

INTRODUCTION

Between 40 and 45 percent of individuals with spinal cord injuries (SCI) need personal assistance with some daily activities. The majority have tetraplegia and often need assistance with getting in or out of bed, managing bowel and bladder issues, bathing, and dressing. The lower the level of injury, the less assistance is needed.

PCA VS CAREGIVER

Most often, a parent, spouse or other close family member is the first to provide personal care following injury. Although this initial care and attention is normal, it is not generally recommended for the long-term. If at all possible, it is best to have a paid Personal Care Attendant (PCA) provide the majority of long-term care while a loved one provides occasional care.

Unfortunately, many individuals with SCI have no option other than to rely on a family member for daily assistance. Whereas a PCA is an employee, a *caregiver* is the term used for an unpaid family member who is primarily responsible for the care of a loved one.

There is no "typical" family following SCI. Each situation is unique, and each caregiver and the person they care for will eventually create a system of care that works best for them.

ADJUSTMENT TO SCI

As a caregiver, you will likely face many unique challenges. First, there is often the initial worry and concern for the condition and recovery of your loved one. There is often stress over juggling work and finances while getting your home accessible for your loved one.

At the same time, you are learning about the many issues of SCI and how to be a caregiver. You may need to learn about bowel, bladder, and respiratory care. You need to learn how to do daily skin checks

and recognize signs of a pressure sore. Likewise, you may need to learn the symptoms of Autonomic Dysreflexia or ventilator care and what to do in case of an emergency. There are a number of educational materials available from reliable Internet sources, and it is to your advantage to familiarize yourself with such resources.

Long-Term caregiving for a loved one can put a strain on any relationship. There are often many lifestyle adjustments that need to be made in providing long-term care. The basis for a healthy relationship centers on open communication, learning the facts about life after injury, a willingness to adjust one's views in many areas, and paying attention to the health of both the individual with SCI as well as the caregiver.

MANAGING SELF-HEALTH

While it is important to learn how to take care of your loved one, it is even more important for you to learn how to take care of yourself. Maintaining self-health is essential for your wellness and your ability to adequately care for your loved one. After all, you cannot expect to effectively care for your loved one when you are in distress.

Recognizing Stress

Stress is a physical, chemical, or emotional factor that causes tension in your body or mind. Most everyone has some type of stress in their life. Stress is common because it is almost impossible to escape.

Stress can quickly become a problem for people who have learned to ignore signs and symptoms of stress until it gets out of control. Continued stress puts people at higher risk for serious health problems including illness, addiction, and depression.

There are several signs and symptoms of stress that you can learn to recognize when stress might be getting out of control. When you are under a lot of stress, you may experience one or more of the following:

Mood (Emotional) Symptoms of Stress

Anxious
Scared
Irritable
Moody

Thought Symptoms of Stress

Low self-esteem
Fear of failure
Inability to concentrate
Embarrassing easily
Worrying about the future
Preoccupation with thoughts/tasks
Forgetfulness

Behavioral Symptoms of Stress

Stuttering and other speech difficulties
Crying for no apparent reason
Acting impulsively
Startling easily
Laughing in a high pitch and nervous tone of voice
Grinding your teeth
Increasing smoking
Increasing use of drugs and/or alcohol
Being accident prone
Losing your appetite or overeating

Bodily Symptoms of Stress

Perspiration/sweaty hands
Increased heart beat
Trembling
Nervous ticks
Dryness of throat and mouth
Tiring easily
Sleeping problems
Diarrhea/indigestion/vomiting
Butterflies in stomach
Headaches
Premenstrual tension
Pain in the neck and or lower back
Weight loss or gain

Source: <http://ub-counseling.buffalo.edu/stressmanagement.shtml>

Adopting a Healthy Lifestyle

A healthy lifestyle includes a balance of things you can do to feel better emotionally and physically. Healthy behaviors reduce stress and increase our ability to cope with problem issues. A few simple acts can be a great foundation for self-health. For example:

- ◆ Get enough sleep.
- ◆ Eat regular, healthy meals and snacks.
- ◆ Participate in regular physical activities because your body can fight stress better when it is fit.
- ◆ Take quiet time for yourself to listen to soothing music, soak in a warm bath or shower, read an interesting book or magazine or go to the park or some other place quiet.
- ◆ Cut down or cut out use of caffeine and tobacco.
- ◆ Do not rely on food, alcohol or drugs to reduce stress.
- ◆ Balance your life with work and play.
- ◆ Spend quality time with friends and family.
- ◆ Enjoy hobbies or crafts.
- ◆ Hug somebody!
- ◆ Be assertive instead of aggressive. "Assert" your feelings, opinions, or beliefs instead of becoming angry, defensive, or passive.
- ◆ Do not volunteer for something if you do not have the time or energy to do.
- ◆ Keep things organized.
- ◆ Seek out social support to share ideas, resources and coping skills.

Getting Help

Getting help is essential to finding time for yourself. Help can come in various forms such as other family members helping with household chores. It may be an understanding boss that allows you to work from home or adjust your work schedule to be able to maintain your job while still providing care.

Asking for help is a sign of strength - not weakness. It may not be easy at times to ask for and receive assistance. This difficulty usually stems from two notions of thought.

First, some people may not ask for help because they do not want to "burden" others, especially family members. If you feel this way, ask yourself if it would be a burden on you to help a loved one in need. We are part of a family; we are part of a society; and we all need each other. We all need help at times, and we rely on each other in many ways, and most people gladly help family and friends if needed.

A person's impression of "independence" is the second problem notion of thought. Some people may not seek

assistance or refuse it if offered because they believe that being independent means doing things without the help from others. The reality is that there is no shame in asking for and receiving help when you need it. And you will probably make your everyday life more of a burden on you if you do not get assistance when you need it.

Caregiving is not a one-person job. You need time away for a healthy lifestyle, and there are going to be times when you are sick or need to get away for other reasons. The best thing that you can do is have a list of people that you can call when you need someone. You might also have one or two people on your list who can be a backup care provider on short notice in case of sickness or crisis.

Learning to Solve Problems

Although avoiding problems might ease stress in the short-run, most problems do not simply fade away. In fact, you can usually expect stress to continue until you resolve your problem issue

Research suggests that having effective problem solving skills is also essential for the health of both the caregiver and care recipient. You can use problem solving skills in almost all aspects of your life. As you set out to resolve problems, it is important to set your priorities. What needs to be done first? What can be left until later? Work on what needs to be done first. There are 5 basic steps for effective problem solving.

STEP 1 - Identify the problem: you must know the problem in order to solve it. You might make a list of your problems and rank them in order of importance. You need to make sure that you break large problems into smaller parts, and select the most troublesome problem to resolve first. Remember to work on one issue at a time and get all of the facts before moving onto step 2.

STEP 2 - Brainstorm for possible solutions: thinking about the problem you most need to resolve, make a list of as many possible solutions to your problem as you can. Be free thinking, and do not judge your ideas at this time. If you have problems thinking of possible solutions, ask your family and/or friends for their thoughts on how they might solve the problem. If you

need more information, you might search on the Internet or at your local library.

STEP 3 - Select the best solution: from your list of possible solutions, choose the solution that you think will best solve your problem. Again, you can ask for opinions on which solution might work best. Once you make your choice, put your list in a safe place to keep for a later date if needed.

STEP 4 - Try your solution: the only way to know if the solution works is to try it out. Take notes on your progress and any problems that you experience.

STEP 5 - Evaluate your tried solution: if your solution works, give yourself a big pat on the back for a job well done. If you are not satisfied with the results of your solution, review your notes. It may be that there were unforeseen obstacles that need to be corrected. Make adjustments if needed. Try another possible solution from your list, or you can do more brainstorming for other ideas and edit your solution list based on new information.

Learning to Relax

Relaxation techniques are additional self-care skills you can learn. You first need to prepare yourself before you can relax. You can dim the lights and quiet all distractions by turning off the television, radio and phones. You can sit back in a comfortable chair.

Self-Guided Imagery:

- ◆ Close your eyes. Focus on your breathing and take slow, deep breaths.
- ◆ Imagine that you are in a peaceful setting such as relaxing on a beach, meadow, or mountain top.
- ◆ Focus on the peaceful setting that you are imagining and pay close attention to all the details. Notice the sounds (any birds, wind rustling the leaves, waves crashing on the shore?). Pay attention to what you feel (warm sun on your skin, hot sand on your feet, cool grass beneath you). Attend to any smells and tastes you may imagine having. Spend some time focusing on all the sensations you are experiencing while imagining your peaceful place.
- ◆ After a few minutes return your attention on your breathing. Notice how you are breathing deeply in and out and focus on what is going on around you

(the pressure of the seat against your legs, the ticking of a clock, etc.).

- ◆ Ask yourself how relaxed you are at the moment using a scale from 0 - 10 with zero indicating not relaxed at all and 10 reflecting the most relaxed you have ever been.

Abdominal Breathing:

- ◆ Slow your breathing down by taking slow, deep breaths.
- ◆ You know you are breathing abdominally by placing your hand on your abdomen and seeing that your hand moves up and down.
- ◆ This is the type of slow, deep breathing that we do while we are sleeping. Slowing the rate of your breathing can slow your heart rate and give you a peaceful sense of relaxation.
- ◆ This takes practice, so keep trying if you are unable to do it the first few times.

Progressive Muscle Relaxation:

- ◆ Beginning with your toes, slowly work your way up through the muscles in your body by tensing and then relaxing your muscles. After your toes, slowly tense and relax your feet, then your calves, thighs, abdomen, arms, hands, fingers, neck, and finally, your face.
- ◆ Take as long as you need to tense and then relax all the muscles in your body.

PARTNER OR SPOUSE CAREGIVING_____

For couples, it is very important to keep the partner/spouse role separate from the caregiver role. One way to do this is to have a routine that keeps the caregiving activities separate from those of a partner. Another way is to have a specific area or room devoted to intimacy - where no caregiving tasks are performed. Keeping the two roles as distinct and separate as possible will help you to avoid confusing and blurring the roles in your mind. When you and your partner are feeling romantic, you will be better able to see yourself as a romantic partner and not as a caregiver.

Couples need to also work to maintain equality within their relationship. Both partners need to make significant and meaningful contributions with every day issues such as parenting, various household chores or money management. This equality will help caregivers not to

become resentful of being "overwhelmed" with daily responsibilities or duties.

Problem Issues

Most couples face obstacles early after injury. For most adults, pre-injury life is routine, familiar, and comfortable. People usually have established views of what they consider "normal," and they generally have defined notions of their relationship.

In most cases, pre- and post-injury routines are very different for caregivers and their spouses or partners. Like many other aspects of life post-injury, changes in views and established routines are usually necessary in adapting to life after injury.

Again, each family is different, so every family will not necessarily experience the same problem issues. As a caregiver, however, you will likely experience many of the same issues as others. Research has shown that caregivers generally report problem issues with:

1. the negative attitude of the person with SCI;
2. personal feelings of guilt;
3. lack of appreciation for being a caregiver;
4. not enough time for personal activities;
5. having to say "no" to the person with SCI; and
6. feeling overwhelmed.

Individuals with SCI expressed problem issues with:

1. wanting to walk;
2. sexual function;
3. pain;
4. bowel and bladder function;
5. lack of money;
6. not being able to do simple tasks; and
7. being anxious.

Although the two groups are affected by the same injury, those reported problem issues tend to be self-oriented. Therefore, the key to a healthy relationship centers on open communication, learning the facts about life after injury, and a willingness to adjust one's views in many areas.

It is essential to talk about problem issues and openly discuss how these issues are affecting your relationship.

In time, hopefully, the two of you can reach a mutual understanding of how, together, you can overcome the situation, resolve problem issues if possible and strengthen the relationship.

Resolving Conflict

You cannot avoid conflict because it is a necessary and healthy element in all relationships. People are simply different. Disagreements are going to occur because everyone has a unique point of view that often results in differing opinions.

If a problem is important to one member of the family, it is important to all. But conflicts with loved ones can be especially stressful for everyone involved. This is why it helps to learn how to resolve conflict to reduce or relieve stress.

STEP 1 - Ground Rules: when two people disagree about an issue, the first emotional reaction is often anger. It is nearly impossible for people to resolve issues when they are angry. Therefore, it is important for everyone to let emotions calm before making an effort to resolve conflicts.

The purpose of conflict resolution is not to have one winner. It is to reach a solution in which all sides agree. When you think of resolving issues this way, people are likely to respond with a willingness to succeed. If the conflict is a question of fact, it is everyone's responsibility to know the facts.

Basic Conflict Resolution Guidelines:

- ◆ Keep things in perspective.
- ◆ Focus on resolving one issue at a time.
- ◆ Be clear and direct when discussing issues.
- ◆ One person talks at a time.
- ◆ Allow each person to respond.
- ◆ Don't use physical contact, intimidation, or threats to get your way.
- ◆ Don't use the "Silent Treatment" and expect others to know what you think or feel.
- ◆ Don't dig up old issues that are not important to the issue at hand.
- ◆ Don't use emotional blackmail by saying "if you really love me, you would..."
- ◆ Don't over exaggerate or use words like "always" and "never."

STEP 2 - State the Problem: you cannot resolve issues unless everyone knows exactly what the issue is. You are more likely to have success in resolving the problem if you are respectful when stating the issue. For example, state the problem in the form of a self-expression, not a personal attack.

Examples of Request:

- ◆ "I feel like my work is not appreciated."
- ◆ "I feel overwhelmed because I am getting no time for myself."
- ◆ "I feel guilty when I take time for myself."

Example of Attacking Statement:

- ◆ "You make me mad when you do not give me a break."

If the problem is about behavior, make it a positive request about behavior, not a demand.

Examples of Request:

- ◆ "I would like you to take a more active role in helping with the children."
- ◆ "I prefer that we do (something) this way."

Examples of Demand Statement:

- ◆ "You have to start acting like a father."
- ◆ "You are going to do (something) my way."

STEP 3 - Listen and Understand: listening is the hardest yet most important part of conflict resolution. Listening requires an open mind to hear what is said. When two people are in an emotional argument, who is really listening? Sometimes people talk over each other hoping the loudest voice wins. Many people who are not talking are thinking about what they are going to say instead of listening. Resolving issues requires a willingness to listen to what is said.

It is tough being a good listener. If you find it difficult, you might try to "repeat" in your head what is being said as another person talks. That way, you stay focused on hearing what is said. There may be times when you hear what is said but do not really understand the other person's meaning. When someone talks to you, it is natural to imply your own reasoning to what is being said. However, people often mean to express themselves differently than you might think. If you are not clear about another person's meaning, you can easily repeat

what they said and ask for more information. If you are open minded, listen and understand; it is easier to suggest possible solutions that both parties can agree.

STEP 4 - Problem Solve for Resolutions: Following the 5 problem solving steps on page 3, conflict resolution is often similar to solving other problems. You want to work together because your goal is to resolve the issue in a manner that is acceptable to all those involved. Work together to pick one or more solutions from your list that everyone agrees offers a realistic chance for success. If you try a solution that does not work for everyone, work together to modify your solution or choose other possible solutions from your list.

STEP 5 - Resolution: the issue is finally resolved when the solution works for everyone.

However, there may be issues that cannot be resolved. If the conflict is a matter of opinion, recognize that it is impossible to control the thoughts of anyone else. You may not change another person's mind even with your best efforts and intentions. Likewise, you cannot change other people's behaviors.

When there is no mutual resolution, you have to resolve the issue for yourself. You might agree to disagree on

matters of opinion, or "let go" of a matter that you simply have no control over. These concepts may be hard to do at times, but they can be the best thing that you can do for your overall health.

CONCLUSION

As a caregiver, you can expect to experience ups and downs. You may feel overwhelmed or stressed at times with all of the added responsibilities you have. You might feel under appreciated for all your hard work and devotion.

Caregiving takes hard work and devotion, and providing care for a loved one is an expression of affection and commitment. After all, you are choosing to be primarily responsible for the care of someone you love. Therefore, it is important to take care of your health to best be able to give your loved one the care he or she needs.

However, it is equally important that you make a commitment to take care of yourself because it is best for you, too. You need care and attention as much as anyone else. Although it takes hard work and devotion, you can find balance in your life if you make that commitment. Do not forget that!

REFERENCES & RESOURCES

Accepting New Help

A brochure from Craig Hospital
303-789-8202

www.craighospital.org/SCI/METS/acceptingNewHelp.asp

Caregiver's Guide to Self-Health: Solving Problems and Reducing Stress

University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=117376

Caregiving

A brochure from Craig Hospital
303-789-8202

<http://www.craighospital.org/SCI/METS/>

[caregiving.asp](http://www.craighospital.org/SCI/METS/caregiving.asp)

Healthy Living: Relationships

An article from the Pushin' On, Vol 19[1], 2001.
University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=36069

Long-term Care Givers

A brochure from Craig Hospital
303-789-8202
<http://www.craighospital.org/SCI/METS/longtermCareGivers.asp>

Personal Care Attendant - SCI InfoSheet #6

University of Alabama at Birmingham
www.spinalcord.uab.edu/show.asp?durki=22411

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