



STRESSED OUT? A CAREGIVER'S GUIDE

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Stress has been of concern to the medical profession since the days of Hippocrates. Walter Cannon, a physiologist at Harvard, however, formalized the modern notion of stress, at the beginning of the twentieth century. Cannon described the "flight or fight response", a heightened arousal state that prepares an organism to deal with threats.

This response has survival value. Primitive man needed quick bursts of energy to fight or flee predators. Today, this response may be adaptive in the face of physical danger or in sports that require fast, rigorous activity. Often, however, this response is not useful. Cannon noted that critical stress levels could disrupt homeostasis and throw the organism off balance. Thus, Cannon hypothesized that stress could cause disruption of emotional and physiological stability, as well as aid in survival.

Following Cannon, Hans Selye did much to popularize the notion of stress and to bring it to the attention of researchers. Selye described the General Adaptation Syndrome (GAS). He hypothesized that the GAS consists of three stages of response to stress. First, as the organism becomes aware of stress or the presence of noxious stimulation, the alarm reaction is experienced. The organism prepares to respond. When ready, the organism enters a stage of resistance to the stress, applying various coping mechanisms and typically achieving adaptation. When these reactions are repeated many times or when they are prolonged because of a recurring problem, the organism may experience exhaustion, the third stage of the GAS. Exhaustion is likely to result in what Selye called diseases of adaptation, stress-related illnesses.

In the latter part of the twentieth century, R.S. Lazarus contributed to the understanding of stress by emphasizing a psychological dimension. Lazarus understood the role of perception and cognitive appraisal in the stress response. He argued that in order for an event to be stressful, it must be appraised as threatening. Only stimuli that are appraised as threatening evoke the stress response.

Body's Reaction to Stress

The physiological and biochemical responses to stress appear to involve two systems. The first, described in 1927 by Cannon, is the sympathetic nervous system. The sympathetic nervous system is responsible for arousing or mobilizing the body for action. It stimulates organs that must increase activity in order to ready an organism for action and inhibits organs that are not involved in such a mobilization. Stimulation of the sympathetic nervous system causes the

adrenal medulla to secrete large quantities of catecholamines (epinephrine and norepinephrine), neuro-transmitters that increase heart rate and other coronary activity, constrict blood vessels, increase conversion of stored energy to usable energy, inhibit gastrointestinal activity, and increase a number of other bodily functions. It dilates vessels to the muscles and generally increases blood flow to areas that will be needed to act. This readying of the body is basic to stress. The second system involves the pituitary gland. The pituitary gland secretes ACTH that stimulates the adrenal cortex to produce corticosteroids, particularly cortisol. Cortisol affects carbohydrate metabolism. It affects muscle tone and the excitation of nerve tissue and increases gastric acid secretion.

Physiological responses to stress may be chronic or acute. Those responses that are short-lived, because the organism adapts or because the stress is eliminated quickly, resemble Cannon's mobilization response and are not usually damaging. When the stress responses are repeated or prolonged, the mobilization reaction is no longer functional. If adaptation is not achieved, prolonged arousal can lead to emotional or physical illness.

Unique Aspects of Caring for Someone with a Brain Injury

There are some unique qualities to caring for someone with a brain injury. To begin, consider who is most likely to sustain brain injuries. Males between the ages of 15 and 24 years have the highest incidence of traumatic brain injuries. Thus, the injury and need for care occurs at a time in the person's life when he normally would be moving toward greater independence. At a time that parents are preparing for decreased responsibilities and increased time for themselves, they may suddenly find themselves immersed in the challenge of meeting the life-long care needs of their loved one. The hopes and dreams they had for their loved one are dashed. For young couples, spouses find themselves providing care for the person who was their chief companion and source of emotional support, instead of planning together for their family's future. It is extremely difficult to adapt to these sudden and dramatic changes in the expectations for the future.

The caregiver's stress may be increased because there are limited resources to address the needs of persons with brain injury and information about brain injury may be difficult to obtain. In addition, there are specific cognitive, behavioral, and psychological changes associated with brain injury that may make care giving particularly challenging.

Consequences of Not Managing Stress

Almost every system of the body can be damaged by stress. Chronic stress can contribute to hypertension and cardiovascular disease, ulcers, colitis, suppression of the reproductive system, changes in lung function contributing to asthma and bronchitis, onset of diabetes, osteoporosis, arthritis, and inhibition of immune and inflammatory systems. Headaches, muscle tension, and fatigue also have been associated with stress.

Stress contributes to sometimes seriously debilitating anxiety and depressive disorders. It is related to increases in negativity, impatience, irritability, and cognitive problems, such as decreases in problem-solving abilities.

If coping is successful, the effects of stress diminish. If it is unsuccessful, stress persists and pathological states such as mental or physical illness become more likely.

Caregivers often feel that taking care of themselves, finding ways to reduce their stress is selfish. The consequence of persistent stress, however, is physical or emotional illnesses that reduce the ability to provide care. Those that provide care for others can do a better job of care giving if time and attention also are given to their personal needs. The success of care giving is dependent on how well the caregiver cares for him/herself. Thus, to be successful and available to loved ones, caregivers must find ways to reduce stress and improve coping.

What Can You Do?

One of the most important aspects of managing stress is being able to take an honest look at yourself. There are external circumstances and events, outside of your control, that cause stress: a traffic jam, financial concerns, or possibly an accident that has changed your life. It is easy to blame others or outside events for your stress, but this reinforces feelings of helplessness and loss of control and only increases the stress. It is more effective to take responsibility for the stress you are experiencing and decide what you can change or how you can cope more effectively with things you cannot change. Stress will always be a part of your life. Your decision to manage or cope with the stress you will face will shape how happy and successful your life will be.

Stress management requires you to take responsibility for your thoughts and actions. Identifying stress is the first step. As noted on the previous page, this requires regular self-evaluation--taking a moment every day to contemplate how you are doing. Scan your body; think about your interactions; assess your mood. Are you experiencing personal signs of stress? Have these signs/symptoms worsened? What may be contributing to these symptoms? Once you have recognized stress and what may be causing it, you can then decide what you can change to reduce stress.

The toughest part of creating change in your life is taking the time and finding the energy to do it. At times of tremendous stress, it is difficult to take this first step. A conscious shift in the use of your energy is required. Instead of focusing on your worries and what you cannot control, time and energy must be committed to the changes you can make.

There are many different stress management techniques. No one technique is best. Everyone has different styles and must find the techniques that are most effective for them.

Some very effective stress management methods include:

- Education--Find out as much as you can about brain injury and rehabilitation. Search the many available web sites that offer information about brain injury. Go to the library. Research care giving. Read. Talk to others. Attend seminars and conferences.
- Join a support group--Locate a local brain injury support group. Often, local support groups also offer groups for the individual that is injured. There are Brain Injury Associations in most states and provinces. Many of these organizations have support groups, peer counseling programs, recreational and social events, and legislative and advocacy groups. Take a chance. Get involved. Go more than once. Talk to others who may be in similar situations.
- Maintain/improve your health--Eat balanced meals. Avoid eating too little or too much. Avoid excess alcohol. Exercise. Moderate aerobic exercise helps to decrease stress-induced hormones and reduce tension. Exercise is good for us both physically and emotionally. Choose an exercise that that you enjoy. Go for a walk or hike. Swim. Go to an exercise class. Walk up and down the stairs. If you enjoy it, you are more likely to continue it. Get enough sleep. Have some fun.
- Relaxation/mediation techniques--Take a deep breath. Slow down your mind. Close your eyes and imagine yourself in a relaxing place. Go on a mental vacation. Light a candle. Listen to soothing music. Learn progressive muscle relaxation. Take a yoga class. Take breaks often. Accept that working harder does not mean working better or smarter. Taking breaks can actually help you accomplish more.
- Set reasonable goals and expectations--Recognize what you can and cannot do. Learn to recognize what others do best and ask for their help. Be specific with your help requests. Negotiate time lines and responsibilities. Focus on one thing at a time. Work on your toughest responsibilities when you are at your best.
- Compose a list of what you have accomplished--Regularly review your list of accomplishments. Learn and recognize the difference between what you would like to do and what you are required to do.
- Practice good communication and negotiation skills--Express yourself assertively. Learn to say "no" to things that are not a priority to you and "yes" to things you enjoy.
- Find the humor--In *The Anatomy of an Illness as Perceived by the Patient*, Norman Cousins, a leader in research on the power of laughter in illness and stress reduction, describes the positive effects of laughter on tension, pain, breathing, and mood. Be aware of how much you smile or laugh. Try to find other people that help bring out the laughter in you. As Anna Quindlen says in her recent book, *A Short Guide to a Happy Life*, "Show up. Listen. Try to laugh."
- Build your self-esteem--Tell yourself things that will help. Become aware of what messages you are sending yourself. Avoid putting yourself down. Stop pushing yourself too hard. Recognize that this is your only life and

you are your life designer. It is up to you. Decide how you want to live your life. Take responsibility for how you feel. David Burns' book *Feeling Good*, offers practical advice about ways to feel better and boost self-esteem.

It is important to recognize that no single stress management strategy is right for everyone. You must take an honest look at yourself and decide what will work for you. Many of these strategies can be effective. Choose the techniques that are likely to be most effective for you and then make the commitment to put them into practice. This requires a plan of action. Write your plan. Enlist others to support your plan. Evaluate the plan's effectiveness on a regular basis. Revise your plan, trying new strategies when the ones you are using are not effective. Stick to it.

Remember, success as a caregiver is dependent on your ability to take care of yourself. Talking care of yourself takes effort. **YOU ARE WORTH IT!**

Caregiver Stress

While each care-giving situation is different, there is an abundance of evidence that care giving is stressful. Sources of caregiver stress include:

Personal limitation imposed by care-giving. The limitations on one's personal life are a major source of stress for caregivers. The attention required by the care receiver limits the time the caregiver has for personal activities. Caregivers may find themselves unable to have an evening out even once a week or once a month, because they are too tired or unable to find someone to provide care. Not only does care giving restrict outside activities and interactions with friends and family, privacy and alone time also are limited. This limits opportunities to engage in activities that may renew and refresh the caregiver. Constant responsibility, isolation, and lack of privacy can result in a build up of anger and resentment toward the person receiving the care, leading to even greater stress.

Competing role demands. Caregiver's function in multiple roles: Paid positions, homemaker, parent, partner, friend, and caregiver. Each role competes for time and energy. The tendency is for caregivers to double up on their responsibilities to others and cut back on their personal time.

Relationship and role changes. Illness or injury disrupts the family balance. Persons who were independent become dependent; persons who received support, now provide support. Adjusting to the obvious and not so obvious changes in relationships is sometimes overwhelming. In addition to changes in how family members relate to one another, caregivers often also have to take on new roles and responsibilities-responsibilities formerly managed by the person now receiving care. This adds to the demands on time and energy.

Old family issues. Historical conflicts with loved ones do not disappear when one becomes ill and the other assumes the role of caregiver. Unresolved conflicts resurface and can intensify, causing anxiety and frustrations.

Conflicts about care. Differences in values and opinions among family members about provision of care can create a considerable degree of interpersonal conflict.

Emotional demands. The emotional demands of care giving represent one of the most significant negative impacts of care giving. The loved one receiving care is often demanding and may display disruptive or aggressive behavior. The behavior may be embarrassing and emotionally draining. At times, caregivers may experience the desire to be relieved of their care responsibilities through placement or even death of the care receiver. This experience is typically followed by feelings of guilt, creating further stress. The person giving care needs to be assured that these feelings are common, even though they may not be expressed.

Physical demands. The physical demands of care giving include addressing the physical needs of the care receiver and often the broader demands of helping the individual maintain a household. Lifting and transferring individuals and assisting with hygiene needs of individuals with limited mobility can be physically demanding, exhausting, and may put the care giver at risk of personal injury. General homemaking and housekeeping activities such as cleaning, laundry, shopping, and meal preparation place additional demands on the caregiver. Even further stress may be created if the caregiver is responsible for maintenance of equipment such as wheelchairs, hospital beds, and monitors.

Financial demands

Caring for a person with disabilities has many financial dimensions. Families may have to deal with the loss of income of the person receiving care or of the caregiver. In addition, the cost of obtaining needed services creates financial strain.

Constant responsibility

Simply being responsible 24 hours a day is stressful. This is exacerbated when the caregiver is responsible for unfamiliar tasks, such as medication administration, wound care, or other medical regimes.

Cognitive, behavioral, and psychological changes that may occur in individuals with brain injury are:

Shallow irritability. Many persons with brain injury display a shallow irritability, resulting in frequent angry outbursts. Family members/caregivers may find themselves walking on eggshells to try to prevent such outbursts. The situation may be made worse because the emotional outbursts may not be evident to persons involved on a more casual level. For shorter periods of time or in well-structured surroundings, persons with brain injuries may be able to exercise control over their behavior. Therefore, persons involved on a casual level may not see the behaviors the caregiver encounters regularly. Caregivers' distress is therefore not understood and needed support may not be forthcoming.

Egocentrism. The tendency to focus almost exclusively on one's own needs is also frequently associated with brain injury. Because of this, persons with brain injuries often view others only as they relate to them. Persons who are limited in their capacity to consider others place constant demands on the caregiver. This leaves the caregiver feeling pulled in many directions, frustrated, and tired. The person with the brain injury, however, often does not recognize this, further stressing the system.

Impairment in social awareness. Persons with brain injury are often impaired in their ability to recognize social signals. This impairment may result in behavior that is embarrassing to caregivers and others. This makes gatherings unpleasant and friends and relatives, therefore, limit their contact. This increases the probability of isolation.

Impulsivity. Behaving before evaluating the consequences of one's actions is common following brain injury. Impulsivity can be displayed in a multitude of forms--impulsive eating, sexual impulsivity, impulse spending. All result in the need for increased vigilance by the caregiver, thereby increasing the burden of care.

Decreased spontaneity and flexibility. The inability to act spontaneously and flexibly represents another problem associated with brain injury. Persons with brain injuries whose flexibility is impaired may become confused in the face of even minor changes. Cognitive deficits such as impaired memory and difficulty organizing and planning exacerbate the difficulties encountered when daily structure is modified. This places caregivers in the position of following unwavering scheduled and routines to maximize the ability of the person with a brain injury to function independently and to minimize emotional outbursts. Such routines interfere with engaging in social activities and further contribute to isolation. At its extreme, inflexibility results in repetitive behaviors that, over time, can become an extreme source of irritation or annoyance for caregivers.

Depression. Whether as a direct result of the brain injury or a response to the losses associated with the brain injury, many of those who sustain a brain injury experience depression. If this becomes chronic, it can have a major impact on the caregiver. The depression tends to erode the caregiver's self esteem and increase feelings of guilt and inadequacy because their efforts to relieve the depression are unsuccessful.