

CARING FOR THE CAREGIVER



Barbara Stone by Rose Mead, 1930

Irritability, anxiety, exhaustion – continual and unrelenting. Eating way too much, gaining weight - or too little, having trouble keeping food down, losing weight “without trying.” Sleeping “all the time,” sitting down and “out like a light” – or can’t go to sleep, can’t stay asleep. Can’t focus, can’t concentrate, can’t make one more decision, forgot to feed the cat, brush teeth, take out the garbage, pay the bills, again. No energy, no motivation, just don’t feel well. Ambushed by weeping, the simplest thing...never know when....

While textbook symptoms of Post Traumatic Stress Syndrome, these are common experiences of The Caregiver. The dirty little secret of the burdens on Caregivers and the effects of these burdens is often not only not spoken of, they’re more often not even realized. Mom, dad, sister, brother is a rock, she can do anything, he’s always done everything. She’s strong, he’s proud. But Wonder Woman has lost her bracelets and Superman has lost his cape – and they can’t find them. Super Caregivers are in trouble.

They’re depressed, they’re isolated, they’re angry. They feel trapped – How long is this going to go on? Is this the rest of my life? They feel hopeless – all that I’ve worked for, lived for, is gone, and it’s not coming back. They feel like failures – if I were a good husband, wife, son, daughter, I could do this with grace, patience, strength, love. And they feel so guilty – How can I feel like this when I’m needed most? Why am I so mad at him? He can’t help it, he’s sick. Why does her illness infuriate me? She didn’t ask for this. What kind of selfish monster am I?

What’s Going On?

For starters, we’re living longer. In days of yore long-term caregiving wasn’t such a problem because most of us died younger and faster of acute illness and injury. The fabled extended family with grandparents, parents, aunts, uncles, cousins and siblings living within a two-mile radius is exactly that now – fable. For most, families are scattered far and wide. The traditional caregivers – the youngest daughter, the daughter-in-law, the maiden aunt – are working full time, raising children, involved in community activities, maintaining their own houses, caring for many lives. Caregivers now find themselves in the position of doing more, in more demanding situations, for longer periods, with less help. And if they feel they had no choice in taking on the responsibilities, the chances are that they experience greater strain, distress, and resentment.

What Are Some Numbers?

(from the National Family Caregivers Association. *Care for You, Inc.* is a member)

- 25 % of all U.S. households are already involved in caregiving.
- More than 50 million people provide care for a chronically ill, disabled or aged family member or friend during any given year.
- Caregiving is no longer predominantly a women's issue. Men now make up 44% of the caregiving population.

- The average length of time spent on caregiving is about eight years, with approximately one third of caregivers providing care for 10 years or more.
- Elderly spousal caregivers with a history of chronic illness themselves have a 63% higher mortality rate than their non-caregiving peers.
- The stress of family caregiving has been shown to impact a person's immune system for up to three years after their caregiving ends, thus increasing their chances of developing a chronic illness themselves.
- Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses the rate is six times higher; for those caring for a parent the rate is twice as high.
- Family caregivers providing high levels of care have a 51% incidence of sleeplessness and a 41% incidence of back pain.
- 44 % of physicians believe that poor care coordination leads to unnecessary hospitalization, and 24 % stated it can lead to otherwise unnecessary nursing home stays.
- By the year 2030, nearly 150 million Americans will have some type of chronic illness, a 50% increase since 1995.
- Family caregivers who acknowledge their role are more proactive in reaching out for resources and talking with their loved one's doctor than non-acknowledged caregivers.
- Both male and female children of aging parents make changes at work to accommodate caregiving. Both have modified their schedules (men 54%, women 56%). Both have come in late and/or leave early (men 78%, women 84%) and both have altered their work-related travel (men 38%, women 27%).
- 15 million days are missed from work each year because on long distance caregiving.
- 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 value of the services family caregivers provide for "free" is estimated to be \$257 billion a year. That is twice as much as is actually spent on homecare and nursing home services.



"Self-Portrait," 1887.
Vincent Van Gogh

What Can A Caregiver Do?

The most important thing you can do is: TAKE CARE OF YOURSELF. This is not selfish – it is essential. Research consistently shows that the combination of loss, prolonged stress, the physical demands of caregiving, and competing demands on obligations and time place the caregiver at risk for significant health problems as well as an earlier death. If you can't help yourself, you can't help anyone else, and everyone loses.

GET HELP. Help can come from community resources, family, friends and professionals. Ask them. Don't wait until you are overwhelmed and exhausted or your health fails. Reaching out for help when you need it is a sign of personal strength. Many don't know how to ask for help. You don't want to "burden" others or admit that you can't handle everything by yourself. You don't have to do everything, nor does anyone else. Help them be helpful, help yourself and help your loved one by building your support. Break down requests into specific, simple tasks. Whether a

person helps once, once a week, once a month, daily – it's all helpful, and takes a bit of responsibility off of you.

The National Family Caregivers Association offers these Tips on How to Ask:



The Chanter
Sentinel for the
Sleeping Giant
hiking trail

- *Consider the person's abilities and interests.* If you know a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal preparation.
- *Resist asking the same person repeatedly.* Do you keep asking the same person because s/he has trouble saying no?
- *Pick the best time to make a request.* Timing is important. A person who is tired and stressed might not be available to help out. Wait for a better time.
- *Prepare a list of things that need doing.* The list might include errands, yard work, a visit with your loved one. Let the "helper" choose what she would like to do.
- *Be prepared for hesitance or refusal.* It can be upsetting for the caregiver when a person is unable or unwilling to help. But in the long run, it would do more harm to the relationship if the person helps only because he doesn't want to upset you. To the person who seems hesitant, simply say, "Why don't you think about it." Try not to take it personally when a request is turned down. The person is turning down the task, not you. Try not to let a refusal prevent you from asking for help again. The person who refused today may be happy to help at another time.
- *Avoid weakening your request.* "It's only a thought, but would you consider staying with Grandma while I went to church?" This request sounds like it's not very important to you. Use "I" statements to make specific requests: "I would like to go to church on Sunday. Would you stay with Grandma from 9 a.m. until noon?"

TAKE THE LEAD in deciding what needs to be done and who's doing it. The person who needs caretaking often wants only a certain family member or friend to provide care. Often s/he has made the decisions concerning home and activities for years, and is adamant about continuing to do so. Now, however, s/he can't do this. S/he may or may not realize this; if s/he does, it can be very frightening. With his or her needs so great, s/he frequently is unable or unwilling to see the extent of these needs and that the caretaker also has needs. S/he as well as the caregiver may think that it is the caregiver's duty. The person in need may behave in a number of disconcerting ways – such as anger, verbal abuse, crying, withdrawal, depression, shaming – to maintain control and get what s/he wants. There are, however, options. While needs do need to be met, no one person MUST or CAN provide everything all the time.

The most loving thing a caregiver can do is draw the line, non-judgmentally and non-confrontationally, and hold it. The person in need will eventually, usually quickly, see and accept that s/he is not abandoned and uncared for, and the main caregiver has more time and energy to devote to the far deeper needs.

LEARN about the condition your family member is facing and how it may affect his or her behavior, pain level, etc., and how to communicate effectively with doctors.

PROTECT YOUR PERSONAL TIME for something you enjoy or something you have to get done. Your loved one's needs doesn't cancel out your own desires and needs. Even if you do it less frequently, continue doing whatever you've always enjoyed - going to church, meeting with friends or family, going to a movie or play, walking the dog, playing cards....

PROTECT YOUR BODY. Give yourself time for exercise, eating well, sleeping enough and personal grooming. Caregivers often do a lot of lifting, pushing, and pulling. Learn the proper ways to do these things and protect your back – ask about going through physical therapy training with your loved one. If you have back (shoulder, arm, etc.) problems, have someone else do this, or assist you.

REWARD YOURSELF. Caregiving is a big job – provide yourself with frequent respite breaks and regular, even if small, rewards.

FIND A SUPPORT GROUP. Use your personal network of family and friends. A support group for caregivers targeted to living with similar issues that you face can provide not only a safe haven, but tips for daily living. There is great strength in knowing you are not alone.

BE OPEN TO TECHNOLOGIES AND IDEAS that promote you loved one's independence.



WATCH OUT FOR SIGN OF DEPRESSION (see the beginning of this discussion topic), and get help.

GRIEVE FOR YOUR LOSSES, and then allow yourself to **DREAM NEW DREAMS.** Consider how you will feel and what you will do after the caregiving ends.

TRUST YOUR INSTINCTS. Most of the time, you're right.