

SPINAL CORD MEDICINE

HANDBOOK FOR PATIENT AND FAMILY



Psychological Care



Frazier Rehab Institute

A service of Jewish Hospital & St. Mary's HealthCare

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THE PATIENT AND FAMILY HANDBOOK

This Handbook is designed to give you the information to better understand spinal cord injury and the tools needed to manage your health care needs successfully. Information is intended for you and your family because, those who love you, will often be involved in assisting you with your care needs while in the hospital, and in the home environment. As you read through the Handbook, your rehab team at Frazier is available to address your questions and provide you more information pertinent to your needs.

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A BRIEF NOTE ABOUT THE FOUNDER OF FRAZIER REHAB INSTITUTE

In her early 20's, Amelia Brown of Louisville sustained a spinal injury in a car accident in the 1940's. With no rehabilitation services in Louisville, she traveled to New York for treatment. After returning to Louisville, she married a physician, Dr. Harry Frazier. Believing Louisville needed its own rehabilitation facility, Mrs. Frazier founded the Frazier Institute of Physical Medicine and Rehabilitation in the early 1950s. Her son, Owsley Brown Frazier, served as Chairman of the Fund Raising Committee for Frazier's new building, named the Frazier Rehab and Neuroscience Center, which opened in 2006.

DISCLAIMER

The information contained herein is intended to be used in accordance with the treatment plan prescribed by your physician and with the prior approval of your physician. You should not begin using any of the methods described in this publication until you have consulted your physician. Jewish Hospital & St. Mary's HealthCare, Inc. D.B.A. Frazier Rehab Institute, its affiliates, associates, successors and assigns, as well as its trustees, officers, directors, agents and employees are not liable for any damages resulting from the use of this publication.

NOTE: Words *italicized* in the text below are defined in the Glossary at the end of this Chapter.

PSYCHOLOGICAL CARE

DEALING WITH SPINAL CORD INJURY AND IMPAIRMENT: GRIEF AND LOSS

This body that I've been living in since I was born, doesn't work as it used to. In fact, some parts don't work at all. I can't feel them. I can't move them. And what I've learned is that they can be heavy like a lump of clay getting from bed to the wheelchair. They feel useless. Me worried? Scared to death. What's next? Don't know? (Jason, age 24, two weeks after spinal cord injury.)

After injury and hospitalization, perhaps, you, like many, sense deep within that life is going to be different from what it used to be. Yet, it is difficult to know exactly what to think, or how to feel, because there are so many uncertainties. Various thoughts, feelings, questions are common, such as:

- Do the doctors really know what's wrong?
- It doesn't really matter what they say because I've always come back from injury—I work hard. Think positive, I've got to think positive.
- What will my friends and family think of me?
- I don't want my girlfriend to see me like this. Maybe I should have died?
- My toes and ankles must be asleep. I must be asleep. This is a dream, it's unreal.

After injury, you may also find it difficult to think clearly. You may experience considerable anxiety or worry and find it difficult to handle emotions. This may be a reaction to the injury and may be due to pain, drugs, poor sleep and/or being in the hospital. You may also have received a brain injury at the time of your spinal injury, which can contribute to mental and psychological changes even though they may be mild or short lived. It is not uncommon to sustain a brain injury and a spinal cord injury in the same accident.

You may have difficulty perceiving your body accurately because of nerve damage. For example, you may feel your legs bent at the knees when in reality they are straight. When sitting, you may feel you are leaning to the left when in fact you are sitting up straight. Some people sense that their body below the neck is like a balloon floating in air or feel a limb move when it is lying flat on the bed. These experiences can add to your anxiety, confusion and concern.

In addition, you may come to discover:

- You have little control over what happens to you or your body early in your hospitalization
- How dependent on others you have become for even the most minor tasks like getting a drink of water

- Small amounts of physical activity can cause extreme exhaustion
- The rehab process feels slow and will require long, hard work
- When friends and family come to visit, the responsibility to put others at ease often falls to you.

Given the above, it is common to think about giving up, and to want to be left alone to stay in bed all day. Feeling emerge of wanting to forget about rehab and focus on the perfect healing. You might even ask yourself if people with injury or impairment and their families usually go through a period of grief and loss, and that answer is commonly, yes.

Everyone's experiences after injury/impairment are different. For example, you may not experience much grief or sense of loss. Instead, you may feel energized, intensely focused and determined to rise above the injury or impairment, determined to move forward. If this is true, you probably will work extremely hard in your rehab and accomplish much. Nonetheless, it is not uncommon to have episodes, sometimes months after injury, when the pain associated with this life style change or the pain of the losses do appear and are intense. Should it happen to you, it is important to be prepared.

THE PROCESS OF GRIEF, GRIEVING THE LOSS

Moving through a period of grief is a normal, healthy reaction when something or someone important to you is lost. Experiencing grief is common regardless of whether the loss is thought to be short-lived or long-term. The grieving process helps one come to terms with the emotions associated with the loss, to accept the reality of life as it is today and to begin to make adjustments so life can be lived with a reason to get out of bed everyday. Those who have no purpose for daily life often become depressed as their relationships with family and friends deteriorate. By contrast, those who live with purpose can find health, happiness and self worth, while maintaining and/or strengthening their relationships with others.

The symptoms of grief are many and can include sleep disturbance, low energy, loss of appetite, increased appetite, lack of motivation, tearfulness, feelings of sadness, social withdrawal, wishes for death, thoughts of suicide, anger, impatience, moodiness, longing, confusion, feelings of guilt, anxiety, loneliness, disbelief and agitation.

These symptoms are not necessarily bad or unhealthy as they represent the normal process of moving through grief and may continue for weeks, months and possibly, years, though the frequency of the symptoms and their intensity may vary. However, you and those around you should become concerned if the symptoms continue, get worse and/or you feel stuck. If this happens, you should consider talking with your doctor, a counselor or psychologist, or trusted individual who has the skills to help. Specifically, thoughts of suicide should not be ignored and professional help should be found.

The symptoms of grief mentioned above need to be addressed by you and your family so they can be resolved. Remaining involved with your rehab doctor and team of professionals at the rehab center is strongly recommended to assist and advise you with life style changes and adjustments as you work to re-enter your community after hospitalization.

COMMON STAGES, GRIEVING THE LOSS

Seeing the Reality of the Loss, Accepting Change. Most would agree a leg amputated due to injury or disease is gone and will not grow back. By comparison, it is more difficult to accept losses due to spinal cord injury or disease because they are often not seen so clearly. For example, you may not be able to move your arm or leg today but they are still attached to the body, seemingly ready to be used. As you sit quietly in a chair or lie in bed, you may look and feel very much as you always did. Recovery is about getting the nerves connected and working again.

Like others, you may have great hope and determination for recovery but struggle that medical science can seldom, if ever, guarantee recovery. Perhaps you don't want to hear what the physicians think about your injury. If you don't improve after a few weeks, months or years, should you give up hope?

Some do give up hope, yet others do not choosing instead to believe in themselves, believe in the power of prayer and that advances in spinal cord research and treatment hold great promise. And it is true there have been significant advances in both the research lab and the clinic settings. Nonetheless, believing in a cure returning you to perfect health is a future possibility. Nevertheless, losing the ability to control your bowel and bladder, to walk as you once did, or to bath independently is about today. How you deal with today is very important to you and those around whom you love and who love you.

One of the first steps needed to deal with loss or change is to see today truthfully. For example, a transfer board and assistance may be required for you to get out of bed; a rolling shower chair and hand held controls might be needed to bath. Admitting to yourself that this is the way it is today hopefully means that you will make great effort to learn to help with transfers and bathing as best you can. Being active with your body may in fact be very helpful to recovery, as researchers have learned that activity causes the spinal cord to be stimulated and that, in turn, can produce movement.

Experiencing the Emotional Pain Associated with the Loss. Having control and sensation of one's body for toileting, mobility, sexual activity, and, in general, to be independent, allows one to maintain a certain life style, which is an important element in how we perceive ourselves. Emotional pain is a reflection that something, valued or treasured, has been lost temporarily or forever.

Those who see the reality of their loss of sensation and control of body typically allow themselves to experience the loss emotionally. The emotions are often very strong and can be difficult to manage. Anger, sadness, hopelessness, guilt, fear and a sense of injustice are very common. Talking, screaming, yelling, cursing, crying, sleeping, praying, biofeedback and deep breathing exercises, looking for the positive, being active, learning the truth about spinal cord injury and disease, and meeting former patients who have been successful dealing with spinal cord injury or disease are often helpful. Eating, watching TV, listening to music, sleeping, medications and daydreaming may be helpful for a break from the emotional pain but can become unhealthy if used too often. Thus, the emotional pain can remain

unresolved or stored up waiting for release, resolution and healing. Those individuals who do not successfully handle this task in the grief process frequently lose motivation and interest in many activities. They withdraw from friends and family, become bitter and resentful, stay depressed, develop poor personal hygiene or eating habits, and many seriously abuse drugs and alcohol. However, those who have some success dealing with the emotions related to loss, move forward.

Making Adjustments After Spinal Cord Injury. Adjustment means effectively learning to deal with the changes caused by the spinal cord injury, disease or impairment. Learning new ways to cope may become necessary. For example, if you ran 2 miles a day for stress relief, you may need to find alternative ways to relieve stress after injury. If you were accustomed to a varied daily schedule with irregular hours for food and sleep, you may find regularity is important for proper control of bowel and bladder and your overall health. If you were used to making plans spontaneously, you will learn that it takes time to prepare for an outing as you consider transportation options, accessibility of buildings and the amount of time needed to prepare yourself for an outing. Additionally, you may need to learn new vocational skills because you may not be able to do your old job as you once did.

An important component of a patient’s rehabilitation program is to:

- Venture out in the community and learn how it is possible to function
- Discover that the fears or discomfort of being in the community often go away with time
- Learn how to appropriately ask others for a little help

Bouncing Back. Bouncing back requires a willingness to take a risk, which is something you have already done many times since injury though you may not have noticed or given yourself credit for taking a risk. For example, you may have been scared and unsure the first time transferred out of bed, the first days of rehab and the first few times going out in public. With practice and experience, these activities and many others become easier and more manageable. If you hadn’t taken a risk, you would likely still be in bed.

Those who do well after injury, take risks often, even though they may be scary or difficult. For example, a woman with paraplegia, always shy and passive, decides it is important to push herself to be more talkative around others in order to feel better about herself and less lonely. Another example of taking a risk is the young man with tetraplegia who enrolls in a community college to learn job skills though he believed himself to be low average student in high school.

Bouncing back also means having goals and having a reason to get out of bed each morning. As said above, those who don’t are often depressed; those who do, create the opportunity to move forward. Success here usually involves setting both short and long-term goals that are realistic and obtainable with effort on your part. Soon after injury, short-term goals are particularly important because of the loss of independence. Thus, setting a goal to lift a weight more today than yesterday, to do better taking your pants off tonight, to bath or brush your teeth with greater independence is good. If you can see daily progress, chances are good you will feel less depressed and more encouraged knowing, “Hey, I can do that. I

might be able to do more.” You are encouraged to organize your thoughts and identify goals that are reasonable to accomplish with effort on your part.

Lastly, bouncing back means allowing laughter and humor to be a part of your daily life. If only for a brief moment, one who laughs, lets go of pain, loneliness and fear. A good laugh is living in the present, not connected to the past or fearful of the future and allows you to relax and experience pleasure. Many patients believe that incorporating humor helped their recovery. Examples include watching a comedy, purposely remembering a funny event, planning an enjoyable event or get-together, teasing someone or telling a joke.

ABOUT YOUR FAMILY AND LOVED ONES

As you may struggle after injury/impairment, those who love you also struggle. Most believe that spinal cord injury and impairment doesn't just happen to you but to the entire family. Though your experiences may be different, there are many similarities. For example:

- They too miss seeing you up and walking around or seeing you do things that you have enjoyed
- They too struggle as you try to dress, bath or brush your teeth, activities which were simple things in the past
- They too have concerns and questions about your future
- They too want your old life back. They too want their old life back

Simply said, rather short term or long term, their life is also different. As such, they too will likely experience many emotions related to spinal cord injury and impairment as described below. If you pay attention to your family's concerns, you can be helpful to them as they are helpful to you. Saying things like, “Thank you for coming to the hospital, for taking care of my apartment/house, for helping with my personal care, for not abandoning me” helps keep you family going, helps them feel appreciated and useful.

SUMMARY

Dealing with grief and loss following injury is often difficult and continues for months and often years. It is important to:

- Be patient with yourself
- Accept that ups and downs are normal realizing there will be good days and bad days
- Take risks to do things challenging or outside your comfort zone
- Work to accomplish something important to you everyday
- Give yourself the freedom to laugh and have fun
- Give yourself permission to ask others for help and assistance
- Practice making decisions about your life...take charge

After injury, many do take charge. David was 16-years-old when he dove into a swimming pool and sustained a C5 complete spinal cord injury. While in the hospital bed, he could see no future other than lying in bed. Twenty years later, he had completed two college degrees, married a wonderful and supportive woman, had a full-time career, drove his vehicle independently, frequently flew for business and pleasure, and enjoyed many leisure activities.

“Back when I was in my hospital bed, I thought it would be impossible for someone like me to accomplish the things I’ve accomplished.”

HOW FAMILIES CAN HELP

When one of your loved ones is hurt or injured, families often come together quickly. Family members drop or put on hold important parts of their lives such as school, work and community activities. Family members often stop taking care of themselves in order to care for the loved one (LO). Stories from intensive care units describe family members staying at the hospital for days or weeks, and eating and sleeping in the waiting rooms. They shower using the sinks in the hospital rest rooms. Family members sit together, worry, often cry and wait to hear the next words from the doctors and nurses. The crisis from injury or illness often unites families, and proves over, and over again they can be incredibly strong.

WHAT CAN FAMILIES DO TO HELP?

Perhaps most difficult for families is their inability to fix the spinal cord and return their LO to life as it was before injury or impairment. If families cannot fix the spinal cord, what can they do to be helpful?

Actually, families can do a great deal that is helpful, which makes a difference even though it may not seem so at the time. Those that have lived with spinal cord injury or impairment have said:

- My family got me through the first few days. Just knowing they were there helped.
- My wife and kids. . . that is why I wanted to live. Without them, I would have given up.
- I wouldn’t be where I am today if it were not for my family.
- My wife said, “You are still you,” even though I couldn’t see it at the time.
- I could see their love for me as they cried when I couldn’t move my arms or legs.
- I knew they still wanted me.

Relate to Your Loved One as You Did in the Past. If you laughed in the past with your loved one LO, expect to laugh together again. If you disagreed about things in the past, expect to disagree again. If you shared special thoughts and feelings and helped each other in important ways, expect that to happen also. If you told your LO when you were angry, when he/she was insensitive, lazy, or stubborn, plan to do it again.

Your Loved One is More than Body. Even though the body may not work as it once did, your LO remains a person of value. Express that to your LO in as many ways as you can. For example, bring in a special food, give your LO a hug, do something you know your LO will know is special, call just to say hello or learn how to do some of the care your LO needs.

Practice Being a Good Listener. A good listener tries not to interrupt or offer too much advice unless asked to do so. Listening to your LO as he/she begins to talk is helpful. You may not like what you hear, but to know your LO’s thinking is valuable. If you become

disturbed by what you hear, you may talk with the psychologist or other staff member for support and guidance. It is not your job to solve all problems or have the perfect answer to every question your LO may have. However, just being with someone at a difficult time, being a good listener is a great way to be supportive.

Encourage the Expression of Feeling. Express interest in your LO by asking questions about what is happening in therapies. Ask what has been good or discouraging difficult about rehab. Ask about things such as current events, sports, family news, etc. As you ask questions of interest, you will encourage your LO to express himself/herself.

Reinforce Independence. Encourage and expect your LO to make decisions about important like discharge plans, as well as other decisions about what to eat for supper, what clothes to wear and what to watch on television. Your LO made decisions about his/her life in the past and will need to again. Be careful as you try to be helpful that you don't make decisions that your LO should be making. Sometimes, you are most helpful when you do not rush in and do things your LO needs to try to do even when difficult.

Learn about Spinal Cord Injury and Impairment. The more you learn, the better you will come to understand what your LO is going through and know better how to be helpful. With more knowledge, you can become more confident and comfortable as you spend time with your LO. If your LO sees you making effort to learn, your LO knows you care and are being supportive.

Attend Family Teaching Days at Frazier. The staff at Frazier wants you and others in your family to attend therapy with your LO. As you participate in what we call Family Teaching, you will see how the therapists work with you LO, you will learn why things are done as they are, and you can practice specific ways to can help your LO. For example, you might learn how you can help with meals but not help too much, how you can help your LO be more comfortable in the wheelchair or in bed, and how to stretch a sore arm or leg. Being comfortable providing hands on assistance to you LO is a wonderful way of expressing your love and support.

Join a Spinal Cord Advocacy/Support Group. Struggling with the realities of spinal cord injury or impairment for many is difficult. Many find it helpful to be around those who have dealt with similar issues and found ways to be successful. You and your LO might consider attending meetings sponsored by organizations like the National Spinal Cord Injury Association (NSCIA). In Louisville, the Derby City Chapter of NSCIA meets at Frazier monthly and welcomes those with injury, family members and friends. For information, contact the Frazier's Psychology Department at 582-7484 or the Therapeutic Recreation Department at 502-582-7618.

FAMILY MEMBERS STRUGGLE TOO

At Frazier, we believe an injury does not just happen to the one who is hospitalized but rather it happens to the entire family. Most everyone struggles trying to deal with many thoughts and emotions. Understandably, most want to care for their loved one (LO) first and their self second. Nonetheless, it is important for you and other family members to take

care of your physical and psychological health so you can be strong and helpful to your LO over the long term.

You may find value in reading the section above on Grief and Loss.

Specific questions and concerns can be directed to your rehab doctor, psychologist or others on your rehab team.

CAREGIVERS

During inpatient rehabilitation, family members will often be asked to learn how to do hands-on care for their LO. This may involve activities of daily living (bathing, dressing, eating), transfers from bed to wheelchair, specific medical care (wound dressing, tube feedings), procedures for skin protection and bowel/bladder management. The level of your LO's spinal injury, will determine the type and amount of care needed in the home environment and the amount of time required to provide care each day.

Family members, now *caregivers*, provide an invaluable service to their LO. If not done, then the LO might not reside in a home situation but rather a long-term care facility in the community. Most caregiving is done as an expression of love. Nonetheless it may put many strains on the caregiver's time, finances, physical and emotional health, leisure time, and social relationships with others including the LO.

Caregivers are advised to learn to give yourself permission to care for yourself, learn how to do it well and do it regularly. Examples would include:

- Learn as much about your LO's injury so you know how to provide the care well but efficiently
- Work to create a daily routine so you have an idea of what should happen when. Accordingly, you will be able to identify time each day of off duty and free yourself to do things you like
- Exercise regularly if only a regular walk around the yard, block or through the shopping mall
- Schedule others to help with your LO's care so you can be away from the situation on a regular basis
- Reach out and ask for help and be involved with others

DEPRESSION

Depression is a mood disorder that affects about five percent of the general population. The frequency is higher (six -10 percent) among those with illness and disability. While most living with spinal cord injury do not experience a Major Depressive Disorder (MDD) after injury, the rate of occurrence after injury is 23-30 percent. MDD unfortunately can result in longer hospitalizations; fewer gains in rehabilitation; increased number of pressure sores, urinary tract infections and other medical complications; increased family and caregiver stress; and attempts at suicide. (Bombardier, Univ. of Washington Newsletter, Summer 2001, 10-2)

The signs and symptoms of depression include the following:

- Feeling down, blue, sad, helpless, guilty or hopeless
- Having trouble falling asleep, awakening multiple times during the night, sleeping only brief periods and then have trouble falling back asleep, and/or sleeping very long periods of time, though still feeling tired when awake
- Loss of interest in people, activities hobbies that were once meaningful or pleasurable
- Feeling irritable or angry more often than normal
- Difficulty with memory and concentration
- Little interest in getting up in the morning, less attentive to bathing, grooming and dressing
- Loss of appetite or weight gain
- Little interest in sexual activity
- Increased use or heavy use of drugs and/or alcohol
- Trying to make things better, but regardless feeling tired and unsuccessful.

You can do an on-line screen for depression at

<http://www.agingwithdisability.org/factsheets/depfactsht.htm>

Fortunately, treatments are available for depression. The most common include counseling and medication. Sitting down with a trained counselor, psychologist, clinical social worker, or marriage and family therapist has proven to be helpful to many. Antidepressant medication, prescribed by your physician, can also very helpful. Such medications, when prescribed properly, impact the chemistry of the brain to decrease many of the depressive symptoms described above. Studies indicate that treatment that employs both counseling and medication is often most helpful.

Your rehab team is sensitive and responsive to the emotional stressors related to spinal cord injury. If you or members of your family are struggling with depression, let it be known so help can be provided in a confidential professional manner.

SUBSTANCE ABUSE

It is clear that alcohol use is a significant factor in traumatic spinal cord injuries although the statistics are not totally clear. Somewhere between 17-49 percent of all traumatic spinal cord injuries are the result of the individual being intoxicated (eMedicine.com, 2005). Some studies indicate over 50% of all traumatic injuries are related to drug or alcohol use.

Abusing alcohol and other drugs can cause additional problems after spinal cord injury. When intoxicated or high, pressure relief and other self-care procedures can be ignored. The likelihood of injury from falls or hitting objects when up in a wheelchair, is increased. One's nutritional status falls. Bowel and bladder function is often negatively affected. Respiratory function is threatened and overall memory and judgement becomes impaired.

You can do an on-line screen for alcohol abuse at <http://www.alcoholscreening.org>

You can do an on-line screen for drug abuse at
<http://www.schickshadel.com/drugtesting.asp>

If you or family members have in the past, or are currently struggling with substance abuse, let it be known to someone on your rehab team or a community based professional so help can be provided in a confidential, professional manner.

BRAIN INJURY AND SPINAL CORD INJURY

At the time of spinal cord injury, it is not uncommon to also have had a brain injury. Brain injury can affect memory, your ability to concentrate and learn new material, judgment, personality, vision, swallowing, balance and coordination, and the ability to read and write, to name but a few. The severity of brain injury can be mild to severe.

Your rehab team may want you to meet with a neuropsychologist to assess your brain function and to make recommendations for treatment if needed.

REFERENCES AND RESOURCES

<http://www.caringinfo.org> - About Caregivers

<http://www.thefamilycaregiver.org> - About Caregivers

http://www.depts.washington.edu/rehab/sci/updates/03sp_alcohol.html - Alcohol and Spinal Cord Injury

http://www.depts.washington.edu/rehab/sci/updates/01sum_depression.html - Depression and Spinal Cord Injury

<http://www.emedicine.com/pmr/topic182.htm> - About Spinal Cord Injury

<http://www.madd.org/victims/9768> - Living with Spinal Cord Injury

<http://www.mageerehab.org> -- About Depression, Substance Abuse, Psychology

<http://www.images.main.uab.edu/spinalcord/pdf/17care.pdf> - About Caregivers

GLOSSARY

CAREGIVER – One who provides care and assistance to another. Caregivers may be family members, volunteers and/or hired employees.

DEPRESSION - Situational depression is a type of depression that is a fairly common response to a loss of a loved one, failure, problem, loss of a job, or some other event like injury/illness. Adjusting one's attitude or activities is very instrumental in constructively dealing with this type of depression.

A second type of depression, often referred to as a Major Mood Disorder has symptoms that include, but are not limited to, the following: too little sleep or too much sleep; change in appetite; loss of interest in happenings that were once stimulating or enjoyable; lowered sex drive; low energy; short temper; and/or no drive to do anything.

Counseling or psychotherapy may be helpful with both types of depression. For the later though, antidepressant medication is often needed.

GRIEF PROCESS - Individuals following a loss typically go through a period of grief. Some elements common to successfully moving through the process are seeing the reality of the loss, experiencing the associated emotional pain, learning to deal with the world given the physiological changes and investing in life in the present.

SUBSTANCE ABUSE – Over use of alcohol or other drugs that can result in physiological and psychological addiction, are sometimes used to deal with boredom, frustration, anger, depression and other stressors.