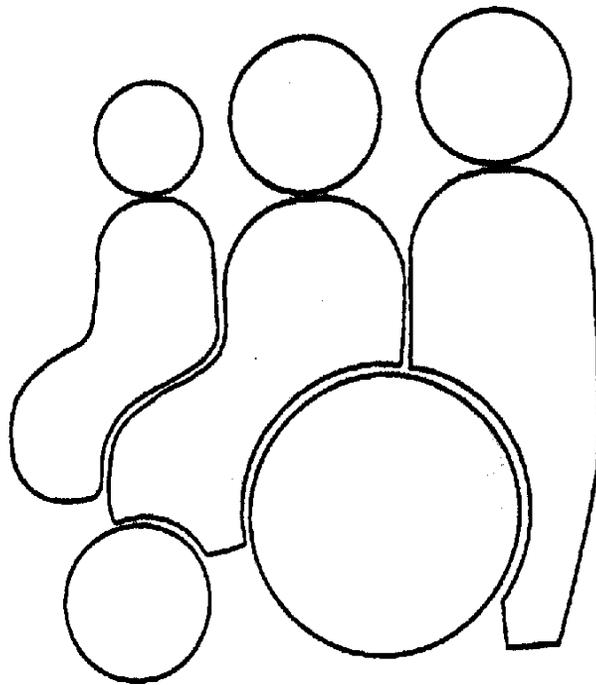


Family Adjustment to Spinal Cord Injury



Rehabilitation Research and Training Center in
Spinal Cord Dysfunction



**SPAIN
REHABILITATION CENTER**

University of Alabama at Birmingham

Family Adjustment to Spinal Cord Injury

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Introduction

This booklet will address some of the concerns and problems which the family of a person with spinal cord injury (SCI) may experience. It will focus on some of the initial questions and concerns you may have about spinal cord injury, as well as some of the feelings that families, such as yours, often experience as they begin to work through the changes that may have or will occur. Also, this booklet will attempt to address how life may be different, not only for your family member with SCI, but for your entire family.

Initial Concerns

“At first you experience disbelief, shock, anger and terror. You just don’t know what will happen. I went to the library and took out every book about quadriplegia I could find. Most of the information I later found wasn’t true. I wish I had known more about what was happening. Sometimes things aren’t going to be all right, and it would’ve been real helpful to talk to someone who had been there. So much is happening; it’s rough to deal with it all alone.” - mother of a quadriplegic.

You will be concerned about many things when your family member is first injured. You may wonder whether he or she is receiving the best treatment. A team of specialists in disciplines ranging from physical therapy to psychology will be involved in helping your beloved one begin to adjust to the spinal cord injury. Any concerns you may have about treatments or therapies should be addressed to a staff member who can help you better understand the rehabilitation center's program.

Other common questions raised are: “Will the injured person get worse? Will he or she be exactly as they were before the injury? Can the injury be cured?” Questions such as these are very important; however, they often have no easy, quick answer. They are perfectly natural questions to have at this time, and it is important for you to ask them. Your physician can give you the best estimate of what to expect in terms of recovery. Receiving answers to your questions is important because it will help you better understand what your family member will likely be able to do and how you can best help.

Emotions Commonly Experienced by the Family

“At first we couldn’t believe it. There was a lot of shock and fear - afraid for her, for us, our life together, her life period. I was with her all the time when she was first in the hospital. Just being there with her and becoming more familiar with her situation over time helped.” - husband of a quadriplegic.

You have been through an emotional ordeal - wondering if your family member will live, who will help with the care, how much care will be needed, wondering how you will pay for the medical expenses and what your lives will be like since the injury occurred. The feelings brought out by a traumatic event such as SCI are thought to be similar in some ways to those experienced when a family member dies. As you begin to deal with what has happened, you will be experiencing many different feelings.

A common first reaction to such a crisis is relief; that yes, the family member is still alive, but shock at the degree of the injury. You may feel numb, confused, frightened and anxious. Not only is there uncertainty about what the injured family member is going through but also about what the future will bring. Such feelings and concerns are perfectly normal. One way to work through them is to ask a lot of questions of the staff who will be working with your loved one. By trying to understand as much as you can about the injury, your confusion and anxiety can be lessened.

“Our situation was kind of different - we didn’t know immediately that he had a spinal cord injury. We didn’t know the paralysis was permanent, at first. At first it was like nothing - I just blew it off - didn’t think much of it. At the time, I was in paramedic school, and I think that knowing what was going on a little bit better helped a lot. It didn’t really hit until he came back from the hospital in Houston. We didn’t truly realize the full extent until he was at the rehabilitation center. At first we were outraged because he had received the wrong operation initially. Once we knew the facts, we realized we had to just forget the past and what had already been done and figure out what to do next.” - brother of a paraplegic.

Many people, both patient and family, often try to deny the seriousness of spinal cord injury in the beginning. Instead they may tell themselves, “It’s temporary” or “not really that bad.” Denial is a normal way of trying to cope with problems that are too big to face all at once. It can be helpful at first in that it prevents you from experiencing overwhelming feelings of despair.

However, denial can become a problem if you get caught up in avoiding reality for too long; for example, telling yourself the problem is temporary, therefore, “I don’t need to learn about his care.” You need to move beyond this to be able to help with the rehabilitation of your injured family member. They need you to do so. Only by facing the reality of the injury can you be open to learning new information and skills to help your loved one and also to better understand the disability and your role in the injured person’s life.

During this period of adjustment, you may also have feelings of grief. These emotions may include a feeling of sadness at the loss you and your loved one have experienced. Not only may the loved one now be restricted in some abilities, but the whole family may feel like it has lost some of its independence, as well. Grief can often be triggered by thoughts of what was or what could have been. Such recurring feelings of sadness, however, are normal and are to be expected. If this happens, don’t be angry at yourself for failing to “get over” the disability, but instead, allow yourself to experience the loss and the pain. You are going through a major change with your loved one, and this is not something that can be worked through in one day. It is not easy to deal with all of these intense emotions at one time. If you can share them with someone who will listen and care, perhaps a friend, minister, staff member or your injured loved one, you can begin to put your life back together again.

As the permanence and “unfairness” of your family member’s injury are realized, anger and frustration often occur. Families sometimes experience anger about the cause of the injury and why it happened to their loved one. Anger may be directed toward the doctors because they can’t “fix it” or sometimes toward the hospital staff and sometimes toward God. At times, anger is also directed toward the injured person. Writing about your anger, pouring your feelings into a tape recorder or having someone outside of the situation (minister, counselor, psychologist, etc.) who will listen and understand are all possible ways of dealing with your anger.

Not only is anger experienced by the family, but it is also frequently seen in the injured person as well. Family members are often confused and hurt when greeted with the angry and, even at times, hostile outbursts of their injured loved one. It might be helpful at times for you to remember that

frequently these are not personal attacks directed at you. Your loved one is also experiencing much frustration and anger about his or her injury, and needs to express these emotions. Unfortunately, those they love most often receive the brunt of their anger. Again, sharing your feelings of hurt with others and perhaps talking with your injured family member about how these outbursts impact you may help you open lines of communication and cope with their outbursts more effectively.

You may also feel guilty. Even when family members had no direct role in causing the injury, they may still have guilt feelings. Thoughts like: "I wish it had been me, they have so much life ahead of them, and why do I deserve to be walking around," describe how many persons feel after a loved one is injured. In some cases, guilt is felt over secretly wishing that you were not responsible for the injured person's care and resentment because of limitations put on your independence.

The injury may mean a big change for you, and such feelings are to be expected. The guilt you may feel over having these thoughts and feelings is also normal and understandable. It is important to explore how your thoughts may be related to the feelings of guilt you are experiencing. Feelings of guilt which are not understood or expressed can lead to overprotectiveness toward your family member with spinal cord injury, misdirected anger, or possibly even physical symptoms due to the suppression of strong feelings. Guilt over something you may have done, said, or thought needs to be talked about with others.

"Depression was there. As time went on, the depression seemed harder and harder to come out of. There was never really any denial - no room for it. I took care of her day and night, so that helped limit the time within which to get depressed. A lot of times, I found that there was no time for me - the balance is no longer there. At times I found myself resenting this, but I've been able to talk about it with my wife from the very beginning, that helps to keep things out front. Communication is very important so you don't hold everything in and then explode. We were able to accept it and move on from the very beginning." - husband of a quadriplegic.

Depression can be thought of as feeling "blue," or experiencing a sense of hopelessness. Depression is often a response to stress or change. If you notice problems with sleeping, weight change, frequent crying or feeling tearful, loss of interest in previously pleasurable activities or pastimes, decreased energy, or difficulty in being able to concentrate or think clearly - these can all be reflections of depression. However, if you have symptoms like these, you should always see your family doctor to be sure they are not coming from some other cause.

One way to get control of these feelings is by trying to identify the thoughts which are causing you so much distress. You may need to step back; look at the whole situation from a distance and try to separate the facts from what you think is true and from your fears. It is important to replace thoughts which are without a logical basis (and that are keeping you feeling down and blue) with more realistic alternatives. Most depression runs its course; however, if it persists and begins to interfere with your ability to do what needs to be done, you may need to seek help for yourself.

“At first we really didn’t know the full extent. My main concern was the use of his hands and arms, as I was eight months pregnant at the time and had two other children. It was a hard, uphill battle from the start. His mother didn’t want to talk about it (the injury), but I did. I thought, he’s to this point now, why not look at the worst of it and move on from there. The first thing is to accept it for what it is. It takes months and months and months to see the light at the end of the tunnel. Day to day dealing with it was the way we coped - time is the healer of anything - death, sickness, even this.” - wife of a quadriplegic.

You may wonder if you and your loved one can ever “accept” the spinal cord injury. If “acceptance” means being happy about it or not bothered by it - perhaps not. There never has been and never will be any “justice” in spinal cord injury. But you will eventually come to realize that the injury has indeed occurred, it is likely to be long-term, and while there is always hope for a cure, it needs to be dealt with now. At this point you will be able to take positive action and begin to reorganize your life so the injury no longer takes all your energy and time. Periodic feelings of sorrow may still occur, but you will have dealt with the worst of the initial pain. You will be ready to invest your energies into regaining a positive quality of life rather than in grieving over or denying the past.

“I know how bad it was when he first came home. Structured routine day to day was the only way I could survive with time for myself. It’s so important to get yourself organized. As quickly as you can, get your life in order so things go smoother.” - wife of a quadriplegic.

“The knowledge of the facts - realizing the true extent of his injury and accepting it - helps you to move forward. You need to just pick up the pieces and drive on. He always told us that it didn’t bother him, why should it bother us. He stressed that he was still the same person - he just got around different.” - brother of a paraplegic.

In general, as you cope with all of these emotions and with the crisis of the disability itself, be aware of the amount of stress you may be under. Trying to perform too many roles at once can threaten your own physical and emotional well-being and your ability to cope. You need to focus only on the things that are of real importance and that must get done. Put others on hold. Be sure to eat and rest (even if it is not uninterrupted, deep sleep) and take breaks from the stress of the rehabilitation center's environment when you can. Physical activity/recreation are very good for tension release. Also, relaxation techniques (which the psychology department can help you with) and being able to talk about your worries and stress to someone who is a good listener can help.

“To deal with what was happening, I kept a journal and wrote a lot. Later I burned it; it had served its purpose. Some in my family were able to talk about it, and others prayed. I also would get to the point where I had to get out, and I would go walking. It was hard for me to ask others to help, but I had to get out sometimes.” - mother of a quadriplegic.

“Getting out into the public with the chair, etc., was one of the toughest things for me to deal with. I think it bothered me more than him. It wasn’t that I was embarrassed to be with him, but I felt for him when people would stare or say things. I think time and getting out more helped to smooth things over.” - wife of a paraplegic.

Particularly during the early stages after injury you may feel abandoned by those outside the immediate family unit or find they avoid you. This may be due in part to their shock and uncertainty about how they should react and what they should say to you. Rather than doing or saying the wrong thing, others who were once close to you will return. What is important is for you as a family to realize this may occur and not to permanently isolate yourselves from the outside world. You may need to take the lead in reestablishing contacts.

While persons who stay isolated may be fairly successful at shielding themselves from hurt, they are also often unable to obtain help and support when they need it. These are some ways that you may be able to handle the cruel or insensitive remarks of others without resorting to isolating yourself:

1. Family role playing - it can be helpful for you to devise and act out responses which can be comfortably used by family members in real situations.
2. Confrontation - learn to stand-up to others and let them know how it makes you feel when they do, don't do, or say certain things. This will enable more honest interchange.
3. A simple explanation may ease the situation.
4. Ignore the situation, small battles are not always worth winning.
5. Drop the “rejecters.” It will be healthier for you to seek out those whom you accept and who accept you, rather than staying with those who are not trying to understand your situation or support your attempts to cope.

How SCI Impacts the Family

Often families in crisis tend to cope by overemphasizing attitudes and responsibilities that existed before their family member was injured. Old patterns of behavior, however, may not work given the new family situation introduced by the SCI. The role of each family member may have to change to accommodate the person who is injured. Not only will others have to take on responsibilities previously held by the injured person, but there may also be new duties relating to the injured person’s care. (These will vary depending on the extent of your family member’s disability.) The entire family should be involved in discussions about the family’s different needs and problems. Tasks should be redistributed so that each family member can assume a fair share of the tasks previously performed by the injured family member, until the injured person can resume some of those responsibilities again. Communication will need to take place on an even more effective level. Everyone in the family will need to be responsible for communicating their needs and feelings (both positive and negative) to those around them. This is necessary in order to better understand how the family unit as a whole is coping with the disability and to reduce any tensions before they become too great.

“I would say our relationship has really changed for the better. Being together all the time - seven days a week - and we’re still very close. Both parties need to be willing to work through it together. Talking over why you feel down; what makes you angry is real important.” - wife of a quadriplegic.

“Faith was an underlying support for us, but it was mostly a matter of physical and mental adjustment. We had the children and were also determined not to let this steal our lives together and the plans we had made. We were determined to live as normally as we could. I treat her the same as before. Love is probably the most important factor in helping you adjust (to the spinal cord injury). It was never at question that I’d leave her. It happened, and now let’s go on.” - husband of a quadriplegic.

Specifically, when a married person is injured, responsibilities for finances, parenting, and day-to-day upkeep of the home may change. Because of the disability, the injured person may attempt or want to become more in control of family activities, while the non-disabled partner may become more passive and even nonsupportive. The additional duties created by the disability and the fact that the healthy partner is likely to be responsible for many of the physical duties related to the care of the family can produce severe stress within the family unit. Good communication and shared decision-making, when possible, can reduce much of the burden of one individual’s responsibility for the entire family’s well-being.

When children are injured, their care will place additional responsibilities on the parents. Resentment may appear in other family members. This situation is more likely to occur if the child is pampered or overprotected. The family needs to know that SCI is not a sickness. While the injured child may still have to depend on the family for some things, he or she should be encouraged to and, in fact, may need to be forced to do as much as possible on his or her own. This should lead to an increase in control over his or her own life, a decrease in dependence on others; and therefore, increased confidence and self-esteem.

“When he first came home - it was hard to get him to do for himself. Often it was easier for someone else to do it for him. Now he’s much better about taking care of himself - more self-sufficient. I guess that came about when we began communicating to him that we were tired. We told him he could do it just as good as we could.” - wife of a paraplegic.

“Now I would say we’re about as normal as the people I used to envy. Seeing him cutting grass or playing ball with the kids are the only real exceptions. He is a lot less dependent on me now but it took time. It doesn’t happen overnight. It’s important to teach yourself not to always be there to pick something up for them. They have to learn to do it all over again.” - wife of a quadriplegic.

How to Respond to the Injured Person

The person who is injured often experiences and expresses strong feelings. Most often the family will receive the impact of these feelings. It is not unusual, for example, for the injured person to be pleasant, cooperative and upbeat with staff, but negative, critical, demanding and passive with family members. You may feel and hear their sadness and anger. You may feel rejected by them and isolated; like they are trying to “shut you out.” Family members often receive the most negative emotional reactions, perhaps because you are “safe” and expected to be understanding and forgiving.

Family members often are not sure how to respond in such situations. There are no absolute rules. Here are a few guidelines, but remember that different situations and persons require different responses.

1. Try to be a good listener. It is important for the injured person to have someone who knows them and cares about them and listens to his or her thoughts and feelings. The best way to be a good listener is to pay attention and be quiet.
2. Do not try to talk the injured person out of negative feelings. Responses like “It could have been worse,” or “You don’t really feel that way” are probably not helpful. A better response is to acknowledge the feeling and except it as legitimate. For example, “You must be feeling very down today.” A statement like this accepts what the person is feeling, but it also implies these feelings may change.
3. Express your feelings, too. Many times family members feel they must keep up a “brave front.” This is not always a good idea. Be honest about your own feelings and express them, too. By doing so, you are showing your loved one that you have been hurt, too. Two-way sharing of feelings is the best way of maintaining emotional closeness.
4. Express your support and reassurance. Tell the person that you still value them as a person and will stick by them. Many injured persons fear but don’t always express concern about being abandoned. You need to tell them and show them that you can be trusted to be there when they need you. It is important, for example, if you say you will be there at a certain time to visit or to do something that you follow through. If you do not, the injured person may “read” all sorts of things into your failure to do what you said you would do.
5. Hold on to hope. Express your determination to live today as best you can and hope for a better tomorrow. Everyone needs hope that things will get better, particularly the injured person. The best message you can give is to reassure them you will work with them as things are now, but you will continue to hope for better things.

Sexuality

You may be worried about your injured family member’s ability to have a satisfying sexual relationship. First, it is important to assure you, the commonly held belief that disabled persons are not

sexually interested or active is NOT CORRECT. The amount of change in sexual function for your family member depends largely on the level and the type of injury which he or she has experienced. Sometimes the full extent of the injury's effect on sexual functioning will not be known for as much as one year or longer. So it is possible the immediate level of functioning after injury may change with time. In men, the ability to have an erection and to experience orgasm are usually affected, and it may be difficult for these men to father children. Women with spinal cord injury do not typically experience orgasm the same way they did before the injury, but they are still able to have children.

When your partner or family member is first injured, sex may be the farthest thing from your mind (or it may be the first thing on your mind). After your loved one has begun to recover, sex will become an important consideration. It is perfectly natural to feel awkward and unsure at first, but there is absolutely no reason why your loved one cannot experience an active and healthy sex life. Members of the rehabilitation center's Psychology Department are available to you and your loved one to discuss your concerns about sexuality. You are encouraged to contact them.

When your child, brother or sister has experienced spinal cord injury, you may be concerned about their ability to engage in successful future relationships. It is very important to remember that such relationships are possible following SCI. You need to help reassure the injured person of this, be supportive, and encourage efforts to establish relationships. Your attention should be focused on your family member's abilities, not their disabilities.

“They need to stop trying to do things they can no longer do - and be encouraged to continue to do the things they can. At first it's frustrating when they need to relearn the things that they can still do, but it's for their own good. It's easy for them to say they can't and quit trying. You need to discourage this and encourage what they can do.”
- wife of a paraplegic.

Life Beyond SCI

“It gets better. When it happens, you go through hell. The person comes out so different than before. Lots of doors can open for them if they want to try. You become a stronger and better person. You learn to put the needs of others above your own. You learn you can survive anything. It takes awhile - actually it took us about ten years - but you'll make it. You'll even be able to laugh about things with time.” - mother of a quadriplegic.

“It does get better. Everybody gets better. Your mind gradually comes to accept it better - you can cope better mentally. It's hard, but not impossible. You shouldn't give up hope but should try to encourage them to do whatever they can. I've seen it happen - even if things improve only a little bit, they do get better.” - husband of a quadriplegic.

There will be a new life ahead for you and your family member with SCI. Once the pain and shock pass, and the grief, anger and depression begin to lessen, you will be in a position to begin anew. Your loved one will begin to be able to do more for him or herself in time and will continue to learn and grow after discharge from the rehabilitation center. While the injury will present new challenges both to you and your loved one, it is important to keep in mind that you all can make it - when you are ready to try.

You and your injured family member will continue to improve and find the disability less and less of an inconvenience. Your family and injured loved one will begin to learn more efficient ways of doing things. With time, the injury will decrease in importance to each of you. While much adjusting, relearning and new learning will occur, sharing and support can also be there. What initially may have appeared to be a devastating experience can become a growth experience which can bring your family even closer together.

“It does get better...there is hope down those lonely months. Talking, working through it - continue to do that and you’ll be fine. Anything you go through, it’s important to remember that others go through it too. You do work through it. It does get better.” - wife of a quadriplegic.