

Quality

Enhancing quality of life for people affected by traumatic brain injury

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Stress Management Following Brain Injury: Strategies for Families & Caregivers

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Strategies for Families & Caregivers

Few illnesses, injuries, or diseases result in the devastating and overwhelming damage which accompanies brain injury. The individual who sustains a brain injury is no longer the same person: he or she may behave differently, think differently and in fact be a different person than before the injury. The differences may be large or small; they are differences nonetheless. And when one member of a family changes, the entire family changes. Learning to live with these changes produces stress for the injured individual and for those who care for that person. The steps outlined below can help lessen the burden and convert stresses into challenges which can be managed and overcome.

1. Identify Stress

Sounds easy. We all know when we are stressed. It's obvious. All your friends and relatives can tell you what is stressing you. We professionals are particularly guilty of telling you what to do and how to do it. Everyone is full of good advice and solutions to your problems. The solutions may range from putting the injured person in an institutional setting to developing some backbone and shouldering responsibility the way you should.

Don't allow others to identify your stress for you. Stress is cumulative and it is very personal. What might be stressful to one individual is not stressful to another. What is stressful to you at one point in time may not be stressful at another point. Only you can determine what is stressful to you. And you can only do that by experience. Spend time each day analyzing what has stressed you in the past 24 hours.

Avoid making moral judgments about stress. Stress in itself is neither good or bad. It is simply a situation in which your body's usual, customary, and habitual responses don't work and you must develop new responses. Your responses are neither good nor bad. You are not a bad person because you become angry at the injured person's behavior, because you become tired in a very short period of time, because you yell at your kids or another individual, because you don't want to change sheets or clothes one more time today. Accept your body's response without making judgments.

Make a list of each and every thing you do on a daily basis. Be very specific, including even the smallest activity. Include things you do for everyone, not just the injured individual. Then rate each one on a scale of 1-10 with 1 being "no stress whatsoever, enjoyable" and 10 being

“a root canal without anesthesia would be much more fun.” Do not show this list to anyone else. Be honest.

2. Reduce or Eliminate Stressors

Also sounds easy but this is the hardest part. I am always amazed at the number and amount of things people do because they have always done them. Absolutely irrational, meaningless things; things which reduce the time available to enjoy life; things which 24 hours later have no meaning at best, negative meanings at worst.

Do only those things which have meaning to you and to others; do them quickly, efficiently and only once. If you're dreading doing something for five hours before you have to do it, you have wasted five hours and still have to do it. Whenever possible, live in the present; avoid the future and the past since you have no control over them anyway.

Once you have your list of things you do regularly, decide which of those you rated over 5 truly need to be done. Objectively need to be done. Those things where life would not continue if they weren't done. Probably they need to be done. I won't argue with you. I will argue that YOU need to do them. Answer each of the following questions:

Do they have to be done the way they are usually done? Can the person with the brain injury do them? Can another family member do them? Can a volunteer do them? Can a group of people do them? Can you reduce how often they need to be done? Can they be done at a different time of the day? Can they be done in a way that makes them less enjoyable (or at least less stressful)?

3. Replace Stressful Things With Pleasant Things

It is truly surprising to me to see individuals who successfully reduce or eliminate stressful situations from their life and within a week add a whole new list of activities which are equally stressful. It seems as if they thrive on stress but everyone who lives with the consequences of brain injury knows that it is not true. The problem is that, unless you actively substitute pleasant activities for unpleasant ones, the time will rapidly fill with equally (or perhaps even more) unpleasant activities.

If you have lived with the consequences of brain injury beyond the acute medical stage you know how difficult it is to allow yourself the luxury of enjoyment and relaxation. There never seems to be enough time for you. Simply and solely because you don't make the time. Every human being is a *[sic]* like a pitcher; you can only serve out what was poured in to you. You cannot continue to give without replacing what you give. If others are not able to give to you, then you must give to yourself. When was the last time you gave yourself a present? A simple, inexpensive present like a walk in the park, dinner with a friend, sleeping late in the morning, maybe even breakfast in bed. Or, even worse, when was the last time you allowed someone else to give you a present of time or assistance?

You may think I have lost touch with reality because you KNOW that other people are not willing to help. You have tried them in the past and they never came through for you. They make empty offers which you know they don't mean. Besides, many of your friends from before the injury no longer call or visit. You're alone in this. There is no help. You have tried

time and time again. I suggest you try again, making sure you are specific about the kind of help you need, when you need it, what is involved, how often you need it, and, most importantly, what you are willing to do in return. Your family and friends can only give to you if you continue to give to them. They are also pitchers that need to be refilled. When they see you stressed out, they assume the same thing will happen to them if they try to help. Try being specific and giving in return. It's worth the effort.

Another alternative is to try new things in which the entire family can participate. Families sometimes fail to try new activities and stick with the tried-and-true favorites. Try to discover new activities in which the effects of the deficits of the head injured person are minimized. Many injured individuals are able to do things they once did as a child or young adult because those activities rely on old rather than new learning. Experiment with activities which can be enjoyable for everyone and feel less like work for the caregiver.

4. Maximize the Capabilities of the Person With The Brain Injury

It is sometimes very difficult to determine just what the injured individual is capable of doing. Therefore, family members may do things for the individual that could and should be done independently. Persons who sustain head injuries continue to improve for years, learning new skills or new ways to do things. If the family doesn't "catch up," they keep on "doing for" rather than letting go. It often feels easier to do it yourself than to work regularly for a long term goal of independence or at least less dependency. But that strategy doesn't reduce the stress for the injured individual or for the family.

Many family members have explored or even participated in newly-developed cognitive retraining programs. They usually begin with a detailed analysis of the person's current capabilities and limitations. From this analysis the treatment program is developed and the progressive steps toward increased independence are outlined. Families can do the same kind of analysis. Start with your stress list. Pick the 5 most stressful situations which require that something be done for or to the injured individual. Evaluate what parts of that task the injured person could do himself/herself. **ASK THE INJURED PERSON FOR SUGGESTIONS ON THIS PART OF YOUR TASK.** That person may well have very good ideas of how the task could be accomplished more independently. Consider the following ways to accomplish the task:

Change the time at which the task is done. If fatigue is a problem, for example, switch the task to an earlier time in the day or after a rest period. Schedule more time for completion of the task. Try to set up all necessary materials so the person can do the task independently. Use written instructions, photographs or picture demonstrations to allow the person to complete the task independently.

Basically I am suggesting you experiment to determine what the injured individual can do. You lose nothing by trying and the injured person may well be much more capable than others (or you) think. Give the person a chance. Give yourself a chance to reduce your stress. Allow the injured individual and the family to grow in a more relaxed atmosphere of increasing independence.

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