

Caregiver Stress and Burnout

THE ONE MINUTE CAREGIVER



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by Benjamin W. Pearce

Caregiver Stress

According to the results of a new study of the health of caregivers, there is mounting evidence that explains why caregivers often become patients themselves while caring for a loved one.

Individuals caring for a spouse with dementia show four times greater annual increases than noncaregivers in interleukin-6 (IL-6), a key immune system molecule linked in previous studies to increased risk of cardiovascular disease, osteoporosis, arthritis, adult-onset diabetes, and a greater likelihood of death, Janice K. Kiecolt-Glaser and colleagues report in the June 30 edition of the Proceedings of the National Academy of Sciences.

Caregivers' relatively higher levels of IL-6 may provide part of the biological explanation for a growing body of evidence implicating care giving as a risk factor for a variety of illnesses. In addition to showing accelerated increases in IL-6, caregivers report greater loneliness and feelings of stress and score higher on measures of depression than noncaregivers.

For caregivers whose spouses died during the study, elevated IL-6 and feelings of loneliness and depression persisted for at least three years following bereavement. One explanation for this persistence may lie in the well-documented social isolation and loss of support that result from extended care giving. Caregivers may emerge from their care giving responsibilities with many fewer social contacts than they had before their spouses developed dementia. Social isolation, which has also been linked to increased risk of illness and death, may be an important factor in perpetuating caregiver stress.

Often caregivers underestimate the demands of providing care for another can have on them. While it is important to try to maintain a positive attitude, often caregivers experience feelings of helplessness and lack of control over their situation. Caregivers who educate themselves about the diseases affecting their loved one will be better equipped to recognize and understand changes associated with progression of the disease and the aging process. This way they can be more capable of anticipating and dealing with changes as they occur rather than being caught surprised and unprepared.

It is also important to set reasonable expectations. A child can never change a lifelong relationship by taking on caregiver

responsibilities as the need arises. Be realistic and understand that if anything, the stress associated with caregiving can often expose already weak areas in a long term relationship in even the best of situations. Appreciation for one's contributions should not be expected by the caregiver or from other family members. Caregivers who provide care without expectation will be rewarded if gratitude is offered and not disappointed if it is withheld. Learn to take pride in your own accomplishments.

It is critically important to strive for balance in your life. Personal fitness, good nutrition, and maintaining social contacts can all help keep caregivers energized. If the caregiver is beginning to feel frustrated, angry or like a martyr, it may be time to consider a support group, or a respite. Most communities, hospitals and churches host disease specific support groups where fellow caregivers can come together to share their experiences and help each other. Sometimes it may be helpful to just come and listen to others and see how they have learned to cope with their caregiver responsibilities. Often caregivers themselves can offer the best support to each other because of their own personal experiences.

Acknowledge your emotions and find an outlet for them. Most caregivers will experience frustration, anger, guilt, resentment, self-doubt, and feelings of helplessness. These can all lead to stress which as the study revealed can contribute to health problems of their own. Caregivers need to find some time to nurture their own needs. Better to consider lowering your expectations when they are unmet rather than allow yourself to become stressed out by them. You can only do so much, better to say "no" if you can then have

your own health slide attempting to do the impossible. Learn to ask for and accept help from others before it's too late. Most siblings will participate in solutions for the care of a parent if they are pushed, asking for help does not need to mean that the primary caregiver is relinquishing control or backtracking. It is better to teach others what the caregiver has learned and empower them to help than to try to do it all one's self.

Maintaining a positive attitude is very important. A stressed out caregiver is highly susceptible to depression. Depression has been known to adversely affect the immune system. This is why people who are left alone and isolated often suffer catastrophic health failures, while their socially active counterparts remain relatively healthy. Learn to recognize when your care giving duties begin to drag you down and find a way to get away for some time alone or with friends. Day care, respite and other short-term stays are available in most senior living communities at reasonable rates. Patients who are around other people tend to perk up and complain less. Most find the experience very fulfilling after a short period of guilt-laden complaining about it. Mother may have "known best" when you were a child, but now that roles have reversed, it may be time for the caregiver to do what he or she thinks is best for them. After all how often did your mother allow you as a child to talk her out of what she thought was best for you? A short term stay can also afford the caregiver opportunity to recharge their own health and attitude treating both to a better situation.

Caregiver Burnout

Many family members who find themselves caring for a loved one may be unable to recognize their own limitation before the strains and stress of their care giving activities turn them into a patient as well. This is especially true for someone who started out providing intermittent assistance to someone with simple tasks as shopping, errands, or bill paying who, as their loved one declines ends up providing heavy personal care such as bathing and dressing. Studies have shown recently that nearly 25% of American families are caring for an aging family member, friend or adult child with disabilities. Part of the art of being a successful caregiver in the ability to set expectations, see one's own limitations and learn to care for ourselves as well as others.

In many cases, care giving responsibilities saturate one's life to the extent that we may not even recognize what was once our "normal" routine. The responsibilities for providing care for someone else can become gradually overwhelming as the personal needs of the loved one inevitably increase over time. But burnout isn't like the flu with defined and recognizable symptoms. It creeps up on you gradually over time. You may wake up one morning look into the mirror and not even recognize the person or professional that you once were.

Symptoms of burnout can have a profound influence on your quality of life. Most caregivers experience a heightened sense of helplessness and depression along with a sense of ongoing and constant fatigue. Care giving activities for others may force a

withdrawal from social contacts and friends who are your primary support structure, or even cause you to lose interest in work where you may receive professional validation. Still others may experience a change in eating habits, or an increasing use of stimulants and alcohol. While most people can endure and recover from some of these symptoms, they tend to accumulate over time and increase in severity. Eventually they can have a dramatic impact on the overall health of the caregiver and their ability to effectively provide care for someone else. Ultimately this can lead to a collapse of the "cushion of care" that was originally intended and render the caregiver a patient himself or herself. This can create a cycle of failure, which becomes self-perpetuating.

Strategies to cope with burnout are critical to maintaining the health of both parties. Acknowledge your emotions and find an outlet for them. Feelings of anxiety, worry, anger, guilt, sadness and resentment are normal, and should be shared with others. Most communities have well-organized networks of support groups. These are groups of people who have experienced similar family crises and have banded together to help one another. Support group meetings such as those sponsored by the Alzheimer's Association provide a monthly forum for caregivers to receive feedback and coping strategies from others in the same predicament.

Recognize the importance of your own identity, and allocate some personal time for things you enjoy such as exercise, hobbies, other family members, and even some "quiet time." Establish some understandings regarding what an emergency is, and more

importantly what is not an emergency requiring your immediate response or interruption. Do not hesitate to say "no" if the problem can wait, someone else's crisis only becomes yours if you accept it. Knowing what things can wait can provide you more control over your life. Also recognize that the more you do for someone, the more dependent they can become. Studies have shown that starting or completing tasks for people can offer more independence for both than doing it all for them "quickly." Try to focus on what abilities remain rather than those that have become lost or difficult. This helps to build confidence, rather than leaving you with the feeling that you can never do enough.

Don't allow yourself to get into a rut. Often caregivers can become so wrapped-up in handling one problem after another that they can lose perspective. Varying the responsibilities of the caregiver is a way to stay fresh. If possible rotate tasks between other family members, or look into day care to give yourself some personal time during the day. Most senior living providers also offer respite programs to allow short-term residency while caregivers take a well-deserved rest or vacation. These programs can provide the caregiver some peace of mind in knowing that professionals are looking after Mother or Dad so that the caregiver can relax, recharge and regain their perspective. Respite can also serve to introduce your parents to the concept of assisted living so that they can overcome any fears they might have of living there one day. Once they see that others have made the choice to live there and how their lives and family relationships have improved as a result, they might consider the option for themselves.

Recognize that you do not have to do it all. Being a good caregiver doesn't mean that you have to be a martyr. If other family members are giving you direction and advice, then they should share in the burden. Learn to ask for and accept help from others, maintaining a balance in your life will help you avoid future burnout. Take time for yourself to recharge and to nurture your own family and friendships. Make time to protect your own health; you will need it now more than ever.

Further Reading

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