Spinal Cord Injury and Returning to Your Life

A spinal cord injury is one of the most devastating and traumatic events. You have a loss of all or some of your movement and it is common to have health problems when you are newly injured. It also takes time to build the strength needed to participate fully in daily activities.

After your injury you will likely experience grief. Grief is a period of mourning similar to what you go through after the death of a loved one. The difference is that you are not grieving death but are grieving the loss of your sense of touch and your ability to walk or use your hands. You will probably have many different thoughts and feelings after your injury. Some of these may be mild and others extreme. Everyone grieves differently; however, some thoughts and feelings are common.

**Denial/Disbelief:** After your injury, you may react as if nothing has happened. You may refuse to accept that your loss of feeling and movement is permanent and you may see the injury as something that will pass with time.

**Sadness:** No one is happy to be injured regardless of the level of the injury. Extreme sadness is common after an injury because of the great loss that you suffered. Sadness is feeling down or blue, however do not confuse sadness with depression.

**Depression:** Depression is a medical condition that requires treatment—see prior information.

**Anger:** Some people react to their injury with strong feelings. You may lash out verbally or want to become physically violent towards others. You may feel angry toward yourself if your action resulted in your injury. You may also feel anger toward God or someone else for causing your injury.

**Bargaining:** After your injury you may begin to admit to yourself that you have a serious condition. You may still want to believe that your injury is not permanent. You may act as if you accept the injury as "the way things are" but you may also believe that you will be through your prayers and hard work in therapy and you will eventually recover from your injury in the near future.
Acceptance: Grieving usually ends when you come to a realistic view of your condition and find meaning in your life. You begin to think about your future as a person with a spinal cord injury and set goals for your life.

Adjusting to Spinal Cord Injury
When you are injured, it takes time to adjust to your life after injury. Some people grieve longer than others so the adjustment period is different for everyone. It may take up to a year to accept the reality of your injury. You will also experience a process of adjusting to the issues that occur in your everyday life as a person with a spinal cord injury.

Problems Adjusting to Spinal Cord Injury
If you have been injured for a year or more and have not adjusted to your injury, it is a good idea to investigate whether or not you are having problems adjusting. Your thinking directly influences how you feel and how you react to events that occur in your life. This is the basis for Rational Emotional Behavior Therapy (REBT). Many counselors use REBT with people who have spinal cord injuries. Treatment focuses on helping individuals gain a healthy view of their lives.

Event- An event is something that happens to you. It can be small or devastating. Irrational Belief-When an event occurs in your life, you talk to yourself about it. This self talk can be based on assumptions that are completely or partially false. If you don’t know all the facts involved, the self talk may be based on wrong information or unrealistic, irrational beliefs about the event. Some self talk based on irrational beliefs: my life is over because I can never live my life and be happy after this injury or I have to walk or use my hands if I am ever going to be happy. These irrational thoughts are common after an injury but the longer you hold on to them, the more likely it is that you are not adjusting well to your injury. Some other examples of irrational beliefs are “I am less of a person because of my injury” or “people should feel sorry for me and do things for me because my life has been unfair.”

Emotion- It is important to know that feelings are neither good nor bad. It is normal to feel excited at times and sad at times or both sad and excited at the same time. Yourself talk may be different from someone else’s so you may feel differently than others about the same event.

Unhealthy Behavior-If your feelings are based on irrational beliefs, your reactions may result in behaviors that are bad for you. For instance, you may not see the value in caring for your skin or bladder or may isolate yourself from others and avoid spending time with family and friends. Individuals with a history of alcohol and/or substance
abuse may return to using their substance of choice. Others may start drinking or taking drugs. Professionals often ask these 4 questions to help determine if a person has a substance abuse problem:

1. Have you ever felt you should cut down on your drinking or drug use?
2. Have people annoyed you by criticizing your drinking or drug use?
3. Have you ever felt bad or guilty about your drinking or drug use?
4. Have you ever taken a drink or taken drugs first thing in the morning as an eye opener to steady your nerves or get rid of a hangover?

If you answered yes to one of the above questions, it is a warning sign that you may have a substance abuse problem. Seek help if you believe that you or a family member has a substance abuse problem.

**Unhealthy Results** - Unhealthy behavior almost always leads to unhealthy results. When you neglect your personal care, you are at risk for developing health problems such as pressure sores or urinary tract infections. These conditions can limit your ability to participate in activities or in extreme cases can lead to death. Substance abuse can make existing medical problems worse and lead to injuries and problems with personal relationships.

**Healthy Adjustment to Spinal Cord Injury**
One of the biggest factors in adjusting to spinal cord injury is personal motivation. Newly injured people are often very motivated to participate in therapy to gain strength and function. At this stage you probably believe that your paralysis is only temporary and you will return to "normal." This hope is common after an injury. It is more likely that people will recover function based on their level and completeness of the injury. Very few people fully recover from their spinal cord injury but this does not mean that all hope is lost for a full or partial recovery. A cure for paralysis may or may not come in your lifetime. A healthy approach to this reality is to move forward with hope that continued medical advances will one day lead to a cure. Don't wait for a cure to move on with your life!

People who adjust well after an injury are usually motivated by their personal goals. The goals are different for everyone and often change throughout your life. For example, you may have a goal today or getting a job and in the future may want to get married. Research has shown that people with spinal cord injuries who are goal oriented are less likely to be depressed.
It is up to you to find purpose in your life. The motivation to reach your goals has to come from you. There is no reason that you can't strive for those things that you wanted before your injury.

**Replacing Irrational Beliefs with Rational Beliefs:**
One you are motivated for change and have set some goals, you may find it easier to identify your irrational beliefs. You can help yourself avoid irrational beliefs by not using words like always, never, no one, all or nothing words or over exaggerating. In addition don't focus on negatives and think things should or must be a certain way. You can replace your false assumptions with information that is true no matter where your level of injury is. It is up to you to learn the facts about living with a spinal cord injury. When you are seeking this information, only rely on reliable sources such as your doctor, nurse, and the medical staff at your rehabilitation facility.

**Examples to help replace your irrational beliefs:**
Instead of saying my life is over because I can never live or be happy after a spinal cord injury take away the work never. When you use words like never, you are not allowing yourself to believe there are other possibilities. You could say "although I hope that my injury is not permanent and I fully recover, I know that many people are happy and living many years with all levels of injury." This is rational self-talk and supports your hope for recovery and supports the fact that you can be happy and live with an injury like other people with spinal cord injuries.

Another false assumption is "because of my injury, it is now impossible for me to ever work or have a family." There are people with spinal cord injuries as well as some family members and friends who do believe that people with spinal cord injuries, especially high level injuries, can't work, get married or have children. If you were a construction worker before your injury you may not be able to return to that job, however, it does not mean that you cannot work. To turn this into a rational belief you could say, "although I have an injury and physical limitations, I can put myself into a position to work and have a family if that is what I want."

**Emotion:** Once you replace your irrational beliefs with those that are based on fact, you will likely feel differently. Instead of feeling sad, you might feel hopeful and instead of feeling worthless, you may begin to feel that you have value as a person, spouse, parent and employee.

**Healthy Behavior:** Usually you begin to act differently when you begin to think more rationally and experience a change in your feelings. If you set goals, you make plans
on how to reach those goals. You may even take better care of yourself so that you can reach those goals. This is healthy behavior and is what you need to improve your life.

**Family Adjustment**
Your injury has a tremendous impact not only on you but also on your family. Your family members may not have to adjust to the loss of their hands or their ability to walk but they may experience a loss of the way their life was before your injury. Your family members may have to adjust to the role of caregiver or they may need to work to help with family finances. This change can lead to stress and anxiety.

Family members also grieve. They may ask many questions about the full impact of the injury in an effort to help ease their sadness and fear. As family members begin to accept the injury, they also have to accept the issues of adjustment similar to those you may experience. Children tend to adjust rather quickly to an injury if their questions are answered clearly and concisely.

**Problems in Family Adjustment to Spinal Cord Injury**
Family members also need to be aware of their irrational beliefs. If a family member says something irrational, it may reinforce irrational thoughts for the family member with spinal cord injury. In addition, family members need to be aware of the things you can do so that you don’t become overly dependent on them. Family members should not ignore the possibility of substance abuse. Doing so may enable you to continue using substances. Prolonged feelings of stress and anxiety can put anyone at an increased risk for health problems.

**Healthy Family Adjustment to Spinal Cord Injury**
As a family member of someone with a spinal cord injury, healthy family adjustment involves taking care of you. You need to do things you enjoy and that bring you pleasure. Doing things you enjoy can minimize your stress and anxiety and clear your mind of false assumptions, unrealistic ideas and irrational beliefs. Learn the facts about spinal cord injury, challenge your irrational beliefs and replace false information with facts.

**Work**
Most people want to work after a spinal cord injury but need support, training and vocational rehabilitation to help them obtain and keep a job. Support may help you manage things that are out of your control such as financial and health care issues, accessibility and employer attitudes.
Work is important for several reasons. It provides an income and sometimes health insurance but also opportunities for interacting with others. Work can improve self-esteem and overall satisfaction with life. Federal and state laws and vocational rehabilitation services exist to help those with disabilities overcome these barriers to employment.

The American with Disabilities Act (ADA) was passed in 1990 and amended in 2008 prohibits employers from discriminating against qualified individuals with disabilities who are able to perform the essential duties of the job with or without accommodation.

- To be protected under this law you have to have a disability that limits major life activities. Not all people with spinal cord injury are protected under ADA.
- The employer has to make "reasonable accommodation" for you if it would not be a hardship on the business. Hardship depends on the size of the business, financial resources, nature of the operation and other factors.
- A potential employer can't ask you about the existence, nature, or severity of your disability even if you are in a wheelchair when you apply for a job. An employer can ask you about your ability to perform essential job functions.
- You may be required to pass a medical examination only if it is job-related and required of all employees in similar jobs.
- If you feel you have faced discrimination from your employer, contact the U.S. Equal Employment Opportunity Commission (EEOC) at 800-669-4000 to find the office nearest you or go to www.eeoc.gov. Many states have disability rights laws also.

The Individuals with Disabilities Education Act (IDEA) is a law that helps young people who haven't finished K-12 receive services to meet their educational and vocational goals. Students eligible under this law may stay in school until age 22 if this time is needed to reach their goals. Contact the U.S. Department of Education (800-872-5327) or http://idea.ed.gov/ for more information.

**What is Vocational Rehabilitation?**

Vocational rehabilitation programs can help people with disabilities get a job. Through these programs you can identify your career interests and skills, acquire education and training, apply for jobs and get work accommodations. For those injured on the job and are covered under worker's compensation, similar vocational rehabilitation programs are available.

**Who pays?**

- Some private health insurance companies pay for vocational rehabilitation. Check with your insurer to see what services are covered.
State vocational rehabilitation programs are funded through federal mandate to provide free vocational rehabilitation to those with a significant disability that limits their ability to work.

State workers' compensation programs provide free vocational rehabilitation for those injured on the job.

The Veterans Administration (VA) provides vocational rehabilitation to eligible beneficiaries with service related disabilities.

**How does vocational rehabilitation work?**
Vocational rehabilitation can take place anytime anyone with a disability needs help related to employment. If you are working and are dissatisfied with your job, you might want to consider vocational rehabilitation.

**Getting started** - You healthcare provider can refer you to a vocational rehabilitation program or you can find these services yourself at http://askjan.org/cgi-win/TypeQuery.exe?902

**Assessment** - Your rehabilitation counselor will help you evaluate your interests, skills, limitations, health needs, work and education histories and personality style. This information is obtained through interviews, questionnaires, medical information from your health care provider and sometimes tests of your academic aptitude and skills.

**Real-life Tests:**
Your rehabilitation counselor may be able to set up a "trial" work situation for you with a potential employer to see if you are able to do the job, if you like the job and what accommodations you might need. These "trials" may be paid or unpaid. After the trial, you and the employer can decide whether it is a good fit for both of you.

**The Job Market:**
If there is a particular job you may be interested in but that job market does not have any opportunities in your area, your rehabilitation counselor can help you look into something different. Your counselor can also help you assess salary, education preparation etc. of other jobs in which you may be interested.

**Setting Goals:**
Your long term goal when working with a rehabilitation counselor is to decide on the career or occupation you want to pursue. You may need to complete several steps along the way. These steps should be clearly outlined and your counselor should come up with a written plan.

**Landing a Job:**
After much planning, some people with spinal cord injury find a job on their own. A rehabilitation counselor can be a good resource to assist you to determine if a particular
job would be a good match for you, do an analysis to determine all the skills needed to perform the job and can help you identify opportunities in your area.

Discrimination is illegal in hiring even if it is not intentional. A rehabilitation counselor can help an employer to overcome prejudices and suggest accommodations that can improve the employer’s comfort with hiring a person with a disability.

**Getting support at work:**
If you need help at work with things such as personal care assistance or positioning, these are not typically paid for by the employer and a funding source for these services should be identified in advance.

**Types of Accommodations:**
Job accommodations can include a modified work schedule, or modifying the tasks or environment. Examples of this are raising the height of a desk with 4 wood blocks so a wheelchair can fit underneath, special hardware or software, shifting the work hours to a later start to accommodate a worker's lengthy morning care needs.

**Work vs. Benefits: Finding a Balance:**
Sometimes people with a disability don't want to work because they fear losing their Social Security Disability Insurance (SSDI), Supplementary Security Income (SSI) or private or state long term disability (LTD) insurance. There may also be concern about the costs of getting to or staying at work. Federal work incentive programs allow people with disabilities to receive benefits and federal health care (Medicare and/or Medicaid) and still keep some of their earnings from employment. This can be a great incentive for someone who wants to work but has many needs such as a van, personal assistance on the job and other services. Contact your vocational counselor with any questions about work-incentive programs.

**If Employment is Not Possible:**
Sometimes it is not possible for someone with a spinal cord injury to obtain work. This may include those in rural areas, older workers or those who can't earn enough by working to pay for their own personal care assistance and other costs.

A person is eligible to receive disability payments from the Social Security Administration (SSA) if he or she is unable to perform any kind of work that is substantial and gainful and the disability is expected to last at least a year.

Social Security Disability Insurance (SSDI) is long term disability funded by payroll taxes. Eligibility is based on your past work history and income.

Supplemental Security Income (SSI) is a federal welfare program for people with disabilities who are unable to work and are low income.
Newly injured people with spinal cord injury should apply for SSA benefits immediately if it appears they will not be able to return to work for at least a year. Sometimes there is a waiting period to receive benefits and once enrolled, a person is immediately eligible for either state Medicaid or after a waiting period, federal Medicare. If you are unable to obtain paid employment, consider volunteering. Volunteering can provide enjoyment and a sense of accomplishment as well as skills, confidence and professional contacts that may lead to paid employment someday.