

Personal & Psychological Supports

Adapting to a spinal cord injury can be a difficult and continuous process. A person's ability to adjust to change is challenged by disability. A disability can impact on lifestyle, the ability to work and earn a living, and relationships. New responsibilities will be created for you and your family and emotional stress should be expected. You may notice that other people feel awkward and uncomfortable and do not know what to say or are unsure of the appropriate way to act.

One of the major goals of a rehabilitation program is maximizing your functional ability. However, one must also be aware of their emotions regarding their current physical status. What you feel is natural and normal. One must believe that they will regain a sense of control over their life and normalcy.

Staying busy can be a good way to avoid being bogged down in feeling bad about your disability. It is important to keep in mind, however, that staying busy can also be a way to avoid how you really feel about having a spinal cord injury. Dealing with your feelings will better enable you to have a healthy life in body, mind and spirit.

Although dealing with your injury may, at times, seem like an enormous life task, once you learn to manage your care needs and start planning for the future, you will have new interests to look forward to. If, at times, the challenges seem impossible, don't hesitate to seek professional counseling. Many newly injured people also find talking with an experienced peer assistant or chaplain helpful. The Connecticut Chapter of the National Spinal Cord Injury Association has an informal network of peer volunteers available. This is the Peer Assistant Program. You may contact the Chapter, in care of Gaylord Hospital, Gaylord Farm Road, P.O. Box 400, and Wallingford, CT 06492 or call (203) 284-1045.

In addition, the Chapter supports various SCI support and information groups that meet throughout the state of Connecticut. The information groups may be contacted individually and/or an individual can contact the Chapter for up and coming events.

SCI Information Groups Around Connecticut

Where: Hospital for Special Care in New Britain, CT

When: 3rd Tuesday of the month

Time: 3:30 - 5:00

Contact: Jennifer Bartiss-Earley at 860-827-1958 ext 5494

SPINAL CORD INJURY SUPPORT GROUP

Where: William W. Backus Hospital in Norwich, CT

When: 3rd Saturday of the month

Time: 11:00 - 12:30 Contact: Amy Anderson at 860-823-6317

SPINAL CORD INJURY SUPPORT GROUP

Where: Rehabilitation Hospital of Connecticut in Hartford, CT

When: dates and times to be ANNOUNCED

Contact: Janet Connely at 860-714-3500

SPINAL CORD INJURY INFORMATION GROUP

Where: Gaylord Hospital in Wallingford, CT

When: dates and times to be ANNOUNCED

Contact: Matt Ginger at (203) 284-2875

FOR MORE INFORMATION CONTACT NSCIA CT-Chapter by: calling 203-284-1045 or E-MAIL nsciatgicomm.net or Visit our Web-Site www.sciact.org

(Excerpts for this chapter were taken from *Health Living with Spinal Cord Injury*, Gaylord Hospital, Wallingford, CT and *Spinal Cord Injury Manual*, Kessler Institute for Rehabilitation).

How Can A Psychologist/Counselor Help?

Contrary to common beliefs, a person does not need to have a serious mental illness to benefit from treatment by a psychologist or counselor. 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.

It is often that until people are home that they begin to feel the emotional impact of their injury. Outpatient psychological counseling can help you and your family adept to 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.

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

Sometimes grieving people experience 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.

Coping With Grief

For some of you, it may seem impossible to live with the change. It is important you help yourself towards recovery by taking care of **both** your **physical** and **emotional** needs.

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.

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 re-evaluate 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.

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.

FAMILY 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 20895-3104, 301-942-6430, 800-896-3650

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

“Caring and Sharing” Southington Care Center, 621-9559

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 NSCIA-CT Chapter is always a good place to start.

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, as 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 and your general happiness. 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 yourself as you are. Try to see both your strengths and weaknesses, and accept them as part of you. Setting realistic and 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.

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. Just remember to love yourself first.

Relationships by Rebecca Stoddard

I am a motivated, respected, intelligent, professional, people's person with a SCI. Re-educating myself lovingly and openly to the big changes surrounding my new way of life. I find different experiences can be a positive thing if we choose this outcome. I grew up with a lot of changes, with experience it becomes easier. Also a sense of humor can help handle a SCI and a world of change that take place in a wheelchair.

Our body's, minds, and spirits, definitely need time to understand all the different feelings of a spinal cord injury, and all the newness that surround these feelings. Each relationship in the beginning is a lot to overcome at first, starting with ourselves then our families, friends, and loved ones. Believing you can feel new feelings. Learning all over again will get more relaxing with more experience. Be gentle with the new experiences. Learning to love your self again can take time; allowing time to heal our pain is hard. Each injury itself is as different as each person is. Living a much happier, healthier lifestyle is up to you.

I don't look at my injury the way I did when I was first hurt; some of the newness is gone. I relearned to listen to my feelings and body. This took time. I believe I was given something special, not at first. Now I can reflect back with a positive outcome. With more answers for newly injured people. Reaching out for help was something I had a hard time with. I had to learn to overcome this. Still refusing not to let insurance dictate my therapy and wellness. Talk about hard; any personal growth comes from within. It's about option surrounding us that can help our wellness. Talking to someone with an injury can be very beneficial to everyone. Reach out for resources, like the CT Chapter NSCIA or others, could help find answers.

I myself find encouragement in people, Aimee Mullin's words of wisdom helped me, "Don't put their disability in a closet, take this disability out, examine it from all sides, don't look at it as a skeleton in the closet, but a skeleton key, than can it unlock your potential." You to will need to find something to unlock your potential. We are all so different, which makes it only harder to give any answers. I can tell you from what I have experienced by not giving up; you will get beyond your natural ability to achieve your goals. You still have this choice. No one can say what you will and can choose. Only you will do this. This will take time. We all need to find strength in something; each person will accomplish this in there own way. No one can say how long this will take.

Asking for help doesn't make us weak, only stronger. . Please reach out and do all you can to find what helps you get through some of lives biggest changes. Believe in yourself and so will others. Talk about your new feelings. We become overwhelmed with changes in our feelings, it happens much to fast to dial with, all at once. So be kind and gentle to yourself and others. This takes time, and experience to learn to do things again, only with a lot of determination from you. I can't tell you what you can or will accomplish from this. I can only tell you everyone's injury is different like him or her. Relationships are similar. Life is way to short to give up now and stop having relationships by isolating yourself. The energy put in is something we relearn in our minds and in time feeling returns different as well, only if you choose to listen.

Love and compassion,

Rebecca Stoddard, QM

Life Only Gets Better **By Bill Mancini**

As I stood there thinking how good this glass water is going to be, something began to happen. A cold sweat came over my body as if I had just gotten done working out in an ice cooler. Little did I change know that was the beginning of a change in my life that to this day, almost 10 years later, still has me saying what if.

I was injured from what I like to call ‘a freak of nature’. Drinking a glass water at 5:00 AM never make me think that life could ever get more difficult. As I run around the kitchen with my legs buckling the only thing I still remember is my parent and brothers watching me with their lower jaw hitting the ground. What could they have been thinking? To this day I have not still answered that question. I feel that I will go to my grave without getting that question answered and only thinking that the answer would be more painful then the blood clot compressing my spinal cord at that very moment.

The plot thickened while I am laying in the emergency room and the ER doctor arguing with the neurosurgeon on call about the correct procedure. I was waiting for anyone to come in and help get this feeling of death off my shoulders. Then, my father and brother were told by the ER doctor that I may have to get my legs amputated. They had no idea what was happening. Minutes later, the wonderful and very understanding neurosurgeon came with his needle to poke at me. He asked me what I felt and if I had taken any drugs the night before. With my tear filled eyes I responded with a swift no and fell asleep.

After being wakened by a beautifully young nurse, I thought the golden gates where being opened for me. Until, she held up a red hose that reminded me of part of this sprinkler system that my dad used to water his garden. Heaven was gone and hell was entering the picture. She then asked me if I had emptied my bladder that morning? I immediately realized that I could not feel the one most important part of the body to a 20 year old male. The tears were back, as if they were ever really gone.

Surgery was next. What fun. “Ok Mr. Mancini we are going to operate and remove....” The doctor explained, as if I was really listening. I made a quick glance at my father and brother and notice that they had inherited the tears too. Before the doctor could finish I asked him if I was going to die. He explained no and handed me this paper to sign. I just grabbed the paper and wiped my tears away with it. My father decided that he would just forge my name.

Those 3 hours are planted in my brain like a tattoo engraved on Ozzy Osbourne’s arm. I thought that things were never going to turn around. After you are laying in bed for weeks, the first time you sit up things come out of holes that you didn’t even realize you had, the shit hits the fan literally. Can things ever get better? I had time to ponder it as I was pulled and pushed by a group of caring family, friends, doctors, therapist, nurses and anyone else who came into my room during those 10 weeks.

10 years later I feel I can finally answer that question without holding back, YES!

At this very minute I am listening and responding to Mr. Mancini. The first time I heard that name I could hardly breath. I now encourage, advocate, teach and guide the future of America. I challenge my students everyday to not give up and preserver though the tough times. When I used to struggle to complete my bowel program, now my students struggle to read and add. I instill in my students the knowledge that mistakes should be taken as learning experiences to further make them who they are.

When I went back to school and sought out a positive and independent lifestyle I searched for something that would make my supporters proud of who I am and where I came from. All the support they gave me never meant much until I went out into the real world and made mistakes. Falling in the middle of the road or a well known drinking establishment, shitting myself in places that would only make me crap all over again or feeling comfortable enough to feel that sex was actually good for both people again are the experiences that make me how I am. Everyone has times in their life they need to look back on and see that without those struggles life would not be what it is.

I can say that Spinal Cord Injury has made me who I am at this point. I have learned to accept challenges. As an advocate and new business owner the struggles make the end result that much more extraordinary. When looking at the difficulties that go long with the daily activities of have a spinal cord injury such as, bladder and bowl care, diet, universal accessibility and maintaining flexibility. The struggles change from day to day.

Acceptance is a difficult thing to do. You will hear some people say that things could be worse. I look back when things were worse and realize that life only gets better.

Bill Mancini

President of the National Spinal Cord Injury Association – Connecticut Chapter