



"Caregivers for SCI"

Who is the SCI Caregiver?

After an individual becomes spinal cord injured there is often the need for assistance in one's daily activities. This can range from help with bathing or dressing to doing one's bowel program or providing transportation. Today with the changes in health care, we see more family members as the source of care and support.

Forty percent of all individuals with SCI use some assistance, with more than half coming from family members (PN/Paraplegia News, 1994) Females are more likely to have a paid attendant as caregiver, while males are more likely to have their spouse or parent assist. (Spinal Cord, 1998: 36(5):337-339)

The family caregiver now is providing both emotional support as well as physical care that was once done by healthcare providers. The family caregiver is now a part of the healthcare delivery system. However, the caregiver often receives little or no preparation, support, or recognition for the work they are doing.

Caregivers for individuals with SCI face different problems than other caregivers because individuals with SCI have longer life expectancies than people with chronic diseases such as Alzheimers or AIDS. This places the caregiver in this role for an indefinite time.

Problems facing the SCI Caregiver

When a family member becomes spinal cord injured, there are many stresses and changes to deal with. First is the worry and concern for the individual's recovery and medical care. Next are problems dealing with money, transportation, and making the home accessible. The caregiver may have to take time off work, change their work schedule, make a job change, or even quit working so they can take on their new role of caregiver.

The family caregiver also may face the difficult role of seeing that the individual with SCI follows their daily programs to maintain good health. This means that while they want to give love and support, they must also take on the role of teacher and supervisor.

It is important to understand that the concerns and problems of the individual with SCI and the concerns and problems of the caregiver usually are not the same. Results from a recent research project show that caregivers see their problems as: 1) the negative attitude of the person with SCI; 2) caregiver's feelings of guilt; 3) lack of appreciation for the caregiver; 4) not enough time to do their own activities; 5) having to say "no" to the person with SCI; and 6) feeling overwhelmed. What the caregivers saw as problems mainly focused on the patient and what the caregiver had to manage.

On the other hand the concerns of individuals with SCI were related to 1) wanting to walk again; 2) their lack of 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. Their problems were more self-oriented.

When individuals are aggravated and frustrated in the pursuit of their goals or routine activities, they are more apt to act in a hostile manner. The caregiver is often the person who is there and becomes the target of their hostility.

Caregiving is not a static experience. Caregivers go through ups and downs. Resources can erode, physical problems can increase, and they may experience depression and anxiety. Some situations get better - some get worse. There is no "typical" family caregiver. Each caregiver and the person they care for are unique in their personal needs.

Caring for the Caregiver

The health and well-being of the SCI caregiver is very important because this can effect the well-being of the individual with SCI. This role as caregiver can place many demands on them. It can impact the caregiver's health as well as their relationship with the individual with SCI. If the caregiver becomes sick or emotionally exhausted, they may be unable to provide good care. This can cause an increase in secondary complications, such as pressure sores, thereby increasing the healthcare expenses.

Recent research looked at caregivers of individuals with SCI who were in this role for the first time. Their level of anxiety, depression, as well as their physical health was assessed. This information was collected both during the rehabilitation period and throughout the first year after injury.

Researchers analyzed the data in a new way, looking not only at the changes in individual characteristics during this period, but also how the changes related to each other. This made it possible to see if caregiver's emotions or health got worse over time, the factors that were related, and how they *interacted*.

The results showed that, overall for the group, caregivers do not necessarily get more depressed or anxious over the first year. But this can be misleading because there are some who got worse as well as some who got better. An important finding was that the group, on the average, had 3 to 4 more physical health problems during that first year, ranging from sinus problems and colds to body aches and pains.

Although new caregivers as a group were not more depressed or more anxious, this study did show that those caregivers who were more anxious during the rehabilitation stay tended to report more physical health problems initially. This anxiety (stress) also led to more health problems during the first year.

These findings are contrary to the idea that the anxiety is related to the newness of the injury and that caregivers will get better when they get home. Instead this research suggests that caregiver stress can get worse. If caregivers are having problems coping right after the injury, they are likely to have problems a year later. This will also effect the caregiver's health.

Another important finding is related to both anxiety and depressive behavior. During the first year after injury, changes in the caregivers' anxiety and depression were related to the degree of *expressive support*. This means that if they did not have people with whom they could talk and express their feelings, they tended to have problems and become more depressed and anxious.

When caregivers who were stressed during the rehabilitation period had someone to talk with who offered support when they returned home, their depression and anxiety decreased. This continued to be true during the first year after injury. If, however, the support was not there, they became more anxious and had more problems with depression over the course of the year.

It is important for caregivers to have other people with whom they can talk. Without this support the caregiver is at greater risk of having problems with psychological adjustment.

Another finding of this study was that caregiver anxiety was related to the age of the patient. The younger the patient, the higher the level of anxiety. This may be because the parent/caregiver is thrown into a situation that was not supposed to happen. It puts them in a quandry about life plans, both their own and that of their child. The older the age at injury, the less anxiety on the part of the caregiver.

Caregiver Stress Test **

Check how each of the following statements apply to you.		Seldom True	Sometimes True	Often True	Usually True	Areas
1.	I find I can't get enough rest.					Health
2.	My own health is not good.					Health
3.	I don't have enough time for myself.					Time
4.	I don't have time to be with other family members except for the person I care for.					Time
5.	I don't get out much anymore.					Time
6.	I feel guilty about my situation.					Support
7.	I have conflicts with the person I care for.					Assertiveness
8.	I have conflicts with other family members.					Assertiveness
9.	I cry every day.					Support
10.	I worry about having enough money to make ends meet.					Financial
11.	I don't feel I have enough knowledge or experience to give care as well as I'd like.					Information

Look at your answers. Is the response to 1 or more of the questions **Often True** or **Usually True**? What topic applies: health, time, support, assertiveness, finances, or information. Look at suggestions for handling stress in each area on the next page. **From *The Caregiver's Handbook*, San Diego County Mental Health Services.

The important points to remember for caregivers and those working with them are:

1. Level of anxiety is the best overall predictor of health. If a caregiver is anxious during the rehabilitation phase and having health problems - they are more likely to be poorly adjusted. The health care team during rehabilitation needs to be aware of the emotional and physical health of the family member as well.
2. The caregiver needs other people with whom they can talk and express their feelings. If they do not have this support, they are at greater risk for adjustment problems.

Help for the Caregiver

1. Managing Stress

The caregiver should be aware of their feelings and what may be the cause of their stress. The **Caregiver Stress Test** on page 2 can help you identify your stressors.

Stress is often brought on by difficulties in one of these areas. Here are some suggestions for handling your stress related to each area.

Health-

Stay healthy. Your health affects how you feel and your ability to handle problems. By being a caregiver, you are at risk for more injury and infections. You are doing more physical activity. Be careful when lifting and moving not to strain muscles. You are in contact with more body fluids and waste. This puts you at greater risk for infection. Wash your hands, take your vitamins, and see that the home stays clean.

Take care of yourself. Keep *your* doctor's appointments.

Eat 3 nutritious meals each day; get enough sleep/rest; take time to exercise. Find ways to relax and have fun/laugh. Try relaxation tapes or read a funny book!

Time -

There are only 24 hours in each day. Making a schedule can help you manage your time better. Good time management lowers stress. You need time for yourself. Put that high on your list.

Let go and share the work! Keep a list of jobs that you need help with or chores that need doing. When someone asks what they can do to help, let them pick an item from your list! This can include shopping, fixing a meal, or caring for your children one afternoon after school.

Do not neglect your needs.

Support -

Find someone to talk to about your feelings. Spend

time talking with a friend each week. Have coffee together or meet after church. If you are unable to leave the house, ask a friend to come by and visit with you. Talk to a friend on the phone several times a week.

Join a caregiver support group. This is a place to get together with other caregivers to share feelings, learn new coping strategies, and feel less alone. If there is not an SCI caregiver support group in your area, you may find a general caregiver support group.

You can also find support on the Internet. There are "Chat Rooms" where you can talk with other caregivers. Avoid isolation.

Assertiveness - Learn to Ask - Speak up!

Not everyone will ask you what you need. It is up to you to tell them how things are and what it is you need. Turn to others - a support group, family, friends, or professional counselors - for help. Let your feelings and needs be known. Caregivers must speak up and assert their rights.

Your needs and those of your family member with SCI are different. It is very important that you communicate and understand each other.

Finances -

Keep your personal finances in order. Be familiar with benefits of insurance policies, retirement funds, health insurance, and other entitlements. Recheck periodically. Protect your assets and finances without severing your relationship with the individual with SCI.

Information - Get more information!

Check with your public library for books, articles, and brochures on SCI and/or caregiving. Contact the rehabilitation center where your family member received rehabilitation services and ask the patient educator for more information.

Look on the Internet. Be sure to check the **SPINALCORD Injury Information Network** at <http://www.spinalcord.uab.edu>.

For videos and information contact:
Spinal Cord Injury & Network International (SCINI)
3911 Princeton Dr, Santa Rosa, CA 95405-7013
Phone: 800-548-2673 or 707-577-8796
Email: spinal@sonic.net

SCINI responds to the needs of individuals with SCI and their families by providing a Video Lending Library and an Information Resource Library.

Learn about resources in your community that may help you. Does your church offer respite care? What agencies provide trained caregivers for hire?

II. Problem Solving

Being able to problem solve is a needed skill for all caregivers. Recent research shows that caregivers with a negative problem orientation are likely to experience distress that may result in more health-related problems for the caregiver and the person with SCI. This could lead to health complications for the individual with SCI and result in financial and emotional strain.

A current research project, **PROJECT FOCUS**, is a problem-solving training program for caregivers of

patients with spinal cord injury (SCI) that is underway at UAB Department of Physical Medicine and Rehabilitation. It was developed by Drs. Tim Elliott and Richard Shewchuk and is funded through a grant with the Centers for Disease Control (CDC).

Individuals living in Alabama or the Southeastern United States who are interested in participating can contact Tim Elliott at 205-934-3454 or email telliott@uab.edu.

Resources

Caregiver's Handbook

Produced by: Caregiver Education & Support Services
San Diego County Mental Health Services
San Diego, CA 92110
619-692-8702

Web: <http://www.biostat.wustl.edu/Alzheimer/care.html>
A guide for caregivers that discusses caring for the caregiver, providing personal care, nutrition, emotional well-being, and legal/financial affairs.

Family Adjustment to Spinal Cord Injury

Produced by: RRTC in Secondary Complications in SCI
1717 6th Ave S, Birmingham, AL 35233
205-934-3283

Cost: \$2 Date: Revised, 1998
A 10 page booklet addressing concerns and experiences which the family of a person with SCI may experience. It focuses on initial questions and concerns loved ones may have about the injury and feelings that families experience.

National Family Caregivers Association

9621 East Bexhill Dr, Kensington, MD 20895
800-896-3650

Web: <http://www.nfcacares.org>
NFCA works to improve the quality of life of America's 18 million family caregivers. Provide information, newsletter, educational materials, support, public awareness and advocacy.

National Association for Home Care

228 Seventh St SW, Washington, DC 20003
202-547-7424

Web: <http://www.nahc.org>
Provides homecare and hospice related information, state associations, publications, legislation, and regulations.

The Resourceful Caregiver: Helping Family Caregivers Help Themselves

By: National Family Caregivers Association
Available from: Mosby Lifeline Publishers
800-667-2968

Cost: \$12.95 Date: November, 1996
A guide for family caregivers with information to help caregivers care for themselves and their loved ones.

References

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Elliott T & Shewchuk R. Problem Solving therapy for family caregivers of persons with severe physical disabilities. In C. Radnitz (Ed.), *Cognitive-Behavioral interventions for persons with disabilities*. New York: Jason Aronson, Inc. 1998 (in press).

Richards, JS & Shewchuk R. Caregivers of persons with spinal cord injury: a longitudinal investigation. *Research Update* [newsletter] 1996. Med Rehabil Res & Trng Center in Secondary Complications in SCI, Spain Rehab Center, Univ Ala Birmingham.

Shewchuk R, Richards, JS & Elliott T. Dynamic processes in the first year of a caregiver career. *Health Psychol* 1998;17:125-129.

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