

Adjustment to Spinal Cord Injury

Spinal Cord Injury
InfoSheet



Level - Consumer

WHAT IS ADJUSTMENT

Adjustment is defined as adapting to a new condition. Everyone makes adjustments during their lifetime. Some of the conditions that you adjust to may be planned and you have time to think about how you are going to react to the situation. For example, you may have to make adjustments in your work hours when you start a new job. Other events may be a surprise, and you are forced to adjust to an unplanned event.

AFTER SPINAL CORD INJURY

A spinal cord injury (SCI) is one of the most devastating of all traumatic events. It results in a loss of some or all of an individual's sensation and movement. It is common for individuals who are newly injured to have health problems. Plus, it takes time to build enough strength to be able to fully participate in daily activities.

Individuals who are newly injured will likely experience *grief*. This is a period of mourning that is similar to that following the death of a loved one. The difference is that you are grieving the loss of your sense of touch along with your ability to walk or use your hands. You will likely experience many different thoughts and feelings after injury. Some may seem extreme and others mild. There is no step-by-step grieving process, but some thoughts and feelings are common after injury.

Denial/Disbelief

You may first react to your injury as if nothing happened. You may refuse to accept that your loss of feeling and movement is permanent. Instead, you may see the injury as an illness similar to a cold or flu that will soon pass with time.

Sadness

Obviously, no one is happy to be injured. It does not matter what your level of injury. Extreme sadness is common after injury because you have experienced a great personal loss. Sadness is that down, or blue feeling

that you have when something bad happens. However, do not confuse sadness with depression.

Depression is a medical condition that requires professional treatment. You may be depressed if you have symptoms such as extreme sadness, inactivity, difficulty in thinking and concentrating, a significant increase or decrease in your appetite and/or time spent sleeping, and feelings of dejection, hopelessness or worthlessness. You may even have thoughts about suicide if you have depression.

Anger

Some people react to their injury with strong feelings of displeasure. You might lash out verbally or want to become physically violent towards others. You may feel angry toward yourself if your actions resulted in your injury. You may even feel anger toward God or someone else for causing your injury.

Bargaining

At some time following your injury, you may begin to admit to yourself that you have a serious condition. However, you may still want to hold onto the belief that your injury is not permanent. You may act as if you accept your injury as "the way things are," but your acceptance may come with the belief that you will be rewarded for your prayers and hard work in therapy and eventually recover from your injury at some point in the foreseeable future.

Acceptance

Grieving usually ends as you come to accept a realistic view of your current condition and find meaning in your life. You begin to think about your future as an individual with SCI and set goals to pursue in life.

ADJUSTMENT TO SCI

Individuals who adjust well to unexpected events generally lead healthy, active, and happy lives after their injury. Individuals who do not adapt well to unexpected

events tend to be less healthy, less active, and unhappier after their injury. You basically experience two primary issues of adjustment to spinal cord injury.

- 1 When you are first injured, it takes time to get use to your life after injury. Some people grieve longer than others, so the adjustment period is different for everyone. It may take as much as a year for you to accept the realities of your injury.
- 2 You will also experience a continued process of adjusting to the unique issues that occur in your every day life as a person with SCI.

Problems Adjusting to SCI

If you have been injured for a year or more and have not come to accept your injury, it is a good idea to look into other areas to find out whether or not you are having problems adjusting to SCI. *You may find it hard to believe upon first thought, but what happens to you is not as important as what you are thinking when something happens to you.* Your thinking directly influences how you feel and react to events that occur in your life. This concept is the basis for Rational Emotive Behavior Therapy (REBT). Many counselors and psychologists teach REBT as a way to help people with and without SCI gain a healthy view of their lives.

You can use [Chart 1](#) as your step-by-step guide showing how events in your life can trigger a “chain reaction” that can have a negative impact on your overall well being.

Event

An event is something that happens to you. It can be something as small as misplacing the keys to your car or something as devastating as a spinal cord injury.

Irrational Beliefs

Anytime an event occurs in your life, you start to talk to yourself about that event. This self-talk is based on what you know or what you believe to be true. For example, a person who gets a promotion at work might think, “I earned it!”

There are times when this self-talk is based on completely false or partially false assumptions about an event. If you do not know all the facts involved in the event, your self-talk may be based on wrong information or a series of unrealistic, *irrational beliefs*,

about the event. Some examples of self-talk based on irrational beliefs are:

- ◆ my life is over because I can never live my life and be happy after a spinal cord injury; and
- ◆ I must be able to walk or must be able to use my hands if I am ever again going to be happy.

Although these irrational beliefs are common for individuals who are newly injured, many persons with SCI continue to hold onto these types of unrealistic, irrational beliefs long after their injury. The longer you hold onto such beliefs, the more likely it is that you are not adjusting well to your injury. You may have even adopted other false assumptions that are limiting your acceptance of your injury. Although there are countless possibilities for self-talk, some other examples of irrational beliefs are:

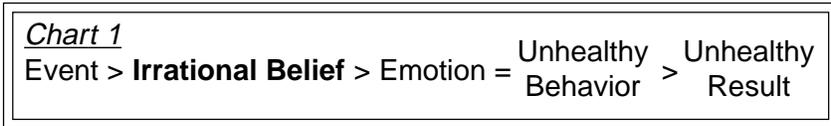
- ◆ because of my injury, it is now impossible for me to ever work or have a family;
- ◆ I am less of a person because of my injury;
- ◆ no one will accept, respect, or love a person with SCI;
- ◆ people should feel sorry for me and do things for me because my life has been unfair; and
- ◆ everyone will take advantage of me because I cannot defend myself.

Emotion

As you can see in Chart 1, what you are feeling, or your emotional response, depends on your self-talk. For example, individuals who are newly injured may think that their life is over because they cannot live with a spinal cord injury. This unrealistic self-talk may lead to extreme feelings such as anger, fear, and/or other emotional responses.

If you have been injured for a year or more, you may feel sad, lonely, hopeless or worthless if you continue to hold onto irrational beliefs such as “no one can possibly accept, respect, or love a person with SCI.”

It is also important to know that *feelings are neither good nor bad*. It is normal to feel excited at times and sad at times. You may feel both sad and excited at the same time. Because your self-talk might be different from another person, you may feel differently than others about the same event.



Unhealthy Behavior

If your feelings are based on irrational beliefs, you can follow [Chart 1](#) to see that your reactions to your feelings may result in behavior that is bad for your overall health and happiness. For example, you may not see the need to take proper care of your bladder or skin if you feel worthless. You may isolate yourself from others and avoid spending time with family and participating in other enjoyable activities.

Individuals with a history of **alcohol and/or substance abuse** may return to their old pattern of self-destructive behavior. Others may start drinking or taking drugs. Either way, substance abuse is unhealthy behavior. People who abuse alcohol will deny there is a problem, but it is estimated that individuals with SCI abuse alcohol at about twice the rate of the general population.¹

Do you have a problem with substance abuse?

- 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?

Professionals often ask these four questions (CAGE Questionnaire) to help identify persons with a drinking problem. If you answered "yes" to one of the above questions, it is a warning sign that you may have a problem with alcohol abuse. If you believe that you or a member of your family has a problem with alcohol or substance abuse, seek help! Ask a family member, doctor, or clergy to help you find help.

Unhealthy Results

Unhealthy behavior almost always leads to unhealthy results. When you neglect your personal care, you put yourself at greater risk for developing a wide range of health problems such as respiratory complications, urinary tract infection, and pressure sores. These problems can limit your ability to participate in activities. In some extreme cases, you may die. Substance abuse can complicate existing medical problems or lead to

other health problems. Substance abuse can also lead to other injuries and a loss of personal relationships.

Healthy Adjustment to SCI

No matter what the *event*, you know that it triggers self-talk. These ideas, thoughts, and/or *beliefs* lead to your *feelings*. Your *behavior* and the *results of your behavior* are guided by your feelings.

One of the biggest keys to adjusting to spinal cord injury is personal **motivation**. Individuals who are newly injured are often motivated to attend therapy sessions out of a desire to gain strength and function. You probably have a strong belief that your paralysis is only temporary, and you will soon return to your old, "normal" self. This **hope** is a common reaction after an injury. Unfortunately, it is far more likely for individuals to recover function based on their level and completeness of injury (for information on recovery, see InfoSheet #4). In fact, only a few people actually fully recover from their injury. This does not mean that all hope is lost for a full or partial recovery. Almost all individuals with SCI continue to hope that they will walk again one day. However, a cure for paralysis may or may not come in your lifetime. A healthy approach to this reality is to move forward with your life after injury with the continued hope that advances in medicine will one day lead to a cure. In other words, do not wait on a cure to proceed with your life!

People who adjust well to life after injury are usually motivated to meet personal **goals**. These goals are different for everyone and often change throughout life. For example, your goal today may be to get a job, and you may want to have children in the future. Research from the University of Alabama at Birmingham (UAB) shows that people with SCI who are goal-oriented are less likely to be depressed and more likely to obtain some acceptance of their disability than persons who are not goal-oriented.²

However, it is up to you to find **purpose** in your life and the motivation to achieve your goals. It may help to think about what you wanted out of your life before you were injured. For example, you may have once strived for good health, an enjoyable job, and a loving family. There is no reason that you cannot continue to strive for the same things now that you have a spinal cord injury.

Replacing Irrational Beliefs with Rational Beliefs

Once you have motivation for change and set your personal goals, you may find it easier to identify unrealistic, unfounded information and false assumptions. You can help yourself avoid irrational beliefs by not...

- ... using words like always, never, no one, everyone and other “all-or-nothing” words.
- ... over exaggerating (making something small into something big or something big into something impossible).
- ... focusing only on negatives and ignoring the positives.
- ... thinking things “should” or “must” be a certain way.
- ... trying to predict the future.

It does not matter what your level of injury, you can challenge your irrational beliefs and replace your false assumptions with information that is based on fact. It is up to you to take time to learn the facts about living with SCI. An individual who is newly injured may want information on bladder or bowel management. An individual who has been injured for a year or more may want information on employment or sexuality.

When you are looking for educational information, only rely on information that comes from a knowledgeable source on issues of SCI. For example, most rehabilitation facilities offer patient education classes for individuals who are newly injured. In fact, you may have been given an informational booklet to take home with you from the rehabilitation center. You can also easily get educational information on the Internet. Web sites such as the National Spinal Cord Injury Association (www.spinalcord.org) and SPINALCORD Injury Information Network (www.spinalcord.uab.edu) have information indexed by topics. These web sites are great starting points for anyone looking for information to assist in everyday living with SCI. You may have access to the Internet at home, school, work or your local library.

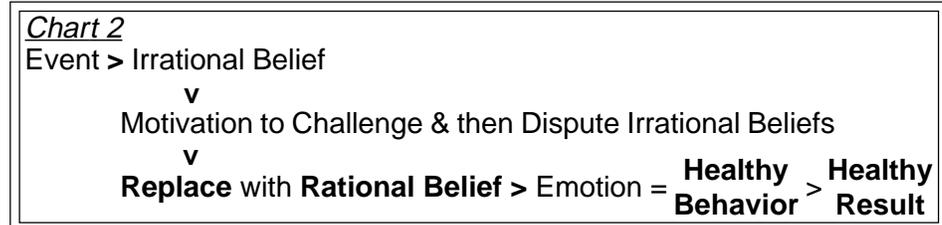
Now you can use [Chart 2](#) to help you develop the skills

to dispute and replace your irrational beliefs. When you challenge your beliefs, it is important to ask yourself what evidence you have to support your beliefs. Is there evidence to disprove your belief? You can then learn to recognize those beliefs that are based on false assumptions. For example;

- ◆ “My life is over because I can never live or be happy after a spinal cord injury.” Individuals who are newly injured often use this irrational belief as a way to deny the possibility that their injury is permanent. Individuals who have been injured for over a year may use this statement as a reason to do nothing. To dispute this assumption, you focus on the word “never.” It is similar to words such as “always,” “everyone,” “no one,” and “must.” This is “all-or-nothing” thinking. By using these words you are not allowing yourself to believe that there are other possibilities. According to the National Spinal Cord Statistical Center’s “Facts and Figures at a Glance,” there are about 243,000 people in the U.S. alone who are currently living with SCI. You are ignoring the fact that many, if not most, of the people living with SCI are happy.

“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 type of rational self-talk is supporting your hope for recovery, but it also supports the fact that you can be happy and live with or without an injury. You are recognizing the fact that other people with the same level of injury are alive and happy.

- ◆ “Because of my injury, it is now impossible for me to ever work or have a family.” This is a false assumption that many people hold onto long after injury. There are some individuals with SCI, family members, friends and others in the community that wrongly believe that “no one” with SCI can work, especially those individuals with high levels of injury. They may wrongly believe that you cannot get married or have children because you have physical limitations. You may even find it hard to imagine that you can work, or your family and friends may try to discourage you from becoming a parent, especially if you need help with your own care. These



are all false assumptions that you can challenge with facts.

“Although I have an injury and physical limitations to what I can do, I can put myself in a position to work and have a family if that is what I want.” This rational self-talk acknowledges the fact that you have an injury. In reality you may have physical limitations that prevent you from doing some jobs, which may include the same job that you did before your injury. For example, if you were a construction worker before your injury, it is not likely that you can return to that job if you have a high level injury. However, this fact does not mean that you cannot work. With job retraining and support from your family, friends and employer, you may find there are a number of jobs that you can do. As far as having a family, you might about people who are married and have children before their injury. It is *irrational* to think that people who are spouses and parents suddenly become “bad” spouses or “useless” parents simply because they become injured. The facts are to the contrary. Individuals with SCI continue to be loving, caring, supportive spouses and parents, no matter what their levels of injury. This fact also applies to people who want to have a family after injury. Although you may need to find ways to get things done, you need not base your desire to have a family solely on your physical limitations.

Emotion

Once you challenge your irrational beliefs and replace them with beliefs that are based on facts, you will likely *feel* differently. Instead of feeling sad, you might feel hopeful about your future. Instead of feeling worthless, you might begin to feel that you have value as a person, spouse, parent and an employee.

Healthy Behavior

When you begin thinking more rationally and experiencing a change in your feelings, you will usually act differently. If you have set goals for yourself, you may make plans on how you intend to reach your goals. You might then take better care of yourself so that you can reach your goals. This is healthy behavior! It is the action that you take to improve your life.

Different people have their own way of getting things done. You may find that you can no longer get things

done the same way as before your injury. It may be necessary to ask someone for help when you need it, but you may want to hold onto your irrational belief that you “must” do “everything” on your own. When you challenge this irrational belief, you may realize that people, both with and without SCI, help each other in many ways. This help may be as little as one person opening a door for another person. Some people simply get more help than others. When you ask for help, you are simply finding ways to overcome obstacles and get things done.

It may be necessary for you to find other ways to get things done. UAB is among the leaders in SCI research. In their studies of individuals with SCI and their family caregivers, evidence shows that good problem solving behavior can help individuals with SCI avoid medical problems, and reach their goals.

Effective Problem Solving

- A.** Define the problem as clearly as possible.
- B.** Brainstorm: Make a list of as many possible solutions as you can.
- C.** Review your list and pick the solution that you think will best solve your problem.
- D.** Try out your solution.
- E.** Ask yourself, “Does it work?”
- F.** Try another solution if your problem is not solved.

Healthy Results

Hopefully, you will notice that healthier behavior leads to healthier results. When you take care of your health, you give yourself more of an opportunity to participate in enjoyable activities. You can solve the problems that prevent you from doing those things that you desire. You may soon discover that you are living a healthier, happier, and more satisfying life. It may take time, but you can reach your goals.

FAMILY ADJUSTMENT _____

As an individual with SCI, it is important to recognize that your injury also has a tremendous impact on your family. Although they may not have to adjust to losing the use of their hands or ability to walk, your family may experience a loss of the way their life was before your injury. For example, they may have to adjust to the role of caregiver. They may need to work to help with family finances. All of the changes that they face can lead to added stress and anxiety.

Family members also grieve. They may ask questions to try and understand the full impact of the injury and to help ease their feelings of sadness and fear. As your family comes to accept the injury, they face issues of adjustment similar to those you may experience.

Children are naturally curious and adjust to events by asking questions. They ask questions because they make few assumptions about how the injury impacts their life. Therefore, children adjust rather quickly to an injury if their questions are answered in a clear, honest manner.

Problems in Family Adjustment to SCI

As an adult family member, you may have difficulty with adjustment if you have your own irrational beliefs about life after injury. For example, you may hold the false assumption that individuals with SCI cannot work. You may hold the unrealistic idea that “no one” with SCI can or “should” have children. You may hold the irrational belief that you “must” do everything for your loved one who is injured.

Your actions as a family member are reflected in what you say and do around your loved one. If your actions are based on irrational beliefs, you may be unknowingly acting with less than supportive behavior. For example, if you continue to do things for your loved one that he/she can do, your actions may be encouraging your loved one to be overly dependent on others. You may also be reinforcing your loved one’s false assumptions that individuals with SCI should be pitied or felt sorry for because life has treated them unfairly. You may be **enabling** your loved one to engage in self-destructive behavior if you ignore or deny the possibility of a problem with substance abuse. Plus, it is also likely that your irrational beliefs will influence your own feelings, which may then lead to unhealthy behavior and unhealthy results. If you experience prolonged feelings of stress and anxiety, you may be putting yourself at risk for serious health problems such as disease or stroke if you do not adjust your views of life after injury.

Healthy Family Adjustment to SCI

If you are a family member, healthy family adjustment is, essentially, taking care of you. For example, you can take time away from your loved one to do those things that you enjoy. You can help minimize your stress and anxiety by working to replace your own false assumptions, unrealistic ideas, and irrational beliefs. You can start by learning the facts about SCI. Then, challenge your irrational beliefs with evidence to dispute your beliefs. Finally, replace your false information with facts. Hopefully, you will soon discover that you too are living a healthier, happier, and more satisfying life.

CONCLUSION

No matter if you have a spinal cord injury or not, you have control over what you feel by choosing how you want to think about your situation. You can be happy and more hopeful about your life, but it will only happen when you work to make it happen. Your thoughts, feelings, and behavior do not change overnight. It takes time to grieve your loss and come to accept the realities of the injury. Then, you face a continued process of adjusting to everyday issues of living with SCI. If you avoid false assumptions, unrealistic ideas, and irrational beliefs, you will give yourself more opportunities to reach your goals and have the life that you desire.

RESOURCES

¹*Aging with SCI: Alcohol Abuse*, a Modular Educational Tract (MET) produced and available at Craig Hospital. Call 303-789-8202 or go to www.craighospital.org for a copy.

²Elliott TR, Uswatte G, Lewis L, Palmatier A (2000). Goal instability and adjustment to physical disability. *Journal of Counseling Psychology*, 47(2). 251-265.

This handout is intended to help individuals with SCI and their families help themselves through the process of adjustment to the unique conditions that follow traumatic injury. This model is to be used as a guide through the process of adjustment - not for the treatment of any physical, emotional, and/or behavioral condition(s).

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