

Chapter 4

PERSONAL AND PSYCHOLOGICAL SUPPORT

HOW CAN A PSYCHOLOGIST OR COUNSELOR HELP?

Psychologists or counselors who work in rehabilitation help people adjust to their disability by helping them see and work through the emotional reactions they may be having.

Often, it isn't until people are home again that they begin to feel the emotional impact of their injury. Outpatient psychological counseling can help you and your family adept to the new circumstances created by this type of injury. Help is also available through private counseling agencies, public social services, support groups or peer assistance programs. Remember that all of your feelings are legitimate. Being able to recognize them and then deal with them in a positive way, is extremely important to your overall adjustment and well being.

PEER SUPPORT

Many people have founds that peer support is very helpful. The **Spinal Cord Injury Association, Connecticut Chapter** offers information, peer support, peer information groups and a Resource Directory.

SCI INFORMATION GROUPS IN CONNECTICUT

- **Mount Sinai Rehabilitation Hospital Hartford, CT**
When: 3rd Wednesday of each month from 3:30 – 5:30 PM
Contact: Paige McCullough-Casciano
- **Gaylord Specialty Hospital in Wallingford, CT**
When: 3rd Wednesday of each month from 5:00 – 6:30 PM
Contact: Tim Kilbride at 203-284-2875

Check the website for additional support groups.

EMOTIONAL ISSUES THAT MAY ARISE AND HOW TO COPE

Body Image and Self Esteem

An essential component of sexuality is how one perceives one's body. A person who is able to see themselves as an attractive and desirable person is far more likely to engage in a healthy and satisfying sex life. Self-esteem generally refers to how you feel about yourself. Some people experience issues of lowered self-esteem and a resulting poor self image following a spinal cord injury. As a person with spinal cord injury adjusts to a new physical reality, it may be difficult to change self perceptions to accommodate the injury in a positive way.

Self-esteem is very important, it affects the way you live, how successful you are in achieving goals, and how you think and feel about yourself and others. Low self-esteem can affect your progress in rehabilitation during and after discharge. It can affect the effort you put into achieving goals. Low self-esteem can also hinder the development of close relationships. It is possible to change self-esteem by thinking positively about yourself and accepting your as you are. Try to see both your strengths and weaknesses, and accept them as part of you.

Setting realistic, attainable goals and rewarding yourself for accomplishing even small steps can help you feel good about yourself. Become involved in activities you enjoy, appreciate the special talents you have, and be proud of whom you are. Be assertive rather than aggressive or passive. This means not letting others take advantage of you, standing up for yourself, expressing your true feelings, but also taking into consideration others feelings. If a person with spinal cord injury has difficulty changing self perceptions to accommodate the injury in a positive way, several books and videos address the concepts of body image and sexuality.

Candid conversations regarding sex, self-esteem and body image may be helpful as they search for different ways to express sexual feelings. It is important you help yourself towards recovery by taking care of both your physical and emotional needs.

Grief

Grief is a healthy, human response. It is a natural reaction to the major losses that may come with spinal cord injury. While the present may seem overwhelming, it is important to know that it will get better with time. Everyone experiences loss and change throughout their lives in different ways. There is no preset pattern of adjustment. If you do experience feelings of fear, loneliness, and helplessness understanding them can help you face the reality of the changes in your life. It may take time to work through your feelings. Time is a great part of healing. The time it takes varies from person to person. Some of the responses that people may experience following spinal cord injury are denial, anger, guilt, depression or loneliness.

Denial

All grieving people share feelings such as shock and denial. These are normal responses. Initially, denial may help the individual cope with the magnitude of the injury.

Anger

Losing something you care about hurts and seems unfair. You may feel resentful and angry with yourself and with others for not preventing the loss. If properly handled, anger can be helpful. If improperly handled, it can be destructive and hurtful to others and us. By recognizing and expressing it in a positive way, it can motivate us to deal with problems and achieve goals we thought were impossible. It can also encourage growth and intimacy in relationships. Learning to blow off steam in a positive way is very important.

Guilt

Guilt is another common feeling grieving people share. It's not unusual to blame yourself for something that you did or didn't do before you were injured. Try to remember that you're human and there are some events you just can't control.

Depression

For a time your mind and body may feel drained, unable and unwilling to perform even routine tasks. You may experience feelings of sadness, anxiety, loneliness, withdrawal from people and activities, physical discomforts, lack of appetite, overeating or sleep disturbance. There are varying levels of depression and it affects people in different ways at different times. Eventually you will take

steps toward becoming more involved in life again. If you feel short-term sadness or mild depression, you may be able to recover through self-help.

Try setting small, achievable goals; become involved in pleasurable activities, and become more aware of your thoughts to determine if they are appropriate and rational. If you should experience symptoms of more serious depression, it is important to help yourself by reaching out for assistance from your family, a friend, or a concerned professional. The longer serious depression lasts, the harder it may be to recover. Trying to ignore it doesn't help. Treatment is available and is very important.

Loneliness

Grieving usually involves loneliness. Increased responsibility and changes in your social life can make you feel lonely and afraid. As you meet each new challenge and develop new friendships, you will learn to handle these feelings.

Loss of Control

Spinal cord injury can often create a feeling of loss of control over life. This effect on sense of independence is very frustrating for most people. The best way for you to begin regaining a sense of control over your life is to become actively involved in your rehabilitation. Setting goals, reassessing those goals, and reaching them leads to a great feeling of control and life. Members of the rehabilitation team can assist you with this process.

Stress

Stress refers to a state of imbalance resulting from a demand to adapt or change, or a threat or challenge to one's ability to cope or perform. All people experience and react to positive and negative stresses. Spinal cord injury forces many dramatic changes in one's life, which create much stress. Signs of physical stress include weight gain, appetite changes, sleep disturbances, headaches, stomach problems, or a tired feeling. Mental signs can include feeling bored, hopeless, fearful, angry, lack of ability to concentrate or enjoy life. Stress can in turn affect the extent to which a disabling condition becomes a handicap. Being able to effectively manage stress following a spinal cord injury is very important to your well being. It is important to know yourself and be aware of what situations create stress for you.

Learning coping skills and maintaining a positive outlook will be helpful as

well as utilizing relaxation techniques. Relaxation allows a person to cope more effectively with stresses. For specific techniques (such as abdominal or diaphragmatic breathing, progressive relaxation, guided imagery, and visualization), seek the advice of your rehabilitation team. Develop a positive lifestyle through proper exercise, eating, rest and relaxation.

One of the best ways to adjust to your injury is by setting goals and working to reach them. The first step in setting goals is always the hardest. Try starting with a short term or daily goal, then build up to one month, one year and even lifetime goals.

It is important to be realistic when setting goals. Make a list of your goals, then rank them in terms of priority. Work on your most important goals first. Recognize your progress; give yourself credit. Check your progress on a regular basis. If necessary, reset your goals. Most importantly, Remember things will take longer. Don't give up!

You may want to try new activities or find new directions in your life. Starting a new hobby or taking a course may be fun and rewarding. You may want to reevaluate your career goals. You may also want to spend some time doing volunteer work. Helping others may help you to help yourself. All this takes time. Remember that grief is natural. Attempting to deal with your loss will enable you to grow from your experience.

FAMILIAL ADJUSTMENT

Spinal cord injury affects the entire family. Families usually experience the same feelings as those felt by the injured person. Very often responses include fear, powerlessness, denial, bargaining, mourning and sorrow, which, if healthy, may lead to family members taking on new functions and views toward the future.

Family members may contribute to successful rehabilitation by learning more about spinal cord injury and the effects it may have on the injured person. Becoming involved in your rehabilitation process, communicating their concerns with one another, you, and the rehabilitation team will allow you all to provide a stronger source of support for one another. There may be a need that a caregiver

may benefit from support groups. The following are available to the general public:

National Family Caregivers Association: 9621 East Bexhill Drive, Kensington, MD 208953104, 3019426430, 8008963650

Plainville Senior Center: 200 East St., Plainville, Ct 06062, 747-5728

“Caring and Sharing” Southington Care Center, 6219559

Adjusting to spinal cord injury is a continuous process. It will not always be easy for you or your family. Remember; do not ignore your emotional needs. What you feel is natural and normal. Address your feelings and concerns, try to maintain a positive lifestyle, communicate openly and honestly with you and others, and don't hesitate to seek professional counseling if the challenges seem overwhelming. The SCIACT Chapter is always a good place to start.

RELATIONSHIPS

After spinal cord injury, it can be difficult at first to resume prior relationships as well as to begin and make new relationships. However, it is your responsibility to pick yourself up and continue productive relationships. It is a common misconception that following spinal cord injury a single man or woman will never find a life partner, or that an existing partner will leave a relationship due to the complications of an injury. This is not the case. The divorce rate following spinal cord injury is only slightly higher than for other populations, and thousands of people have been in meaningful relationships, been married and begun families after a spinal cord injury. Relationships like responsibly stay the same each person sets their own goals.

HOW TO HELP YOURSELF

Physically, you can help yourself – Get plenty of rest each day. You will have more energy to handle problems and get involved again in activities you enjoy. Eat the right foods and get enough therapy and exercise. Drink enough water. Stay away from alcohol, tranquilizers, and other potentially harmful substances. Caffeine may also affect the nervous system too. Be alert to problems such as nausea, dizziness, headaches, weight loss, difficulty sleeping and a lack of energy. Your body will tell you in a different way something is not right. It's important to understand the new signs. Everyone is different.

Emotionally, you can help yourself – Don't be afraid to express your feelings aloud so that you can admit your anxieties and fears. Holding painful feelings inside may only create more serious problems. Ask for help when you need it. Relatives and friends want to help but often don't know what to do until you make your needs known to them. Understanding and support can make hard times easier. Be kind to yourself and be patient. Some days will be harder than others, but it is important to keep believing that you will get over your pain and adapt to your injury. Being gentle with your feelings is part of being patient.

POWERFUL TOOLS FOR CAREGIVERS

The CT Chapter of SCIA has become a key contact to disseminate the national Powerful Tools for Caregivers program in Connecticut. The outline below highlights information about the Powerful Tools for Caregivers program from their national website:

www.powerfultoolsforcaregivers.org.

Powerful Tools for *Caregivers*

It is now well known that caregivers face multiple challenges. Research shows high rates of depression and anxiety among caregivers, and increased vulnerability to health problems. Caregivers often report the feeling that they have no control over events. The sense of powerlessness can have a significant negative impact on caregivers. Physical and emotional health, lack of time for personal activities and a diminished social life are also frequently cited as problems faced by caregivers.

The Powerful Tools for Caregivers (PTC) program is an educational resource that empowers caregivers to address these challenges more effectively. One of the main goals of the program is to help caregivers to thrive as individuals. Since the program began in 1998, Powerful Tools for Caregivers has reached over 70,000 caregivers, and over 1,700 Class Leaders have been trained in 30 states. The program is divided into six weekly classes, during which caregivers develop a wide range of self-care tools designed to help reduce personal stress; change

negative self-talk; better communicate their needs to family members and healthcare/service providers; communicate more effectively in challenging situations; recognize the messages in their emotions, and cope with difficult emotions. This educational program also supports caregivers in making tough caregiving decisions such as nursing home placements, driving issues, or finances.

The class design emphasizes hands-on learning, experiential activities, peer support, and facilitated group discussion. Participating caregivers create independent action plans and as part of the group, practice new techniques, try out communication strategies and learn practical tips. The benefits of stress management tools such as breathing for relaxation, listening to music, and seeking out humor are encouraged. Class participants receive a copy of The Caregiver Helpbook (2nd edition), a user-friendly workbook developed specifically for the course. This book is also an excellent stand-alone resource for those caregivers who may be unable to participate in a class.

A great deal of research, evaluation and revision has been done to ensure its continued value and success. A summary of course evaluations indicates a number of positive outcomes such as:

- Improved self-care behaviors;
- Reduced anger, guilt and depression;
- More self-confidence in coping with caregiving demands; and increased use of community services.

Caregivers from many different backgrounds have benefitted from the 6-week class, including caregivers from rural areas, ethnic minorities, adult children of aging parents, spouses/partners, as well as caregivers at differing stages in their caregiving role, and from diverse living situations, financial and educational backgrounds.

To learn more about the PTC program nationwide, please visit the national PTC website www.powerfultoolsforcaregivers.org.

To find out about PTC 6-week classes for caregivers in CT or to become a trained PTC class Leader in CT, please contact the SCIA Connecticut Chapter at (203) 284-2910 or www.PTCinCT@sciact.org.