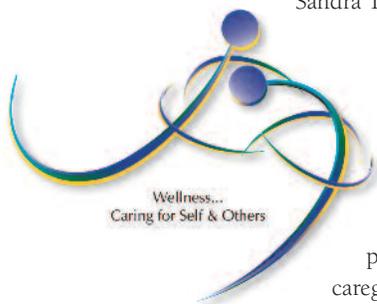


Understanding Caregiver Stress Syndrome

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An increasing number of Americans are finding themselves taking care of someone who is aging, disabled, or seriously ill. Former First Lady Rosalynn Carter stated that there are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

Caring for an individual with a disability is stressful and contributes to physical and psychiatric morbidity. Researchers have also suggested that the combination of loss, prolonged distress, the physical demands of caregiving, and vulnerabilities of older caregivers may compromise their physiological function and increase the risk for health problems, including high blood pressure, diabetes, and a compromised immune system. Further, elderly caregivers have a 63 percent higher risk of mortality than noncaregivers in the same age group. Studies found that the physical symptoms of caregiver stress are a result of a prolonged and elevated level of stress hormones circulating in the body. Researchers also suggest that exhausted caregiver stress hormone levels are like those suffering from posttraumatic stress disorder. As a group, caregivers report more anxiety, depression, and increased use of alcohol or other drugs.¹

This condition is increasingly being referred to as “caregiver stress syndrome.” The stress is not only related to the daunting work of caregiving, but also the grief associated with the decline in the health of their loved ones. Often their stress is associated with physical strains, financial constraints, emotional effects, and social isolation.

Similar symptoms are experienced by parents caring for children with complex medical needs. In addition, a significant number of war veterans returning from Iraq and Afghanistan with blast-incurred brain injuries require multiple levels of caregiving. Unfortunately, with an aging population and a healthcare system that increasingly expects families to provide informal healthcare for ailing loved ones, the situation is not likely to improve in the near future.²⁻⁴

Most of us will be informal caregivers at some point during our lives. It is reported that during any given year, more than 44 million Americans provide unpaid care to an elderly or disabled person 18 years or older. Thirteen percent of caregivers are themselves elderly; 61 percent are women. Fifty-nine percent of informal caregivers also have jobs outside the home.²

Caregiver stress is also a common feature of the personal and professional lives of many nurses—making them “double-duty caregivers” who must constantly try to balance the boundaries between professional and personal caregiving roles and experience.⁵

Some nurses feel obligated to take a leave of absence without pay, or use their sick or vacation time in order to provide care in the home. Others may move to part time or leave the workplace.⁵ Today, professionally trained family members are taking on more frequent and complex caregiving responsibilities than in the past.

According to studies, the majority of caregivers go through a period of shock followed by a major adjustment in their roles, resulting in anger, resentment, and guilt. In such an emotional state, it can be difficult to provide high-quality care to loved ones. Caregivers are less likely to set aside time for rest and exercise.^{2, 3}

Caregivers are usually so immersed in their role that they neglect their own care and often do not seek help, largely because they may not recognize that they have a serious chronic condition. Studies found that fewer than half of caregivers were asked by their doctors whether they had symptoms related to caregiver stress.⁶ Such symptoms include feeling overwhelmed, sleeping too much or too little, gaining or losing a lot of weight, loss of interest in favorite activities, irritability, frequent headaches, chronic sadness, and abuse of alcohol or drugs, including prescription drugs.²

A growing body of research shows that stress level is affected by how we feel about being a caregiver. There is strong consensus that societal expectations and attitudes influence our thinking. Often we are not even aware of our own personal rules and expectations that may guide our behavior and influence our attitude toward caregiving.^{6, 7}

Some caregivers experience constant anxiety related to problems at work, conflict with a friend or another relative, or a situation with a child. Chronic worriers are subject to greater generalized stress. Even experienced caregivers may worry about caregiving, although we understand there is nothing more we can do, and we may have trouble admitting that we need support.¹⁻³

Caregivers who can be flexible and feel more in control have a much lower sense of stress. Understanding the stress you are feeling will help you manage your responsibilities. Seek help from family and friends to accomplish specific tasks or provide companionship for your relative/partner. Individuals can find great relief by talking, having a good cry, and getting any issues off their chest. Finding a support group that shares your experiences is an essential component to prevent chronic stress.

Caregiving may last from weeks to decades. Conflicting emotions can be difficult for a caregiver who is already stressed and vulnerable. This conflict may explain why nearly one in three caregivers meets the medical diagnosis for depression. We cannot automatically make emotions go away, and need to allow ourselves to feel angry and not feel guilty. It is important to understand that it is acceptable to have mixed feelings. Unfortunately, if nothing is in place to process emotions in a healthy way, they may be processed in unhealthy ways.^{2, 3}

Research suggests there are benefits to long-term caregiving: greater intimacy, increased patience, being needed, and being grateful that you are able to make someone you love happier, secure, and comfortable. Caregiving can be a joyful and beneficial experience for the one who gives, especially with proper respite and support.^{2,7}

Caregiving presents considerable physical, emotional, and economic challenges. The significant number of war veterans returning from Iraq and Afghanistan has brought increased attention to the issue of respite care and other support services. In May 2010, Public Law No. 111-163, was passed. The law directs the improvement for healthcare of veterans and to recognize the important role that family caregivers play in the recovery of wounded personnel. The law gives caregivers a stipend to care for a severely injured veteran and creates a support program including education, counseling and mental health services, and respite care (including 24-hour, in-home respite care).⁸

Resources for Caregivers

Multiple resources are available to caregivers. For example, the Rosalynn Carter Institute for Caregiving includes the Cooperative Extension Services, a website that strives to meet the educational and decision-making needs of family caregivers and the professionals who support them. Featuring articles, online educational sessions, and an "Ask the Expert" section, the website assists caregivers in finding and accessing local resources.⁹

It is easy for caregivers to get discouraged and overwhelmed. Taking care of ourselves is crucial: Get enough sleep, eat a well-balanced diet, and make time for exercise.

We must also nurture our spirit, acknowledge losses, and most of all, laugh. Learn as much as possible about the condition or disease you are dealing with. Learn time management and flexibility. Seek professionals to be your allies and learn about services, including overnight respite.

Celebrate milestones such as wedding anniversaries and birthdays, and participate in family or other social gatherings. Find diversion in work, hobbies, or community and church activities. All provide a change of pace, validation, and additional social support. Seek the services of a mental health counselor if you need assistance. Talk to clergy or your physician.

Keep a caregiver journal. There are no rules for what to write. It is one more way of expressing our feelings, our hopes, our sadness, our losses, and even our gratitude. We need to learn to support and comfort ourselves. Practice relaxation techniques, meditate, have a massage, or use other stress-reducing methods to keep stress in check. Self-talk is important. Understand that it is OK to be sad. We

*One person, caring about another,
represents life's greatest value.*

Jim Rohn

need to let ourselves be human. Talking to ourselves, taking care of ourselves as we would a good friend will not change our situa-

tion, but it might lift our burden just a bit. ■

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