



Caregiving: Taking Care of Them, Taking Care of You

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Caregivers need care, too! Physical, emotional and economic implications of caregiving can be significant for family, friends and neighbors, who stand by loved ones facing chronic illness or disability. For caregivers the key to avoiding burnout is taking care of themselves as they take care of others. This article focuses on facts, tips and suggestions to enable caregivers to realize the joys and deal with the challenges of caregiving.

“There are only four kinds of people in this world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.” In these thought-provoking words, former First Lady Rosalynn Carter summarizes the ever-increasing need for caregiving and caregivers. Consider this statistic from the National Family Caregiver Association: More than 50 million people provide care for a chronically ill, disabled or aged family member or friend during any given year.¹

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Caregiving in the United States is no longer predominantly a women's issue. Men now make up 44 percent of the caregiving population. As of 1995, people over 85 years of age are the fastest growing segment of the population. Half of them need some help with personal care. Sixty-one percent of “intense” family caregivers (those providing at least 21 hours of care a week) have suffered from depression. Studies have shown that caregiver stress inhibits healing. Heavy duty caregivers, especially spousal caregivers, do not get consistent help from other family members. One study has shown that as many as three-fourths of these caregivers are “going it alone.” Approximately 80 percent of home care services are provided by family caregivers. Metropolitan Life Insurance Company estimates that American businesses lose between \$11

billion and \$29 billion each year due to employees' need to care for loved ones 50 years of age and older. The economic value of services that family caregivers provide "for free" is estimated at \$257 billion a year. Fifty-nine percent of the adult population either is or expects to be a family caregiver.²

In the so-called "graying of America," the median age of the United States population has been rising and is expected to continue to rise well into the mid-twenty-first century. In 1900 one American in twenty-five was age 65 or older; in 1984, one in nine. By the middle of this century, it is estimated that one in five Americans will be elderly as the "baby-boom" generation continues to age.³

Senior adults are not the only people who require caregiving, however. Advances in medicine and medical technology result in people with significant physical and cognitive needs living longer and in greater numbers. More and more, family members are called upon to become caregivers to mentally-challenged adult siblings, loved ones with life-changing injuries, extremely premature babies and children with significant disabilities.

Another trend in American society finds senior adults caring for relatives under the age of eighteen. According to the 2000 U.S. Census Data, more than two million grandparents have taken on primary responsibility for their grandchildren's basic needs.

As the need for caregiving increases and impacts almost every family and workplace, caregivers must learn to take care of themselves as they take care of others. For caregivers, unresolved emotions easily can lead to burnout. Gerontologist Nancy Wexler states, "It is entirely understandable and human that any person who shoulders full responsibility for another should burn out. Caring for someone who cannot survive without you is both emotionally and physically draining, no matter how much you may love the person."⁴ In other words, caregivers need care, too!

Taking Care of You

A recent study by the National Alliance for Caregiving and the American Association of Retired Persons (AARP) found that more than half of those who provide major care for a loved one experience stress and emotional strain. AARP considers this finding a major concern since prolonged stress can lead to significant emotional and physical consequences. As a result, taking care of ourselves is one of the most important aspects of taking care of others effectively. "Because you are responsible for the welfare of another person, taking care of yourself is doubly important," according to the American Heart Association. "You need to stay rested, refreshed and energetic both for yourself and for the person you care for."⁵

PacifiCare offers similar advice: "You, the caregiver, are incredibly important. The welfare of another person depends upon you. If you are not in good health, that other person may also suffer. So, if you have taken on the role of a caregiver, you also have accepted a special responsibility to take care of yourself. That means taking care of yourself physically, emotionally, mentally, spiritually, interpersonally and financially."⁶

What are some practical ways that caregivers can take care of themselves? AARP offers these suggestions:

- Take care of your health, especially nutrition, exercise and sleep.
- Maintain or establish social contacts to avoid isolation.
- Ask friends and relatives for help with daily tasks and errands.
- Deal constructively with negative feelings.
- Find time for yourself to unwind and to have fun.

Also, avoid bottling-up your feelings by talking with family and friends about the rewards and challenges of caregiving and by sharing your experiences with coworkers in similar situations.⁷

Sleeping and Resting. Have you ever felt like the poet Robert Frost when he wrote, "...for I have promises to keep and miles to go before I sleep"? All of us experience days when we have more things to do than hours in the day to do them. Caregivers tend to push themselves long and hard, and then when they finally have a few hours to sleep, they can't or don't! The Alzheimer's Association identifies "sleeplessness" as one of ten warning signs of caregiver stress. When anxiety about facing another day or what the future holds or a seemingly endless list of concerns robs the caregiver of sleep, exhaustion makes it nearly impossible to complete necessary daily tasks.⁸ Yet, as Dr. Dan Crawford points out, "Not even the greatest athlete can run all the time. Rest is as much a part of fitness as is activity... Sometimes the most crucial thing you can do is sleep."⁹

Dealing with Anger. Even the most patient caregiver can find herself battling against anger, which may cause her to lash out at her loved one, which leads to feelings of guilt, which can make her feel angry again. Experts call it the anger-guilt-anger cycle, and it is quite common among caregivers.¹⁰ "Anger comes in many forms," writes Dee Dee Hunt for the International Scleroderma Network. "Anger that they are thrown into the position of caregiver; anger at downward changes in their loved one's condition; anger and frustration at the financial consequences experienced if there is a loss of income and mounting health care costs; anger at having feelings of anger; anger that no one seems to notice how overwhelming the caregiver's job can be; and anger at loss of control over the situation."¹¹ No matter how much the caregiver loves the care recipient, never becoming angry is almost impossible. What matters is what is done with that anger and how it is handled. Here are a few suggestions to get through the eye of the storm:

- Leave the room. Walking away, even for a minute or two, may keep you from

doing or saying something you will later regret.

- Keep your perspective. Is the situation really worth getting angry about?
- Laugh. Recognize and appreciate the humor in your day-to-day experiences.
- Do not beat yourself up. If you slip into anger, find a constructive way to deal with it instead of taking a guilt trip.
- Monitor the frequency and intensity of your anger. If anger permeates your life, you may need to consider a support group or counseling.¹²

Saying "No." Saying no can be one of the most difficult tasks for a caregiver, especially when the care recipient is a parent. Brenda Jones Vieregge, one of the authors of *Fourteen Friends' Guide to Eldercaring*, identified part of the problem in this way: "The reason eldercaring is so difficult is that... it involves the longest relationship of our whole life, and so you bring all of the emotions of that relationship into the caring process."¹³ Yet, setting limits by saying no is sometimes necessary in the caregiving relationship for at least two reasons. First, saying no is vital when it is in the best interest of the loved one receiving care.

Illness, disability or the aging process may cause the care recipient to have unrealistic expectations or the desire to participate in activities that are no longer appropriate. A common example is driving after it is no longer safe for the loved one to do so. Even though it is difficult, the adult child, adult sibling, or caregiving spouse needs to say no for the safety and well-being of the care recipient as well as others. Additionally, setting limits by saying no is sometimes necessary for the physical and emotional well-being of the caregiver.

Finding a balance in taking care of your loved one and taking care of yourself can be tricky. "Your care receiver may need constant reassurance about his/her safety, your love, medical care or costs, changes

in your life together... or any other number of personal concerns. Your ability to listen to their concerns is very important," advise caregiving experts. On the other hand, "All caregivers should receive respite regularly. Give yourself permission to ask for help. Turn to other people for help—your family, friends, church/synagogue and neighbors. Allow yourself a break from your caregiving responsibilities."¹⁴ Accomplishing this may mean saying no at times—even to a parent—without feeling guilty.

Controlling Anxiety. Most likely, you are familiar with the Serenity Prayer of Reinhold Niebuhr: *God grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference.* In his prayer, Niebuhr reminds us of the futility of worry. In essence, he tells us that it is useless to worry about things we *can* change. Rather than worrying, we should use our energy and time to accomplish change. Similarly, it makes no sense to worry about things we *cannot* change because no matter how much we worry, they are not going to change. Instead, we should channel our efforts in a more positive and productive direction. In caregiving, issues arise over which we have no control but about which much time and energy can be wasted by worrying. Often, these are "how long" questions: How long will I have my loved one with me? How long will our finances hold out? How long will I hold out? How long will my loved one remember me? How long until the condition worsens? While worries and fears are normal in caregiving, excessive anxiety can interfere with daily functioning and can even cause physical symptoms such as headaches, stomach upsets, rapid breathing, fast heart rate, trembling and irritability. "The key to managing anxiety is to find the balance between reality, fears and worries. Stay focused on this balance, and do not give in to excessive negative thoughts," psycholo-

gist Dr. Shachi Shantinath tells caregivers. "Pay attention to your breathing when you feel anxious or fearful. Take deep, full and slow breaths, and that will help to return a sense of calm." Additionally, he suggests prayer and meditation are effective ways to still the mind when worries are rampant.¹⁵

Relating to Others. Like it or not, caregiving can impact not only the relationship between caregiver and care recipient, but also other relationships with family, friends and co-workers. For instance, family members who see the loved one infrequently may think the caregiver exaggerates the extent of care needed. Out-of-town siblings may become critical of the care being given, question decisions made by the caregiver, or experience feelings of guilt for not being able to help more. These reactions can then cause the caregiver to feel resentful or unappreciated, resulting in strained family relationships.¹⁶ Friendships can also bear the brunt of caregiving stress. As mentioned previously, caregivers have a tendency to isolate themselves from friends and social situations for many reasons, not the least of which is lack of time and energy. Additionally, caregivers for those whose functioning has changed because of severe illness or injury report that friends sometimes seem uncomfortable with the new situation and, after the initial outpouring of concern, tend to drift away. In the work arena, caregiving responsibilities may affect the employer/employee relationship in a negative manner. "Employers might not recognize that they have an employee who comes to his/her job and works a full eight- or ten-hour day, then that same employee leaves work to go care for an elderly parent or loved one," says Brad Hancock of Paragon Senior Care. "The employee's day may not come to an end until very late in the evening." While employers and co-workers are generally understanding of childcare problems, they may not understand eldercare needs. Accord-

ing to the National Family Caregivers Association, however, eldercare is projected by 2005 to replace childcare as the number one dependent care issue in the United States.¹⁸

A Final Thought

You board an airplane and settle into your seat. As the plane leaves the gate, the flight attendant recites the safety instructions given at the beginning of every flight. "In the unlikely event that our cabin loses pressure, an oxygen mask will drop in front of you," the flight attendant demonstrates. "If you are traveling with a child or another person who needs assistance, secure your own mask first, and then help the one who needs assistance." At first blush, that particular instruction may sound selfish or even foolish. After all, a parent's natural reaction in a crisis is to come to the aid of her child first, even if that means putting herself in danger.

Upon further reflection, however, the instructions make perfect sense. We are not being told to take care of our own needs *instead of* another's. Rather, the airlines are reminding us to take care of ourselves first so that *we will be able* to take care of others. That is a reminder caregivers need, as well. Caregivers must give themselves permission to nurture themselves without guilt and with as much compassion as they reserve for others. "Figure out what *your* needs are," urges Professor Alice Domar of the Harvard Medical School. "Then figure out how others in your life can help you meet each need. Each morning, think about something you might do for yourself that day. Remember, if you do not care for yourself, you are less able to care for others."¹⁹ Δ

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