be raising other healthy children as well. If they are a caregiver for their spouse, they may also be fathers/mothers, friends, siblings, sons or daughters. Adding caregiving to that list can easily lead to frustration and exhaustion. They might need to navigate social service systems, call doctors while at work, advocate for the care receiver, and take care of their day-to-day needs, while trying to do all of those things for themselves and their families. Eventually, something has to give, and for many caregivers, it is often their own mental and physical health that begins to suffer.

“Most caregivers do not prioritize their basic needs for sleep, healthy diet, exercise and socializing,” says Christina Mangurian, MD, MAS, professor of clinical psychiatry at the University of California, San Francisco School of Medicine, and mother/caregiver of a young child with Wiskott–Aldrich syndrome. “Doing these things helps them maintain their own well-being, which is directly related to how well the care recipient does. I encourage caregivers to think about ways in which they can incorporate more self-care into their daily regimen.”

Few people step into the role of caregiver having been trained to do the broad range of tasks required. As a result, they may end up with back strain because they haven’t had the benefit of training from a physical therapist on how to correctly transfer someone from bed to chair or wheelchair to car. Or, perhaps they find themselves battling with a spouse who refuses to remain compliant with prescribed medications. These situations can make them feel isolated, but according to the Family Caregiver Alliance, they are extremely common, regardless of the care recipient’s diagnosis.¹

If caregivers are unsure the title fits them, here are some common tasks typically required of someone in a caregiver role:

- Buy groceries, cook, clean house, do laundry and provide transportation.
- Help the care receiver get dressed, take a shower and take medicine.
- Transfer someone out of a bed/chair, help with physical therapy and perform medical interventions: injections, feeding tubes, wound treatment and breathing treatments.
- Arrange medical appointments, drive to the doctor, sit in during appointments and monitor medications.

- Talk with doctors, nurses, care managers and others to understand what needs to be done.
- Spend time handling crises and arranging for assistance — especially for someone who cannot be left alone.
- Handle finances and other legal matters.
- Be a companion.
- Serve as an unpaid aide on call 24/7.

RESEARCH SHOWS FAMILY CAREGIVERS OF ANY AGE ARE LESS LIKELY THAN NONCAREGIVERS TO PRACTICE PREVENTIVE HEALTHCARE AND SELF-CARE BEHAVIOR.

Taking Care of Themselves

We are all familiar with airplane safety instructions: Put on your own oxygen mask first before you assist anyone else. The same principle applies when caring for a loved one with a chronic illness. Caring for themselves is one of the most important — and one of the most often forgotten — things caregivers can do. When their needs are met, the person they care for will benefit, too.

Research shows family caregivers of any age are less likely than noncaregivers to practice preventive healthcare and self-care behavior. Regardless of age, sex, race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities.²

What’s more, caregiving can be an emotional roller coaster. On the one hand, caring for a family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are enormously stressful. Ironically, caregivers are more likely to develop a chronic illness than are noncaregivers, namely high cholesterol, high blood pressure and a tendency to be overweight. Studies show an estimated 46 percent to 59 percent of caregivers are clinically depressed.² “The tragedy of a debilitating illness goes far beyond the patients themselves,” explains Karl

Hawver, MD, a psychiatrist in Kensington, Md. “Caregivers suffer the loss of their dreams, just the way the patient does, and this can make them angry and resentful.”³

These feelings of loss and disappointment can manifest in different ways. Some caregivers don’t acknowledge how upset they are, but instead develop physical symptoms such as headaches, back pain and chronic fatigue. “These are real physical ailments,” adds Dr. Hawver, “but they’re due to the underlying sadness. They won’t be cured until the true emotional problem is faced and dealt with.”³

For other caregivers, there is an insidious, steady sapping of their energy and enjoyment of life. Slowly but surely, their lives become marked by unhappiness, and it all happens so gradually, they’re not even sure how or when they became so sad. “Caregivers can spend so much time giving care that they neglect tending to their own needs,” Dr. Hawver cautions. “The result is that their lives become devoid of gratification, and they sink into a profound despair.”³

Of course, just because someone is a caregiver doesn’t mean he or she will automatically be afflicted with a mood disorder. Extreme stress is also common and can lead to many troubling symptoms, including:

- Feeling overwhelmed or constantly worried
- Exhaustion
- Getting too much or not enough sleep
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities previously enjoyed
- Feeling sad
- Having frequent headaches, bodily pain or other physical problems

- Abusing alcohol or drugs, including prescription medications

Too much stress, especially over an extended period of time, can harm health. It’s important for caregivers to find positive ways to alleviate stress. Reaching out for help and talking to friends and family can help. “I encourage caregivers to talk about the situation with friends, family, colleagues, spiritual leaders, counselors — whatever fits them,” says Dr. Mangurian. “Also, there is no shame in seeing a psychiatrist to get medication if they need it to get through a difficult time.”

Practicing Caregiving Stress Strategies

The emotional and physical demands involved with caregiving can strain even the most resilient person. That’s why it’s so important to take advantage of the many

resources and tools available to help caregivers provide care for their loved one. It’s true, if caregivers don’t take care of themselves, they won’t be able to care for anyone else.

Here are some tips to help caregivers manage stress:

- Accept help. Prepare a list of ways others can help, and let the helper choose what he or she would like to do. For instance, a friend may offer to take the person they care for on a walk a couple of times a week. Or, a friend or family member may be able to run an errand, pick up groceries or cook.

- Focus on what you are able to provide. It’s normal to feel guilty sometimes, but no one is a perfect caregiver. Caregivers need to believe they are doing the best they can and making the best decisions they can at any given time.

- Set realistic goals. Break large tasks into smaller steps that can be done one at a time. Prioritize, make lists and establish a daily routine. Say no to requests that are draining such as hosting holiday meals.

- Get connected. Find out about caregiving resources in the community. Many communities have classes specifically about the disease a loved one is facing.

- Join a support group. A support group can provide validation and encouragement, as well as problem-solving strategies for difficult situations. People in support groups understand what caregivers may be going through. A support group can also be a good place to create meaningful friendships.

- Seek social support. Make an effort to stay well-connected with family and friends who can offer nonjudgmental emotional support.

- Set personal health goals. For example, set goals to establish a good sleep routine, find time to be physically active on most days of the week, eat a healthy diet and drink plenty of water.

A Helpful What Not to Do List

Toni Bernhard, JD, is the author of *How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers*. A frequent contributor to *Psychology Today* on topics related to living with chronic illness, Bernhard (whose husband is her caregiver) offers sage advice on what not to do when tasked with the role of caregiver.⁴ “Many people (including myself) have written about the need for the chronically ill to go through the same type of grieving process that’s triggered by other life-disrupting events, such as the break-up of a relationship or the death of a loved one,” she explains. “If you’re a caregiver, you need time to grieve, too. The drastic change in your life can be a shock. One day, you were free to go out whenever you wanted and hang out with whomever

you wanted. The next day, you were tied to the house and expected to understand how to take care of someone who may need help with the most intimate of life functions.”⁴

Bernhard goes on to explain that in addition to grieving the loss of their own freedom, caregivers may be grieving the loss of the relationship they once had with the person they’re caring for. “In my life, except when we were at our respective jobs, my husband and I used to do almost everything together. Now, when he goes out, he almost always goes out alone.”

In addition to embracing the grieving process, Bernhard says it’s also vital to find moments of both frustration and joy, without guilt. “Let yourself have ‘bad’ days when, even though you’re doing what needs to be done for the person you care for, your heart isn’t in it and you wish you were free of the obligation and the burden. Don’t feel guilty if resentment arises now and then.”

Finding Relief Through Respite

No one can expend their energy, strength and time giving to someone else, especially in the demanding role of family caregiver, without replenishing their own reserves. Respite care brings temporary relief to primary caregivers from the continuing demands of someone with special needs. Respite care may be planned or emergency, in home or elsewhere, for a few hours or perhaps a couple of weeks. The purpose of respite is to allow caregivers to rest, recharge and remember that life exists beyond caregiving.

The question is, once they’ve decided they should take respite, how do caregivers begin to look for good respite care? A preferred respite choice for most people is having someone come into the home to allow the caregiver to leave for a few hours on a regular basis. In some cases, family members can meet this need. If this is not feasible, help from a community-based volunteer group or a home healthcare agency can be considered. The choice depends on the skill level that will be needed and on the ability to pay for respite services.

When a trained volunteer is not sufficient for respite (such as when medical skills are required or when volunteer groups are not a choice in the community), another option may be a home healthcare agency. Good places to start are local affiliates of the Visiting Nurse Associations of America. Visiting nurses essentially invented home healthcare more than a century ago, and since 1983, local groups have organized to offer help that is nonprofit, community-based and Medicare-certified. Working with a home care agency has a number of advantages. A primary one is while caregivers get some

respite, a home care aide can actually provide more detailed bed and bath or other caregiving services, so when they return from respite, some of the heavy-duty work of caregiving has already been completed. Respite care is not covered by health insurance, whether Medicare or private, so caregivers should be prepared to pay out of pocket if they contact a home care agency.⁵

RESPIRE CARE BRINGS TEMPORARY RELIEF TO PRIMARY CAREGIVERS FROM THE CONTINUING DEMANDS OF SOMEONE WITH SPECIAL NEEDS.

Caregivers Are Not Alone

Caregivers new to their role can rest assured they are not alone. Estimates suggest two-thirds of the U.S. public expect to be caregivers in the future, and 43 percent report it is very likely they will become a family caregiver at a future time.⁶ According to the National Center on Caregiving, families typically provide 80 percent of the long-term care in this country, and the need for information, training and education for this growing population is significant.⁷ To meet the growing need, the organization has pioneered an online Learning Center (www.caregiver.org/caregiver-learning-center) that offers information, training, classes and more. According to the website, “By taking our most popular education programs and putting them online, we have brought the classroom to you. Our goal is to provide high-quality information and training that is accessible and convenient for family caregivers.” ■

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