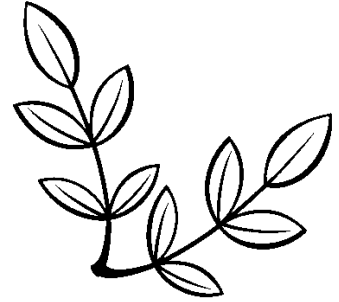
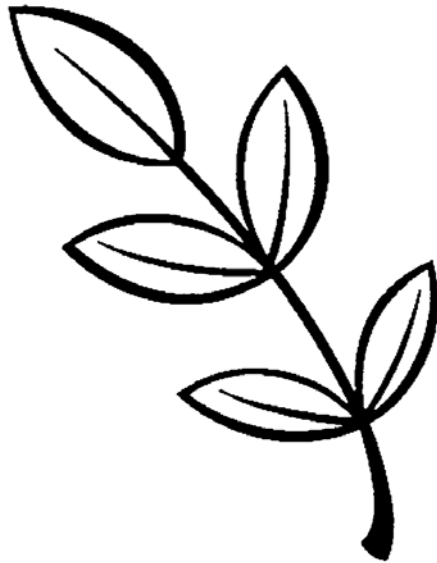


A Handbook
for



Families
about **Brain**
Injury



Produced by the health care team of the
Acquired Brain Injury Program
Hamilton Health Sciences
Hamilton, Ontario.

2003





This handbook is for families of individuals with an acquired brain injury.

It looks at the effects of brain injury on a person and his or her family.

The handbook helps the family understand what happens after a brain injury and how rehabilitation works. It also looks at what to expect in the future.

Most importantly, it gives suggestions for dealing with problems that may arise.

We recommend that you read the sections that concern you at this moment.

Refer to the handbook as needed. We hope that it will be useful to you long after your family member leaves the hospital.

This handbook is for your general knowledge only and is not intended to replace medical advice from your family member's treatment team. As health information changes rapidly, we cannot guarantee that the information provided in this handbook is accurate or complete.







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Introduction

"Will he or she be normal?"

"How long will it take?"

"What can I do?"

These questions may sound familiar to you. As a family member of someone who has just suffered a brain injury, you may feel confused, scared and worried. You may not be able to sleep or eat. You may have headaches or stomach aches. And you likely have questions about your family member's recovery.

This handbook is designed to help answer your many questions and concerns. You will learn about:

- how the brain works
- the effects of an injury
- the rehabilitation program
- your role in your family member's recovery
- strategies for coping as a family

Keep this handbook close at hand. You can go back to it many times to review the sections that have meaning to you.

Recovering from a brain injury can be a long, slow and uncertain process. Therefore, it is important for you to take care of your own well being. Taking care of yourself will help you take care of your family member.

Medical terms are explained at the back of this handbook.



Part 1: Brain Injury

In this part you will learn about:

- what a brain injury is
- the different types of brain injuries
- how the brain works
- how we know the extent of damage
- how the brain heals
- how long healing takes





What is an acquired brain injury?

An acquired brain injury (ABI) is damage to the brain which occurs after birth. It is not related to a disease, such as Alzheimer's or multiple sclerosis. An acquired brain injury can cause problems with how a person moves, thinks, feels and behaves.

There are 2 types of acquired brain injuries:

- a traumatic brain injury
- a non-traumatic brain injury

Traumatic brain injury

A traumatic brain injury occurs when the brain is injured by an outside physical force. The force may also cause the brain to bounce against the skull. This injury may be a result of a motor vehicle or other traffic accident, a fall, an assault or a sports injury.

Types of traumatic brain injuries:

- **Primary Injury (Immediate Injury)**

The immediate injury can occur in specific parts of the brain. This type of injury can result in hematomas (bleeding), contusions (bruising), lacerations (cuts), penetrating wounds and skull fractures.

More damage to the brain can also occur as the brain bounces and twists in the skull, causing shearing and tearing of the brain cells.

- **Secondary Injury (Delayed Injury)**

A delayed injury happens hours or days after the immediate injury. A delayed injury is the result of changes in the brain caused by the immediate injury. An example of this is when parts of the brain become swollen. This causes further damage due to the effects of pressure.



- **Mild Traumatic Brain Injury (MTBI)**

Loss of consciousness in MTBI is usually very brief, lasting a few seconds or minutes.

Typical symptoms include:

headache, fatigue, sleep disturbance, irritability, sensitivity to noise or light, balance problems and poor concentration and memory.

- **Moderate and Severe Traumatic Brain Injury**

These types of injuries can cause many changes to a person's behaviour, movement, thinking and personality. They involve a longer period of unconsciousness. Recovery is variable. The person may be able to do most things for themselves or need long-term help and follow-up.

In a severe trauma, the person could remain in a persistent coma or die.



Non-traumatic brain injury

A non-traumatic brain injury can result from a stroke, aneurysm, tumor, anoxia or infection, such as encephalitis.

Types of non-traumatic brain injuries:

- **Stroke**

In a stroke, blood flow to a part of the brain is interrupted or impaired. This occurs because a blood vessel is deformed, blocked or weakened. Persons most at risk for stroke include those who have high blood pressure, heart disease, diabetes mellitus, a family history of stroke, are obese or smoke.

- **Aneurysm**

In an aneurysm, a sac forms on the wall of an artery. When the sac swells or ruptures in the brain, it can cause brain injury.

- **Tumors**

A tumor occurs when there is new, uncontrolled and progressive growth of cells. This causes an enlargement. The enlargement can interfere with the normal functioning of nearby parts of the brain.

- **Anoxic Injury**

Anoxic injury occurs when the brain is deprived of oxygen, such as when the heart stops.

- **Encephalitis**

Encephalitis is a swelling of the brain, usually caused by a virus.



How the brain works

Frontal Lobe

Personality, behaviour, emotions, judgment, reasoning, problem-solving, inhibition, initiation, motivation, planning, self-awareness, word formation, planning movements, bladder and bowel control.

Parietal Lobe

Sensation, recognition of objects by touch, perception of space, strength.

Occipital Lobe

Vision.

Cerebellum

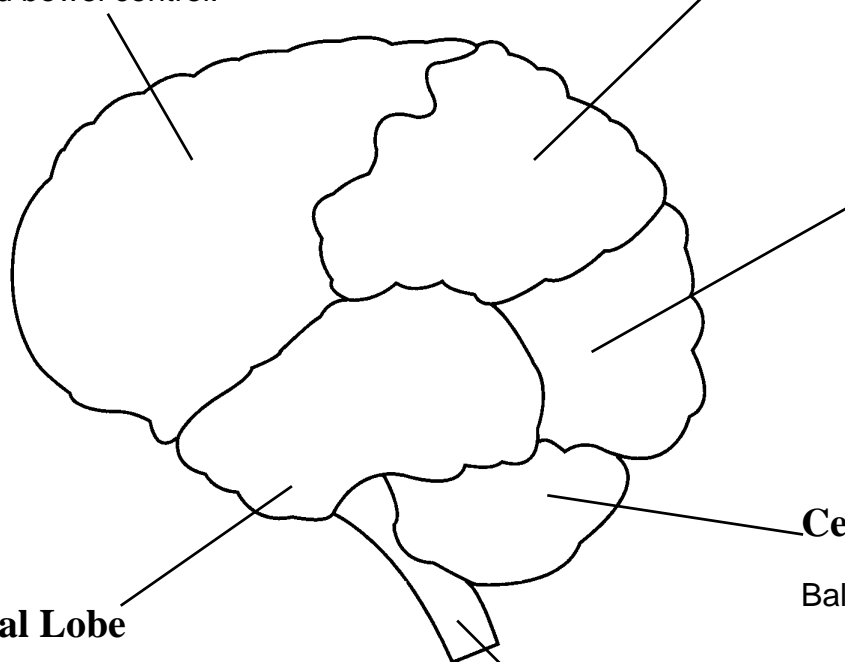
Balance, coordination.

Temporal Lobe

Perception, memory, hearing, naming of objects, language comprehension.

Brain Stem

Sensory, motor and reflex functions. Control of heart action, blood vessel diameter and respiration. Control of facial nerves, movement of eyes, swallowing, movement of and sensation on tongue. Control of sleep and wakefulness.





How do we know the extent of the damage?

Sometimes, it is difficult to tell the extent of damage early on. To identify how much damage has occurred, the health care team will review:

- the person's ability to do everyday activities
- the findings of the physical examination
- the length of the loss of consciousness
- the amount of memory loss or amnesia
- the results of medical tests
- the results of neuropsychological tests which assess thinking and personality

It is important to realize that medical tests may be limited in showing the full extent of damage. Sometimes, it's best to look at what the person can or cannot do.

Medical Tests

EEG (Electroencephalogram)

Sometimes an EEG is ordered. It measures electrical activity in the brain. This test helps to diagnose seizure risk, as well as severity, location and extent of the brain injury.

CAT Scan (Computerized Axial Tomography, also known as a CT Scan)

This is a series of x-rays which may show the location and extent of damage, and whether surgery is needed. The CAT scan may not show all of the damage from the injuries. It may also be done later on to see how the brain is recovering.



GCS (The Glasgow Coma Scale)

The GCS is a scale which measures the level of consciousness and coma. On this scale, a person in a coma:

- does not open his or her eyes
- has no motor response to a pinch
- does not utter understandable words

The severity of an injury is often described using the GCS scores. The scale is a 13 point system which ranges from 3 to 15.

GCS Score (within 48 hours of the injury)	What does it mean?
Less than 9 points.	A severe injury.
Between 9 and 12 points.	A moderate injury.
13 points or greater.	A mild injury.

Amnesia

A person with amnesia for an event is not able to consciously remember that event, even with prompting.

There are 4 types of amnesia:

1. **Post-Traumatic Amnesia (PTA)** - is not being able to remember events that happened since the injury. It refers to a gap in memory from the time of the injury, to the time a person can make continuous memories. PTA usually lasts from a few minutes to several days.
2. **Retrograde Amnesia** - is not being able to remember experiences that occurred before the injury.
3. **Anterograde Amnesia** - is not being able to consciously remember new information.



-
4. **Memory Problems** - Most people with a brain injury have problems remembering events and people since their injury. The extent of the problem will vary from person to person. Often, many memories from before the injury can be recalled, although some gaps in past memories can also occur.

How does the brain heal?

Neurons are cells in the brain that send messages to other parts of the brain and body. Damage to these neurons can be temporary or permanent. When neurons are damaged, they may:

- recover on their own
- die, which could result in the loss of certain abilities
- make new connections and take over the job of the damaged neurons

The brain can begin to heal when the swelling goes down. This can allow the neurons to start sending messages properly.

With time, the person will start to regain function. In the beginning, certain abilities may be lost. He or she will need to practice them over and over again in order to regain them. Some abilities may never be regained.



How long does it take for the brain to heal?

Recovery is most rapid during the first few months after a brain injury.

The speed of recovery in the early stages can lead the family to expect continued rapid or even complete recovery. While progress continues to be made, it is much slower in the later stages. This can be disappointing for families.

There are delayed consequences from a brain injury. These can include depression or sleep disorders. When these arise, they may slow or stop recovery, or even worsen it. Any significant slowing or worsening of the recovery should be reported to the doctor.

Recovery can continue up to 1 to 2 years after the injury. Recovery can continue for longer in some cases, but at a much slower rate.

There is no limit to learning new ways to overcome a disability.



Part 2: The Rehabilitation Program

In this part you will learn about:

- what rehabilitation involves
- who is on the rehabilitation team
- how the team works
- how long rehabilitation takes
- your role in rehabilitation





What does rehabilitation involve?

The purpose of rehabilitation is to return your family member to as much independence as possible. It involves re-teaching your family member the skills he or she needs in everyday life. This includes:

- relearning old skills
- learning ways to make up for skills that have been lost

If independence is not possible, then the focus of rehabilitation is to improve your family member's quality of life.

Who is on the rehabilitation team?

You will meet many members of the rehabilitation team. We work together to help your family member learn skills to function in the home, community, workplace or in all of these areas. You are an important member of our team. Other members may include:

- physiatrist, a medical doctor who specializes in rehabilitation
- nurses
- rehabilitation therapists
- occupational therapist
- physiotherapist
- speech language therapist
- dietitian or dietetic assistant
- recreation therapist
- respiratory therapist
- psychologist, behavioural and neuropsychology
- psychometrist
- behaviour therapist
- psychiatrist
- social worker

Check the chart on pages 17 and 18 to understand each of our roles.



How does the team work?

The health care team designs a program based on your family member's individual needs. A registered practical nurse or rehabilitation therapist will begin to work with your family member initially. During the first few days or weeks, your family member will also meet with many of the other members of the health care team.

The registered practical nurse or rehabilitation therapist works closely with your family member under the direction of the other team members. This allows your family member more time to practice his or her skills. The team monitors your family member's progress on a regular basis. For example, if a goal is to eat independently, the team will keep track of how often and how much the person eats without help. The team will also modify the program to meet the changing needs of your family member.

Some goals may be impossible to achieve. The team will talk to you about this and help to create more achievable goals.

How long does rehabilitation take?

The length of stay in the hospital will depend on your family member's goals and progress. However, the health care team will work with your family member until he or she is able to continue rehabilitation on an outpatient basis.

We work closely with you and your family member to prepare for discharge. We help to arrange community-based rehabilitation and support services. These services allow your family member to continue making progress even after leaving the hospital.

“Recovery is not so much about regaining what is lost, but loving what remains.”

The Never Ending Journey Begins



Your role in rehabilitation

We want your family member's stay to meet his or her goals and needs. Speak with the clinical coordinator or any member of the team if you have questions or if your expectations are not being met. Keep a journal to help you keep track of your questions and concerns.

We want to hear any information that you believe will help us understand your family member's unique personality and background. This valuable information can guide us in providing the best care for him or her.

As we work together, we will provide you with education and support to keep you up-to-date with your family member's care and progress. You will have the option to observe and participate in some therapy sessions.

The goal of rehabilitation is to return your family member to as much independence as possible. Most importantly, we hope to help your family member achieve the best possible quality of life.



Your Health Care Team

Team Member	How They Help
Physiatrist (Medical Doctor in Rehabilitation)	<ul style="list-style-type: none">• monitors the person's health• prescribes and reviews medications and procedures
Registered Nurse and Registered Practical Nurse	<ul style="list-style-type: none">• cares for medical and nursing needs• helps the person practice rehabilitation activities, such as bathing, dressing and eating• gives medications and teaches the person or family to manage medications• assesses and manages bowel, bladder and skin problems
Rehabilitation Therapist	<ul style="list-style-type: none">• helps the person relearn and practice skills through everyday activities such as dressing, walking, doing chores, hobbies and community outings• works with registered health care providers to determine how best to carry out these activities
Occupational Therapist	<ul style="list-style-type: none">• designs ways for the person to do daily tasks such as dressing, going to the bathroom, eating, household chores and skills needed for work• assesses and recommends wheelchairs and seating positions• completes a home assessment when possible
Physiotherapist	<ul style="list-style-type: none">• helps the person regain strength and range of motion in joints• helps the person with moving, walking, balance, fitness, strength and coordination
Speech-Language Therapist	<ul style="list-style-type: none">• helps the person with spoken and written communication problems• assesses and makes recommendations for managing swallowing problems
Registered Dietitian/ Dietetic Assistant	<ul style="list-style-type: none">• assesses the person's nutritional needs and provides a specific diet• provides nutritional education to the person and family
Recreation Therapist	<ul style="list-style-type: none">• helps to identify old interests and introduces new interests• links the person to resources in the community



Team Member	How They Help
Respiratory Therapist	<ul style="list-style-type: none">• provides breathing assessments, oxygen therapy and treatments to help reduce respiratory infections
Neuropsychologist	<ul style="list-style-type: none">• assesses and treats changes in thinking and emotion• explains the results and meaning of neuropsychological tests — these tests assess thinking and personality
Psychometrist	<ul style="list-style-type: none">• does a variety of tests to assess how the person thinks and feels• works with the neuropsychologist
Behavioural Psychologist	<ul style="list-style-type: none">• assesses and treats changes in behaviour• guides team members in how to best manage behaviour problems
Behaviour Therapist	<ul style="list-style-type: none">• works with behavioural psychologist to recommend specific ways to manage behaviour problems• suggests ways to teach more productive behaviours
Neuropsychiatrist	<ul style="list-style-type: none">• assesses problems in thinking, mood and behaviour• prescribes medication to help treat the problems
Social Worker	<ul style="list-style-type: none">• helps the person and family cope with the changes in their lives• arranges for support services in the community when the person goes home

All team members are involved in teaching and supporting you and your family members.

While the neurologist and neurosurgeon are not part of the rehabilitation team they often treat the person during the acute stage of the injury.





Part 3:

Physical Changes

In this part you will learn about some of the physical changes that could happen after a brain injury:

- movement
- joints
- pain
- senses
- speech and language
- seizures
- arousal
- weight
- swallowing
- bladder control
- bowel control
- skin
- fatigue
- drugs and alcohol





After the injury, your family member may have a number of problems. Common problems are described below.

Movement

A change in the ability to move is one of the most common problems after a brain injury. A person may have one or more of the following:

- paralysis or weakness of one side of the body
- paralysis involving one or both legs and one or both arms
- poor balance
- low endurance
- difficulty planning movements
- poor coordination
- muscle stiffness, tension or trembling
- inability to control the trunk of the body
- damage to muscle and bone tissue

Joints

As a result of chemical changes in the brain and reduced activity, extra bone may form around some joints. This is called heterotopic ossification. It may be very painful and restrict movement. People with this problem need to exercise. Medications may also be helpful.

Due to changes in brain activity, contractures could also occur. A contracture is when muscles or tendons become permanently shortened. This causes a limb to become deformed. Surgery and splints may help.



Pain

Pain and headaches can result after a brain injury. This can make it hard for the person to concentrate or remember. Pain can also affect sleep and mood.

The person may resist doing things to avoid feeling pain. To treat the problem, he or she may take pain medications and be taught ways to manage the pain.

Senses

Any of the senses such as, hearing, vision, taste, smell and touch, may change following an injury. This may be the result of damage to:

- the area of the brain that controls that sense
- the sensory organ itself, such as damage to the ear
- the nerve carrying the messages from the sensory organ to the brain

The person could have any of the following sensory problems:

- over-sensitivity to touch — this may result in withdrawing, crying, yelling or striking out when touched
- inability to feel pain, touch, hot or cold
- inability to see certain objects in view
- loss of vision, double or blurry vision, sensitivity to light
- lack of attention to one side of the body or room — this is called neglect
- changes in sense of smell or taste
- ringing in the ears, intolerance to noise
- sensitivity to movement or lack of awareness of movement
- inability to understand where limbs are located in relation to the body and surrounding space



Speech and Language

A person may have problems with communication.

Some speech problems involve:

- making sounds
- pronouncing words

Some language problems involve:

- expressing thoughts
- finding the right words
- understanding what people say

Seizures

Seizures can occur after a brain injury. They can cause a part of the body or the whole body to shake. Most often, seizures cause lapses in attention.

Signs to tell you someone may have had a seizure include changes in:

- the way a person thinks
- a person's sensations
- the way a person behaves
- a person's moods
- a person's level of alertness

These signs are important, especially if the person appears very tired after showing one or more of these signs.

Seizures may occur early after the injury, or not until months or years later. They can be triggered by drinking alcohol or using over-the-counter medications. If a person has had seizures, driving a car



is unsafe. The person may lose his or her driver's license for the time being or forever. Most seizures can be prevented or controlled by medication.

Arousal

Arousal is a person's ability to be alert. During the first stages of recovery, the level of arousal can vary from hour to hour or day-to-day. To make the most of rehabilitation efforts, the team will schedule activities during periods of alertness. Medication may increase arousal. Arousal can improve with recovery.

Weight

Weight loss right after an injury is not unusual. One reason is the high level of physical stress on the body. Another reason is that the person may not even feel hunger. To prevent further weight loss, the person may need to be reminded to eat or be provided with frequent small snacks and meals.

Later on, weight gain might become a problem. Weight gain can occur because the person can't tell when the stomach is full or forgets that he or she already ate.

Changes in activity and the way the body burns calories may cause weight gain as well. A lower calorie diet and fewer snacks can prevent weight gain.

People who have had a brain injury have the same need for nutrition as everyone else. This means eating a healthy diet based on Canada's Food Guide to Healthy Eating. Canada's Food Guide to Healthy Eating includes a balance of fruits, vegetables, meats, dairy and grains.



Swallowing

A person may not be able to chew and swallow regular foods or drink liquids. A special diet may be recommended. It may include pureed foods, such as mashed potatoes or thickened fluids. Thin liquids are harder to swallow than solids because the muscles in the throat need to contract more. Thin liquids such as water, are often not recommended.

Some people cannot eat at all or not enough to meet their nutritional needs. They will have a tube put into their nose or stomach. Liquid food is then fed through this tube.

Bladder Control

A brain injury can affect the bladder in these ways:

- the bladder may be overactive or underactive
- the person may not feel the urge to urinate or know what to do if they do feel the urge

These changes can allow bacteria to grow in the bladder, causing bladder infections. To prevent infections and flush out bacteria in the urine, the bladder must be emptied regularly.

Some ways to manage bladder problems include:

- going to the bathroom regularly
- wearing diapers, if only temporarily or when needed, such as for outings
- using a condom drainage system for males — a condom drainage system is a condom with a tube leading to a urine bag
- using intermittent catheterization where a catheter is inserted into the bladder through the urethra — the bladder is drained and the catheter is removed
- using an indwelling catheter, which is left in the bladder



Bowel Control

A brain injury can affect the bowels in these ways:

- the bowels may become overactive or underactive, causing either many loose bowel movements or constipation
- the bowels may not empty completely
- the person may not be able to communicate the need to move his or her bowels

Bowel problems often improve as the brain heals. To have regular bowel movements, the person should:

- eat a healthy diet — this includes foods high in fibre, such as whole wheat products, fresh vegetables and fruits
- drink lots of fluids — hot drinks may also help
- use a stool softener, laxative or suppository as needed
- maintain a regular routine
- keep proper positioning in a bed or chair
- maintain overall muscle fitness
- sit on a commode in an upright position

Skin

Changes to the skin are common after a brain injury. The person's skin should be checked routinely for any sores, abrasions or changes in colour. Special attention should be paid to the feet, back and buttocks. The following are common changes that can occur in the skin:

skin sores - may be caused by rubbing the skin on sheets or clothing too often or by not moving enough. When a person does not move enough, the weight of the body restricts blood flow which causes tissue to die. This can result in a decubitus ulcer. This happens most often on a bony area such as the skin over the tailbone, ankles, heels, elbows or ears.



rash - may be caused by contact with urine or bowel movements, or by sensitivity to diapers.

bruises or cuts - may be caused by improper transfers from bed to chair or neglect of a paralyzed limb.

acne - changes to the brain may signal the oil glands in the skin to work very hard. This can cause acne on the face, back or chest. Acne may also be caused by some medications.

The person's skin needs to be cleaned regularly with a shower or sponge bath. Special cushions or mattresses may be of benefit. Eating healthy foods and getting enough fluids can promote healthy skin.

Fatigue

Fatigue is common for many reasons. The body needs extra rest for injuries to heal. When the person begins rehabilitation, there is even more demand on the body's energy.

The injury to the brain can also cause mental fatigue. It can affect the person's sleep and make it harder to think and learn. A person with a brain injury can be easily overstimulated by noise and activity. An injured brain will tend to shut down when overloaded.

Some people have both physical and mental fatigue.

To improve learning, the person should rest in a quiet room when tired. The person may not know that he or she is tired and may need to be reminded to rest.

If fatigue is a problem, it may be best to schedule activities for shorter periods of time, followed by a rest period. As the person recovers, he or she may be able to do longer activities with shorter rests.

“The most difficult part of brain injury is that he cannot remember and I cannot forget.”

The Never Ending Journey Continues



Drugs and Alcohol

A person who has had a brain injury should not take recreational drugs or drink alcohol. The brain injury can affect balance, coordination and decrease control over emotions. Drinking alcohol or taking drugs:

- makes balance and coordination worse, which increases the risk of falling
- further reduces self-control
- affects recovery of brain cells

The combination of alcohol and some drugs can cause:

- seizures
- visual problems
- additional loss of brain cells
- unpredictable reactions to medications



“I wished, once again, that brain injuries came with instructions - for the survivor and for all those people that would come in contact with them. I wished for something visible, something that would give undeniable proof that I had been hurt... damaged... changed. I wished for something that would relieve me of the responsibility of always having to prove that my differences were not an intentional ploy to get people’s sympathies or mere laziness; that just because the injury couldn’t be seen or touched didn’t mean it didn’t exist. I wished I could show them the anger, the loss, the grief that I feel each time someone expects me to ‘snap out of it’ or tells me that I could control the problems if I really wanted to.”

Through this Window: Views on Traumatic Brain Injury





Part 4:

Levels of Recovery and How the Family Can Help

In this part you will learn about the different levels of recovery:

- what the levels can tell you
- how to recognize them
- what you can do to help





Levels of Recovery and How the Family Can Help

The following levels of recovery were developed by the Rancho Los Amigos Medical Center. They are used to describe a person's recovery from a brain injury:

Level I	No Response
Level II	Generalized Response
Level III	Localized Response - Inconsistent
Level IV	Confused - Agitated
Level V	Confused - Inappropriate - Non-agitated
Level VI	Confused - Appropriate
Level VII	Automatic - Appropriate
Level VIII	Purposeful - Appropriate

Persons with a brain injury move through the levels at their own rate. Some people may:

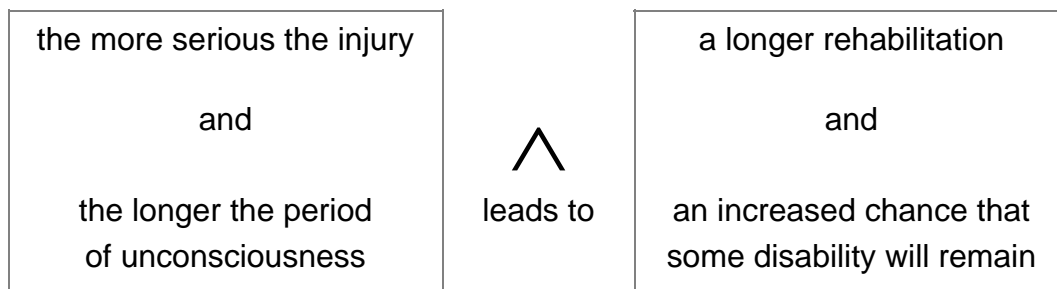
- move from one level to another
- never be at the lower levels
- never reach the higher levels
- be in more than one level at the same time

The levels describe a pattern of recovery. How fast and how much the person recovers are affected by many things, such as:

- type and severity of the injury
- length of coma
- other injuries
- complications
- age and general health of the person



In general,



The levels of recovery are described on the following pages. Find the level that most suits your family member and start from there.



Rancho Levels I & II & III: Little or No Response to Surroundings

What you see:

- moans or moves to touch or pain
- people or noises may or may not get a response
- may follow simple commands
- may be agitated

What you can do:

- Touch and talk to your family member to improve awareness. Stimulate only when he or she is awake and for short periods of time.
- Speak in a calm, slow, normal voice.
- Let the staff know all about your family member, including his or her job, hobbies and interests. Put it in writing if possible.
- Make sure you meet the team and feel free to ask questions. Remember that a lot of answers are not known early in treatment.
- Although your family member may not understand everything that is being said, do not discuss medical concerns as if he or she were not there.
- Ask the team about ways to stimulate the senses:
 - to stimulate taste, a Q-tip[®] can be dipped in lemon, mint or salt and touched to the tongue
 - to stimulate smell, hold some garlic powder, shaving lotion or peanut butter under the nose
 - say what it is and ask your family member to indicate if he or she can taste or smell it
- Play music that your family member would enjoy. See if you get a reaction when the music is turned on or off; don't leave music on all of the time or it will become meaningless background noise.
- Make one-step requests, such as "lift your finger", and wait at least 5 seconds for a response.



- Each time you see your family member, say who you are, the date, and where you are. If advisable, let him or her know what caused the injury.
- Record your family member's progress in a journal.
- You may need to limit the number of visitors to no more than two at a time. Encourage them to leave messages in the journal.
- Ask questions that require a simple answer such as "yes" or "no"
- Try to find what your family member can do to communicate "yes" or "no". Consider using eye blinks, head nodding or a thumbs up/ thumbs down signal.
- Ask your family member to focus on an object, sound or person as they move from side to side. This is called "tracking".
- Talk about familiar people and things. Bring in the family album and pictures of objects to help explain your conversations.
- Help your family member do routine activities, according to his or her ability or as indicated by the treatment team.



Rancho Level IV: Confused - Agitated

What you see:

- may be confused
- seems more aware of information, but still unable to make sense of it
- can get easily agitated: may swear, hit or shout

What you can do:

- When your family member is not agitated, use this time to help him or her respond. As an example you may make simple requests, such as "hold my hand" or "look at me". Be sure that the room is quiet and reduce distractions when possible.
- Help your family member practice daily tasks, such as brushing teeth. Use the scripts or steps outlined by the team.
- Be as active as possible in rehabilitation so you can learn how best to work with your family member.
- Talk quietly in simple words and sentences. Have only one person talk at a time.
- Limit the number of visitors at a time and reduce the amount of noise and activity. Too many things happening at once causes confusion.
- Correct wrong responses gently, but clearly. If your family member continues to give the wrong response, don't argue and change the topic instead.
- Do not leave your family member alone if agitated or in danger of hurting him or herself, or others.

Rancho Level V: Confused - Inappropriate and Rancho Level VI: Confused - Appropriate

What you see:

- memory improved but still some confusion
- needs instructions and cues to do tasks
- simple problems can be solved but still needs supervision
- poor judgment about limitations and situations
- social behaviour can cause embarrassment
- appears self-centred

What you can do:

- Talk about family and friends. Photo albums may be a way to stimulate memories.
- If both you and the team feel that your family member is ready, tell him or her any painful information related to the accident, such as if someone else was killed or badly injured. The person's upset may be temporary. While he or she can understand facts, the ability to grieve returns much later.
- Help your family member recall information that is not easy to recall. Ask a question and if the correct answer is not given, provide some clues. If clues don't work, then give the missing information.
- Ball games and simple card games are all good for learning. If your family member's performance is inconsistent, be patient.
- Your family member may sometimes confuse kissing, hugging or stroking as sexual messages. If he or she is sexually inappropriate, say so in a matter-of-fact way. If your intention is only to show affection and encouragement, use verbal praise and limit physical contact to pats on the shoulder or pecks on the cheek.



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- Praise everything that your family member is able to do. Do not overwhelm him or her with more than one task at a time. It may lead to frustration and aggression.
 - Help with "homework" that is given by the team. Either help your family member write in a journal or write your own observations and interactions in the journal. This can be helpful to team members.
 - Your family member may need to rest during the day, but may not realize it. Don't ask if he or she is tired. Instead, keep the activity level moderate and schedule rest periods.
 - Ask your family member to tell you about things immediately after they are done. Ask what he or she watched on television and have the person record this if possible.
 - Your family member may not be able to sort out events, times or actual occurrences after being unconscious. Calmly and gently distinguish fact from fantasy. Do not argue about false beliefs he or she may have. Instead, distract the person from the conversation.
 - Every day tasks may still be difficult. Ask your family member to describe the steps involved in a particular task, such as making orange juice, then have him or her do it.
 - Slowly increase independence.
 - To speed recovery, keep things simple, consistent and maintain a routine.

Rancho Level VII: Automatic - Appropriate

What you see:

- functioning almost normally
- mostly independent at home
- insight and judgment are poorer than before the injury
- thinking and problem-solving are slower than before the injury
- needs help with new or complicated tasks

What you can do:

- Discuss safety and emergency measures with your family member. Have him or her tell you what to do to avoid dangerous situations.
- If there are problems with memory or the person is easily distracted, encourage your family member to write things down.
- Encourage your family member to make a list of things to do everyday.
- Try to do activities together, such as using a map or going grocery shopping.
- Work on a computer to help your family member follow steps and instructions.
- Ask the team about useful programs and activities. Learning how to follow steps can be applied to other tasks such as cooking.
- Make sure your words, actions and gestures are all clear and consistent. Teasing and sarcasm can be misunderstood.
- Do not let your family member drive a car, take a boat out alone or operate any dangerous equipment unless this activity is approved by the doctor.
- Involve your family member in choosing activities. This will help improve thinking skills.
- Be patient and creative. Involve the person in planning the activity.



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- Your family member may be blurting out what is on his or her mind without regard to social manners. Offer calm and gentle feedback for such behaviour.

It's tough, it's trying... it takes a lot of energy. Real issues like running the gas lawnmower. Is he OK to do that? What if he wants to drive the boat? How do we tell him he can't? Things you don't think about while you're in the hospital. And even two years later you're still learning things... learning new things about it. Things are popping up. Problems he had two years ago he doesn't have now, but he has different ones. And so it's always kind of... just when you think you're getting into a groove, everything changes on you.

Forever Different: Experiences of Living with a Sibling who
has a Traumatic Brain Injury

Rancho Level VIII: Purposeful - Appropriate

What you see:

- more able to learn new information
- able to plan and carry out most activities independently
- able to manage most social situations
- less able to reason, tolerate stress and use good judgment in unusual circumstances than before the injury
- some problems with thinking and memory may remain

What you can do:

- Keep the physical and mental limits of your family member in mind. Encourage him or her to get involved in various activities in the home or community, at a pace that is comfortable.
- Help your family member make schedules and reminder lists to manage time and remember important tasks.
- Encourage his or her participation in taking the correct dosage of medications at the proper times.
- Encourage your family member to do activities on his or her own, such as taking public transportation or balancing a chequing account.
- Keep the daily routine stable. Frequent changes can cause confusion, frustration or fatigue.
- Watch out for your family member when it comes to situations requiring insight. Others may take advantage if he or she is naïve and open to peer pressure or suggestions.
- Avoid sayings or clichés. They may seem confusing to a person who understands most things in a concrete way. For example, instead of saying: "killing two birds with one stone", it's better to say: "getting two things done at once".



- Give feedback and explain things in a calm manner. Your family member may make the same mistakes over and over again. Generalizing from one situation to another may be difficult. Calm feedback and explanation can help the situation.
- Do not compare your family member to how he or she was before the injury.
- Throughout everything, be patient.
- Encourage and reward independence, yet provide support and feedback in more difficult situations.

“I look back to when it happened... so it’s really just turned our lives kind of upside down, but I would say that since about late fall we’ve kind of been getting more back to normal - like not really normal, but we’ve all kind of gotten into a rhythm at home that wasn’t there for a long time. I think that our pace has slowed down a little bit. Well, instead of going out a lot and rushing off to this show or that show or going away for the weekend or having people over to dinner ... not as much of that is happening, not because we’ve lost friends or we feel unsociable or something, its more because we sort of like relax more and enjoy each other’s company.”

Forever Different: Experiences of Living with a Sibling
Who has a Traumatic Brain Injury





Part 5: Changes in Emotions and Behaviour, and How the Family Can Help

In this part you will learn ways to deal with the different emotions and behaviours you may see in your family member. These include:

- agitation
- confusion
- denial
- depression
- disorientation
- egocentricity
- emotional instability
- excessive eating
- excessive talking
- forgetfulness
- high sexual interest
- impulsivity
- irritability
- lack of motivation
- low sexual interest
- non-communication
- perseveration
- restlessness



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- sleeplessness
 - social dependence
 - suspiciousness
 - temper tantrums
 - varying alertness
 - verbal outbursts



Changes in Emotions and Behaviour, and How the Family Can Help

This chart describes some of the problems that may occur after a brain injury.

Some problems only occur in more serious injuries.

The chart gives you general guidelines for dealing with these problems.

Use your judgment in deciding whether they are useful. How you deal with a problem will depend on the person, place and situation. Your comfort in using the strategies is also important.

Ask a professional for advice if you are unsure.

Behaviour or Emotion	What You See	How You Can Help
Agitation	<ul style="list-style-type: none">• alternates between being hyperactive and sleeping• cries, yells, flails arms or thrashes in bed• hits others• is self-destructive	<ul style="list-style-type: none">• touch or talk to the person during periods of attention• ask simple, short questions• limit the number of distractions to create a quiet setting
Confusion	<ul style="list-style-type: none">• is inattentive• is forgetful• asks questions over and over again	<ul style="list-style-type: none">• give one step instructions• use memory "tools" such as a calendar or date book• repeat answers patiently



Behaviour or Emotion	What You See	How You Can Help
Denial	<ul style="list-style-type: none">• does not admit to changes or problems• believes is ready and able to do things that he or she did before• makes excuses for not completing tasks• manipulates others into performing tasks	<ul style="list-style-type: none">• tell the person calmly that he or she is in denial• if it is not dangerous, let the person try a desired activity• once you feel the person is ready, show that an "impossible" activity is simple to do• make sure that lack of confidence or ability is not the real root of the problem
Depression	<ul style="list-style-type: none">• cries frequently• lacks interest in life in general• appetite and sleep patterns are changed• lacks motivation• withdraws from social contacts• talks about dying	<ul style="list-style-type: none">• if symptoms persist or suicidal thoughts are expressed, seek professional help• use activities and exercise to get the person's mind off depressive thoughts• give praise for progress made• try to engage the person in activities that he or she can tolerate or enjoy
Disorientation	<ul style="list-style-type: none">• talks in a disorganized, disconnected way• mixes fact and fantasy• isn't aware of location, date, own identity or identity of others• mixes up time periods	<ul style="list-style-type: none">• review details like who and where you are, date, and so on• talk about familiar things and people• use calendars, pictures and favourite music to orient the person



Behaviour or Emotion	What You See	How You Can Help
Egocentricity	<ul style="list-style-type: none">• is self-centred and insensitive• misinterprets other people's responses or actions	<ul style="list-style-type: none">• do not allow the person to get everything he or she wants• do not expect the person to respect your rights — you may have to demand them• get the person involved with a brain injury support group
Emotional instability	<ul style="list-style-type: none">• can't control emotions• expresses emotions at the wrong time and in the wrong place• has mood swings	<ul style="list-style-type: none">• do not criticize• praise the person when he or she shows self-control• do not confront the person about this behaviour — it may cause embarrassment• model calm behaviour yourself
Excessive eating	<ul style="list-style-type: none">• constantly eats• secretly eats• doesn't remember eating• frequently complains of hunger despite having recently eaten	<ul style="list-style-type: none">• seek medical advice• provide other activities, such as exercising or hobbies
Excessive talking	<ul style="list-style-type: none">• talks constantly• doesn't remember previous discussions• can't come to a conclusion or solution• can't break the cycle• can't take turns in a conversation	<ul style="list-style-type: none">• redirect the person's attention to a task• if the talking seems related to anxiety, tolerate some talking• do not feel obligated to respond• suggest listening to music



Behaviour or Emotion	What You See	How You Can Help
Forgetfulness	<ul style="list-style-type: none">• forgets to complete tasks• can't remember events since the injury or certain periods of time before it• recalls information slowly	<ul style="list-style-type: none">• provide a quiet, calm setting• correct wrong answers gently• give clues to remind the person• when clues don't work, tell the person the missing information• use signs or other visuals to reinforce what needs to be remembered — include a memory book, calendars and clocks or watches• exercise the memory by asking for a recap of events or activities• try not to interrupt — the person may forget what he or she wanted to say
High sexual interest	<ul style="list-style-type: none">• makes inappropriate remarks to the opposite sex• manipulates the necessity for physical contact• makes sexual advances• becomes threatening when the partner is not willing to be sexually involved	<ul style="list-style-type: none">• tell the person that his or her behaviour is not acceptable• make him or her aware of the consequences of such behaviour• do not feel obligated to respond to the person's sexual demands• inquire into medication and counselling• discuss self-gratification options• if necessary and where possible, remove yourself or the person



Behaviour or Emotion	What You See	How You Can Help
Impulsivity	<ul style="list-style-type: none">• tends to speak or act first, think later• acts on inappropriate or confused thoughts• is excessively demanding	<ul style="list-style-type: none">• set short-term rewards for brief periods of self-control• suggest more acceptable behaviour
Irritability	<ul style="list-style-type: none">• gets angry quickly• worries about small things• can't interpret situations accurately• can't perform simple tasks well	<ul style="list-style-type: none">• do not confront your family member on the bad mood• provide a calm, relaxed setting• where possible, do things that irritate the person somewhere else, for example play music in another room• don't take the bad mood personally
Lack of motivation	<ul style="list-style-type: none">• is unable to plan activities• has no desire to do any activities	<ul style="list-style-type: none">• help the person to make decisions• give the person a choice between two activities• break down an activity into smaller steps• find activities the person might enjoy• help the person find a role to play that contributes to the family• understand that the lack of interest or motivation may be due to brain injury and avoid getting angry with the person



Behaviour or Emotion	What You See	How You Can Help
Low sexual interest	<ul style="list-style-type: none">• avoids sexual advances• does not dress or groom attractively	<ul style="list-style-type: none">• do not take partner's disinterest personally• do not pressure him or her into a sexual relationship• remind yourself that disinterest may come from lack of confidence or low sex drive resulting from the injury
Non-communication	<ul style="list-style-type: none">• occasionally appears interested in the surroundings but can't communicate thoughts and wishes	<ul style="list-style-type: none">• try using eye blinks (1=yes, 2=no), picture cards or written signs to help the person communicate• keep communications short and simple• use questions that have a "yes" or "no" answer
Perseveration	<ul style="list-style-type: none">• obsesses on a particular idea or thought• stays on one topic for a long time	<ul style="list-style-type: none">• if possible, ignore• redirect the person's attention to a new idea• reassure him or her• praise the person's progress to reduce anxiety
Restlessness	<ul style="list-style-type: none">• constantly moves• can't sit still• paces	<ul style="list-style-type: none">• try to find things for the person to do• do not leave the person alone• sometimes you may need to tolerate excessive talking —this will help the person to work through agitation• model calm behaviour



Behaviour or Emotion	What You See	How You Can Help
Sleeplessness	<ul style="list-style-type: none">• gets up in the middle of the night• sleeps during the day• is hyperactive	<ul style="list-style-type: none">• keep your family member active during the day• save calming activities for the evening• gradually reduce length of naps and increase activity• keep bedtimes and waking times the same everyday, even on weekends• avoid caffeine, exercise and emotionally or mentally challenging activities before bedtime
Suspiciousness	<ul style="list-style-type: none">• falsely thinks people are doing things to, or talking about him or her• misinterprets people's actions	<ul style="list-style-type: none">• ignore accusations• do not argue or defend yourself• report any paranoid statements to the team
Temper tantrums	<ul style="list-style-type: none">• can't express feelings• can't control impulses• gets angry about trivial things	<ul style="list-style-type: none">• do not hold grudges• protect yourself by leaving, if necessary• do not display fear• say what you think he or she may be feeling
Varying alertness	<ul style="list-style-type: none">• has alternate periods of alertness and unresponsiveness• may respond to simple commands• may try to turn or push away nursing care	<ul style="list-style-type: none">• stimulate only when the person is awake, using all the senses• speak in a calm, slow voice



Behaviour or Emotion	What You See	How You Can Help
Verbal outbursts	<ul style="list-style-type: none">• blurts out thoughts even if it is rude• curses excessively• thinks or speaks inappropriately	<ul style="list-style-type: none">• do not take it personally• ask for help if he or she is upsetting you• when possible, ignore it• redirect the person's attention to something else• be direct about your feelings, but not critical. An example is to say, "My feelings are hurt when you talk to me this way."

Brain injury support groups can help you find ways to respond to new and challenging behaviours. Some support groups have meetings just for families. We recommend that you check out this option.





Part 6: Family Recovery

This part describes the experiences of the family:

- what you may be feeling
- words you might hear yourself say
- coping problems
- role changes in the family
- coping with changes in family roles
- adjustment
- coping with a family member who is "slow to recover" or "minimally responsive"





What you may be feeling

Although your family member has had an injury, you and your family are also suffering.

Your stress is not just emotional, but often physical and financial as well. You may have feelings or say and do things that you never thought possible. This is common.

This section will describe the experiences that many families go through. We hope it will help you feel less guilty and confused about your feelings. You will also learn some new ways to deal with the situation.

Frustration and anger

Your family may feel frustrated about the many things that are out of your control. Some examples are:

- you may feel that your expectations have not been met — for instance, your family member's progress may slow down and seem to stop
- you may grow angry toward the hospital staff — you may believe they are not doing everything they can to make your family member better
- you may feel that your family member is not trying hard enough

Sometimes a family thinks that if everyone would try harder, full recovery could be made and the ordeal would be over. It's not easy to come to the realization that recovery may be life-long. While this realization brings on sadness and grief, it is the beginning of a family's adjustment to the situation.



Feelings of grief

Your pain and grief may be very similar to that of having a death in the family. In fact, some say that dealing with a brain injury is just as difficult or more difficult. The person you loved and may have previously depended upon is now a "new" person, with a different personality, abilities and goals. Your family must accept that the person you knew may never be returned to you. This dramatic change can put your family on a roller coaster of emotions. At the same time, you may feel that you have no time to deal with these feelings because your family member needs immediate attention.

The roller coaster of emotions

Your emotions can swing wildly over time. You may even feel opposite emotions at the same time. These are some of the feelings you may have:

- **Shock, denial or numbness**

Families often feel shock, denial or numbness when first told of the crisis. They may think, "No, this can't have happened".

This numbness can protect them during the early stages. They do not feel the full impact of the crisis all at once. They are still able to make necessary decisions.

- **Gratitude and hope**

When families learn that their family member will live, they feel gratitude and hope. However, they do not know that this is only the beginning of the struggle towards recovery.



- **Anxiety, fear and anger**

As time passes, the severe nature of the injuries becomes known. Hope for the future is less certain. Families begin to realize that there might be long-term effects from the injuries. They begin to feel anxiety and fear. The health care staff cannot give definite answers to their questions. This makes their anxiety worse. Families can feel a great deal of anger about all of the changes in their lives.

- **Mourning and acceptance**

To deal with the "new" person who emerges after a brain injury, families must mourn the loss of the "old" person that is gone from them. Eventually, families may come to accept the changes and adjust to the situation as it is.

Other losses

Your family may suffer other losses, such as:

- companionship and support
- income
- future plans and dreams
- familiar routines
- sense of identity and security
- feeling of being in control of life

It is natural to mourn these losses. It can be very difficult because the person is still around to remind you of the losses. You may choose to view the person you knew before the injury as being dead. You may say, "I grieve for the person I lost. I am learning to accept the new person who has replaced him".



“My relationship with my wife has grown immensely. We have changed our priorities, as life is too precious. Sometimes, we just lose perspective. My injury has given me a new beginning. I now appreciate things a lot more.”

Through this Window: Views on Traumatic Brain Injury

The meaning of the injury

The meaning of the injury will be different for each member of the family. Each person may react in different ways. There is no right or wrong way to feel. Some may feel conflicting emotions at the same time. They may feel grateful that their family member survived, but angry that the injury has changed the person they knew.

The process of grief is not neat and orderly. It may feel like taking two steps forward, then one step back. It is a constant challenge to adjust to all of the unknown and uncertain losses, especially within the first one to two years.

Reaching a plateau

Your family member will reach a plateau. This is where changes occur at a much slower rate. Your family may begin to accept that this is the way your life is going to be. However, grief may occur many times over. It can be triggered when you are starting a new stage of life. Here are two examples:

1. It is the beginning of September and your son dreamed of starting college last fall. You dreamed of his success. Because of his injury, it is now impossible and you feel grief over the loss of this dream.



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2. While the children were small, you dreamed of travelling when you retired. Your adult daughter was injured and now you look after her. You are preparing for your retirement and cannot travel as you had hoped.

While you are grieving many losses, so is the one who has suffered a brain injury. As your family member recovers, he or she will become more aware of the losses. The person may begin grieving at a different time than everyone else. It may happen just when you and your family feel that you can get on with life. It is difficult when people are at different stages of grief.

Words you might hear yourself say

Denial

- “I don't want to think about it.”
- “Everything is fine, not much has really changed.”
- “She’s always been like that.”
- “The staff talk about differences in his thinking, but all he really needs help with is walking.”

Sadness

- “I miss my old husband so much.”
- “I cry when I think of how things used to be.”
- “It hurts to think that she'll never be the same again.”

Anger

- “It's not fair, we don't deserve this.”
- “Why us?”
- “He should have known better than to drive in that condition.”



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- “How did the driver walk away from the accident and our son almost get killed?”
 - “How dare the staff talk to us about a wheelchair for her?”

Depression

- “There's no pleasure in our lives anymore.”
- “I can't seem to make any decisions and I'm getting forgetful.”
- “I never feel like eating and I don't sleep well.”
- “Life isn't worth living anymore.”

If you develop symptoms of depression, please seek help.

Despair, hopelessness or helplessness

- “What's the point of going on like this?”
- “I can't do anything that will make a difference.”
- “There's no hope for the future. I give up.”

Guilt

- “If only I had called a taxi instead of letting him drive.”
- “How could I have yelled at him? It's not his fault.”
- “I feel so trapped. I wish he had died. How could I think that way?”
- “I spend so much time with him at the hospital that I'm neglecting my kids at home.”

Anxiety

- “We always feel on edge because he could blow up at any time.”
- “I feel as if I'm walking on eggshells around her all the time.”
- “I have to look after him and the kids, pay the bills, try to budget for the future and I never have enough time for anything.”
- “I always worry that she'll be taken advantage of and end up pregnant.”



Resignation

- “This is our life now.”
- “We know that we'll never have our old lifestyle back again.”
- “We have stopped looking for another rehab program for him to go to after he's finished this one.”

Adjustment

- “We've learned how to cope with the changes in our lives now. We've found a way to deal with the new roles and responsibilities we have.”
- “We go with the flow, we have good days and bad days, but we're getting on with our lives.”
- “She can't handle all her courses now, so she's doing one course at a time and is getting help from special services.”
- “Life is different, but there are still many good things about it.”

I realize now this emptiness I feel inside, is as much about losing me, as it is about losing him. I miss him, but even more, I miss the way I used to feel when we were together.

The Never Ending Journey Continues: Despair, hopelessness or helplessness

Coping problems

Do some families have trouble coping?

Yes, some families find it hard to cope. Here are some situations that could happen.



Denying what's wrong

Denial is one way of coping. It can be helpful in the beginning. After all, there is nothing wrong with optimism. Denying that the person will never be the same may relieve some of the pain and suffering. But if denial continues for a long time, it could prevent the family from seeing what is really going on. An example is when the family becomes too concerned about one type of skill such as walking. They may be tempted to ignore "invisible" problems such as forgetfulness.

It is important that the family and the team agree on the problems and arrive at common goals. Otherwise, the family may become frustrated with the rehabilitation process.

Expecting too much or too little

The family may expect too much from the person. The family may want him or her to get better, often faster than he or she is able. This may result in the person returning home too early. In this way, the family can set the person up for failure.

On the other hand, the family can expect too little of the person. The family may do too much. This can prevent the person from learning needed skills and becoming more independent.

Before they know what's happened, the family can make the person the centre of their lives. If everyone in the family does things for the person to make things easier, it encourages him or her to be dependent on others. The person can resent this, and so in time, can other family members.

Losing contact with life

You have put the needs of your family member first. As a result:

- you may lose contact with friends and withdraw from the outside world
- you may stop taking proper care of yourself and begin eating and sleeping poorly
- your ability to tend to your roles and responsibilities may suffer



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- your new responsibilities may drain your energy
 - you may even withdraw from your family member to keep from having to always face the changes and the loss

If you notice any of these situations in your family, please talk to a professional, or to someone you trust.

Role changes in the family

After the brain injury, you may have to handle situations that you have never faced before. You may have to behave in different ways. Under the strain of everything new, it is natural to feel distressed.

The Partner

Sometimes you may see your partner behave in an unexpected way. This can increase your anxiety and fear of uncertainty. An example of this is a man may act in a childish way. His wife may say, "It's like having another kid at home." She may have to take on roles she never had before. Their intimate relationship may also change where she becomes more of a caretaker than a partner.

Children

Children are also affected. They may become confused if their mother or father acts differently. They will sense their parent's stress and grief but not know what to do about it.

It may help for the whole family to talk about their feelings. It is important to include the children in treatment.

It is also important to remember that children are still children. Do not give responsibilities that are too difficult for them. They still need attention from their parents. Children's needs can easily get disregarded when the family's attention is on the person who has been injured. If you are a



parent and feel that you cannot give your children what they need, ask others for help until you are able to be a full-time parent again.

Parents

Roles change during the life of the family. It is expected that when children grow older, they will leave home to start their own lives. The parents learn to live alone as "empty-nesters" and later retire. If an adult child is injured, parents may become caregivers again and put retirement plans on hold.

“To be sure, I grieve for and miss the old Gary. There are times when I see a certain smile, hear a particular laugh, detect a gesture reminiscent of the old Gary, and tears flow spontaneously. But I also love the new Gary, and I can truthfully say that our lives would be empty without him. With him, we are a family again - perhaps a slightly dysfunctional and unconventional family, but a family nonetheless. He has transformed carefree parents into more caring parents. He has given new meaning to our life, a reason to start each day, to stay strong and healthy. This acceptance, this transformation, this resolution didn't happen overnight. It has taken years. Time is a masterful healer.”

Brain Injury: A Family Tragedy



Coping with changes in family roles

How do you cope when family roles have changed?

There are many ways that family members cope with the changes in their lives. Be prepared to learn some new ways of coping. Here are some suggestions:

✓ **Share the work**

Each person should fill part of the injured person's role as best as possible. This can help your family adjust to your new day-to-day reality.

✓ **Protect your own physical health and mental well-being**

If not, you may become emotionally overwhelmed by the uncertainty of your future.

✓ **Find a focus outside of the family**

Leisure activities, hobbies and friendships can provide the balance you need in your life.

✓ **Get help and support**

If you need help to adjust to all the changes, contact the hospital social worker or a brain injury support group. You may want to talk to other family members, a close friend, your religious leader or other staff at the hospital.

Changes in the roles of family members do not come easily. They are often emotionally and physically stressful. Accept all the help that you can get.



Adjustment

Will you adjust?

You are going through a wide range of feelings and reactions. At some point, you may accept the changes in your family member's life. You may not like the changes, but have come to terms with them. Even so, there may always be moments of sadness.

The new feelings and reactions that you are experiencing are normal. Families can forget that they are recovering from a traumatic experience as well.

You need to take care of yourself if you plan to take care of your family member.

What if your family member is "slow to recover" or "minimally responsive"?

If your family member is described as "slow to recover" or "minimally responsive", then he or she will have little change over time. Your family member will also have a wide variety of needs. Your experiences will be unique.

Your family member may come to rehabilitation from an acute care hospital, a chronic care unit or from home. You may feel some anxiety about coming to the rehabilitation program.

If the injury is recent, you may feel overwhelmed. You may also be frustrated by the lack of information about your family member's prognosis.

If the injury is not recent, you may have had a mixture of good and bad experiences with the health care system. You may feel that you have not been given enough answers. Some answers may contradict others. This can



lead to distrust and unrealistic expectations. You may also feel worn out from advocating for your family member.

If your family member has come from home, you may not want to give up the control that you are used to having. Giving over the care to the hospital may feel threatening. At the same time, you may be secretly relieved that the constant stream of health care professionals are gone from your home for the time being. You have some privacy again.

Challenges

Although your family member should be medically stable at this point, the challenges he or she faces are extraordinary. There are high nursing needs. Your family member requires 24 hour care and has little control over movement. The best combination of medications may not have been found yet. He or she may have:

- a G-tube for feeding and a tracheostomy
- seizures and spasticity
- problems with pain, breathing, vision and hearing
- incontinence, dental problems and heterotopic ossification

Your family member may be unable to speak to you. He or she may act inconsistently and be easily distracted. Periods of alertness come and go. You may be unsure about how to read movements and facial expressions. You cannot tell how he or she perceives the world and experiences emotion. Often, you are left to guess, based on the patterns you see over time.

Discharge

As your family member's treatment is known and understood, preparation for discharge will begin. The "slow to recover" person will need a large amount of help. You may find that community resources are limited, even with private insurance funding. This can lead to financial worries and fears that your lives may be permanently disrupted. Your family must make hard choices about how best to care for your family member in the long term.

Different discharge options include returning home, going to another hospital or a nursing home. Going home may cause a stream of



professionals to move through your house, which takes away your privacy. Discharge to anywhere else may involve loss of control over the care of your family member and require regular travelling. Discharge options will be discussed in the next chapter.

Balancing needs

You may be forced to balance your needs with your family member's needs. There may seem to be no solutions without drawbacks. Nothing may seem to make life feel normal again. It is helpful to consider the following when making your decision. Your family member needs:

- somewhere to live
- someone to care for his or her needs
- something to do
- someone to love

Ways to reduce anxiety

While your family member is in hospital, there are ways to reduce your anxiety:

- Ask questions and state your worries to the team.
- Use your time in family-team meetings to full advantage. Write down your questions before the meeting so that you are prepared.
- Know that you are considered part of the team because you know your family member better than anyone else.



- Accompany your family member to therapy sessions. You will be better able to understand the problems and their solutions.
- Take part in outings and special activities.
- Read what you can. Contact the Ontario Brain Injury Association and your local support group for information and support.

The role you play

Be clear about the vital roles you play in the rehabilitation process.

Role You Play	How It Helps
Source of Information	helps the team to understand your family member
Main support	provides your family member with steady doses of comfort and encouragement
Advocate	ensures his or her needs are being met
Planner	makes the final decisions about what is financially and emotionally realistic for you and your family

Your family may be amazed at your ability to adjust to the situation. Over time, most families find a way. Remember that you don't need to do it alone. Banding together with other families, attending brain injury support groups or talking to professionals can help you through this.



Notes





Part 7:

Towards the Future

In this section, you will learn about:

- discharge options
- community supports
- legal supports
- financial supports
- returning to school
- returning to work
- love, sex and intimacy
- quality of life





Discharge options

What are our discharge options?

Where a person goes to live after discharge varies. Options include:

- home
- a publicly funded residence, such as a supported independent living apartment, group home, lodging home, nursing home or chronic care centre
- a private inpatient rehabilitation facility or residence

Community supports

What kind of support can we expect from the community?

There are services in the community which provide ongoing support. They are available to people who return home or to a residential facility. They include:

- medical, psychological or psychiatric services through specialized outpatient clinics
- private or public agencies providing case managers, therapists, nurses and home support workers
- family doctor and medical specialists
- vocational rehabilitation services
- brain injury support groups

Legal supports

What about legal supports?

Depending on how the injury took place, you may benefit from working with a personal injury lawyer. A personal injury lawyer may be able to file a lawsuit to obtain additional payments and services.



You might also speak to a personal injury lawyer if you are wondering whether your insurance company is acting fairly. If you think you may benefit from having a lawyer, contact The Law Society of Upper Canada for a listing of personal injury lawyers in your area. The Law Society can be reached at 1-800-268-8326.

It may be helpful to talk to people who have already gone through a similar experience to find out how their cases were resolved. Also, the Insurance Bureau of Canada can answer general questions about insurance rights at 1-800-387-2880.

Financial supports

What financial support is available?

If your family member was injured in a car accident, your insurance company will provide financial support. Depending on the severity of the injury, you may receive benefits for:

- lost income
- attendant care in the home
- medical and rehabilitation services and equipment
- expenses such as housekeeping, home maintenance and certain items that were lost or damaged as a result of the accident

For more information, call your insurance company, a personal injury lawyer or the Insurance Bureau of Canada at 1-800-387-2880.

If your family member was injured at work, the Workplace Safety and Insurance Board, formerly Workmen's Compensation Board, can provide financial support and rehabilitation services.

If you were employed full-time, you may have short and long term sick benefits available to you through your workplace.



Your family member may also qualify for these government programs:

- Canada Pension Plan Disability Benefits
- Unemployment Insurance Sick Benefits
- Ontario Works, formerly General Welfare Assistance
- Ontario Disability Support Program Income Benefits

There are also various programs that will fund:

- equipment
- medications
- job re-training
- transportation

You can discuss your financial options with the community intervention coordinator or social worker.

I guess the thing I would like mostly for the world to know is that we are still the same person we always were - maybe a little slower, but we still have the same hopes, dreams, desires we always had. This surely is a "silent epidemic" we have, but everyone needs to remember that it is not contagious, and we still enjoy participating in life's activities.

Through this Window: Views on Traumatic Brain Injury



Returning to school

If your family member wishes to return to school, contact the school last attended or the Board of Education. The Board will put you in touch with the Special Education or Special Services Departments. These departments will work with your health care team to come up with the best learning plan. Your family member may qualify for an Educational Assistant.

If your family member is 16 to 18 years old and not in school right now, he or she may choose to:

- start regular school with a full or reduced course load
- take a correspondence course and work at home
- enroll as a mature student for night school

Colleges and universities also have services for special needs students. These services include:

- teaching study skills
- providing special equipment to assist learning
- giving information about bursaries for tuition, books and disability related equipment

Returning to work

To see if returning to work is possible, the team looks at:

- what your family member is capable of doing
- the type of work he or she did before the injury

If returning to the previous job is unrealistic, even in a modified form, other jobs can be explored. There are vocational assessment services that can assess your family member's work skills. They also provide work retraining programs.



If returning to work is not possible, the team can help your family member find hobbies or volunteer work.

Love, sex and intimacy

For the Couple...

Sexual problems may occur after a brain injury. They could happen for a number of reasons. If your partner has changed, then so has your relationship. Changes in your relationship affect your sexual feelings. You may feel like a parent or caregiver, instead a partner. Also, stress and fatigue could make sex the last thing on your mind.

From your partner's point of view, he or she may be depressed or suffering from low self-confidence. The changes in the brain brought about by the injury may have increased or decreased his or her sex drive. Sex drive is usually decreased. There may be physical problems, such as impotence for men. Your partner might be misreading your behaviour and make tactless attempts at intimacy. He or she may have less self-control and be more self-centred, which may hurt your feelings.

Relationship problems that were present before the injury may become obvious after it. These problems may get played out in the bedroom.

Creative Solutions

Spouses often say that poor sexual performance is not the main source of unhappiness in the marriage. It is the lack of intimacy or feeling of closeness. It's important that a couple be open to creative solutions to post-injury problems. Better communication and more couple time helps strengthen a relationship. Sexual aids, alternative sexual activities, medications and setting limits may be useful. Education and counselling can help when the problems are too great to work out as a couple.

Sex doesn't end with brain injury — it just changes. Love, sex and intimacy are all intertwined. Giving attention to one makes the others better.



For the Single Person ...

If your family member is single, his or her challenges are different. Dating can cause anxiety. Society may see the person as less sexual. The family may fall into this same trap if only to protect the person from possible rejection. Often, the family has been so focused on recovery, that sexuality gets put on the back burner. It may stay there if you and your family member never accept the changes brought on by the injury.

Education, with a bit of courage, are needed here. Re-learning social behaviours and trying them out at low-key social gatherings can help build confidence.

Gathering with people having the same interests improves the chances of connecting with others. So does gathering with people having the same disabilities. But beware of the birds-of-a-feather notion — not everyone wants to limit their relationships to other people who have had a brain injury.

Accepting Sexuality

Accepting one's sexuality is an essential part of a person's recovery. It is a basic need. Having opportunities for sexual expression often reduces improper sexual behaviours. Having sexual outlets can also reduce problems such as depression and social withdrawal. If the main goal of rehabilitation is to return to the "real world", then it must include matters of love, sex and intimacy.

Even though I still have a ways to go, I have come a very long way and I am just beginning. Brain injury lasts a lifetime. That makes me a permanent survivor. I guess I've finally come to grips with that. So I've got a lifetime to learn to live with "the only me that's left"... and it might just take me that long.



Quality of life

When inpatient rehabilitation is done, you will likely encourage your family member to continue with rehabilitation activities. But at some point, the activities may become meaningless because there is little progress. That is when your goals, along with your family member's goals, should be reviewed. You might focus on quality of life instead.

This means choosing activities for the pleasure they give, instead of for the skills they might recover. It means living a life now, not waiting until "after the work is done". A life fully lived might include artistic, intellectual, physical and spiritual interests. It does not continually revolve around the brain injury. There is life beyond being a patient.

A family member who is slow-to-recover may not be able to express his or her needs and wishes fully. Yet, there are many ways to create the best quality of life possible for this person.



This would be a great story if I had been able to return to the practice of medicine. It would be great, too, if the blind could see and the paralyzed, walk... Because [my rehabilitation team] deals in the practical, they helped the new me develop, and showed me a way past my unfulfilled hopes so I would not remain immobilized by grief. At the same time, it would be simplistic to think that grief ends — it is neither finite nor simple. Longing for what one had has a way of popping up at unexpected times. But over time, the intensity eases.

If I were asked, I would counsel someone with a devastating injury not to focus on their loss and what might have been, but to fully live the life they have now and to carve out new and achievable dreams to fit it.

This new life is truly mine. I own it and I am earnestly trying to learn ... what God intends me to do with it.

I was a happy woman before my injury,
I am a happy one today.

Over My Head. A Doctor's Own Story of Head Injury
from the Inside Looking Out



Notes



Part 8: Some Final Suggestions

In this part there are suggestions to help you cope with the injury.





Some final suggestions

Coping with a brain injury is difficult. These suggestions may help you to cope better:

- Do not blame yourself for brain injury that cannot be undone. Some people never improve enough to be able to meaningfully interact with others. It doesn't matter how much the family has given of themselves.
- Do not panic if your family member gets worse after getting better. It's usually temporary and there are often reasons for this.
- Do not discuss complaints about the therapy program in front of your family member. He or she may focus on them and not cooperate in the program. Speak face to face with staff instead.
- Do not ask questions beginning with "why" such as, "Why don't you...?" or "Why do you...?". It may cause the person to feel nagged and act defensively. It is more helpful to say "Can you help with...?" or "Will you please do...?"
- Do not be alarmed if you are concerned that your family member is only interested in meeting his or her physical needs. This is often only a stage of recovery. Emotional and social needs will eventually become important again.
- Pace your rehabilitation efforts. No matter how hard you try, you cannot teach a brain something it is not yet able to learn. Your efforts should be gradual and appropriate. The person will need lots of repetition before a skill is re-learned.
- Correct the person when his or her memory fails, but do not be critical. This will only cause frustration.
- Give calm feedback. Most of us perceive denial or aggression as a "psychological" problem. But these can be normal problems for someone with a brain injury. Calm, consistent feedback, and not psychotherapy, are what the person may need.



-
- Help the person to help him or herself. Understand that the person is not to blame for some of the changes. However, this does not mean that changes should simply be accepted.
 - Realize the person may not be traumatized by the accident or by medical procedures. Since most people do not remember these events, they will not feel the impact of them in the long run.
 - Know that your efforts do make a difference.
 - Down the road, you may meet different problems than described in this handbook. Dealing with a brain injury over a long period of time can wear you down and you may need help of a different kind.

Thinking back, I tried to remember how healing occurs. The critical element was regaining trust. Not the unconditional faith of an innocent child, who believes nothing bad could happen to her or anyone she loves — that no longer exists for me — I know, deep in the crevices of my being, how vulnerable we all are. Instead, I now trust myself; to respond with grace and courage to all that life bestows. To taste it all, and embrace with gratitude, the compassion, empathy and insights that only experience provides...

I'll Carry the Fork. Recovering a Life After Brain Injury



Notes



Other Information Sources

Additional information and support are available through:

- The Ontario Brain Injury Association (OBIA) 1-800-263-5404.
- Your local brain injury support group. You can get the number through OBIA.
- Your Program.
- The Internet.





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Many of these materials can be borrowed through the Rehabilitation Resource Centre, Chedoke Hospital - Hamilton Health Sciences.

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Stories

Bob's story

It took some time for me to accept the fact I was injured, then an even longer period of time to accept the actual injury and its symptoms.

Along with my bump on the head, I had several broken bones, and a left knee that had been operated on before that was now causing some pain. When my mind allowed me back into this reality (I was conscious but not functioning or remembering very well for 6 to 8 weeks after the accident), all I had was a sore knee, broken clavicle, and a broken tooth. Those I could and did understand, the lack of memory I could not.

The fact I was in a hospital, and watched very closely with everyone, caregivers and family treating me like a seriously injured person had me confused. All I had was a sore knee, broken clavicle, and a broken tooth. They treated me very fair, but I could not and eventually would not accept the fact I was still injured, and needed their care to that level. Heck, I even told them my home phone number, what day it was for a week straight, and I felt just because I confused my dog's name with our first dog (now long gone) I was being 'imprisoned'. Now I understand the term 'unseen injury'. I certainly did not at that time.

Of all my misunderstandings during my recovery, the one that took the most to accept was that I could actually injure my emotions and learned abilities. I felt I turned rather 'stupid', always had my feelings upset by innocent comments, felt threatened by my family and friends when they disagreed with me, or simply would not let me do what I wanted to. I felt less than I was before, less strong emotionally and not quite as sharp. The reason I felt 'stupid' was because I was afraid to let anyone know that I still had other problems, and I felt I was holding up getting home and back to earning a living because I was not able to deal with these injuries



I could not see. I actually lost the ability to read, and to remember what happened five minutes ago. I got lost constantly, and had to fake not being totally confused, but act like I was in control. I lost my driver's license. Add all this up and because I would not accept this unseen injury, the only answer I could give myself, was I must have turned 'stupid'.

I will point out that this attitude of 'stupid' was my idea, not that anyone gave me that name. I did remember being smart, active (never lost) and a very fast reader. I did not remember yesterday, the accident or how to read. I must have really hurt myself and I have to hide the fact I turned 'stupid'.

In actuality, I did hurt my emotions, I did become sensitive (my wife lovingly kids me as 'the sucky' now). What I lacked was the ability of accepting these injuries. I took a year of restructuring my work, home life, and followed my counsellor's advice of taking time to heal and accept there might be some permanent damage. Of all the things I needed the most, it was the time to accept the injury. With help I remembered how to read, to make myself notes so I would not forget things so easily, regained my ability to find my way around, and now have my driver's license back. But there is more.

I used the injury to change some things in my life that needed fixing. As everyone around me knew, I was seriously hurt with an extensive hospital stay. But with some help from my counsellor, I used this as an excuse to 'tune up' myself, because we do have trouble making changes without a reason. Now I had a reason, maybe something good could come from this accident. I also realized how much my family and friends mean to me, and the turmoil I put them through. So first up, 'the sucky' became sensitive to other people, stopped getting angry so easily and did more for less in return. A good thing. I drew the line and worked less to spend time with family. A good thing. I began to accept that I was injured, but am able to function, even if I need to change some habits to accommodate the occasional forgetfulness. A good thing. I stopped speeding in my car. A good thing. Did the injury cause all of these changes? That is my belief, but I could have made the changes without



the injury, I lacked the will power to do so. So yes in that way the accident did cause the (good) changes in my life.

Almost two years from the injury, I have returned to work, re-established myself with my family, and for all understanding, recovered. I now have changed my thought that I turned 'stupid' to that of being broken. Fixed now, but I was broken. I was in too much of a hurry to get 'better'. The unseen injury, the injury of emotions and memory take a healing process. I did not understand then. I now accept the changes in me due to the injury, and have a much better understanding of the recovery process. Bottom line is the injury you might be experiencing either directly or as a friend or family member will get better, but in the advice I used to get all the time, don't rush it. And don't be afraid to ask for help. Luckily it came to me, but I should have asked for it.



Achieving greatness

Kim's story

Why is it that we measure our success as an individual and judge ourselves so very harshly on the basis of the "greatness" we have achieved; the accomplishments we have accumulated and scattered around our home and office walls? The trophies, the diplomas, the ribbons and bows that are tied neatly on our "success" boxes. Why is it that we take this invisible measuring device, called "achievement", and actually compare it with the accomplishments of others? To accomplish, to be accomplished - be better - the best - and to finally achieve... achieve "greatness".

What is this yardstick we call "greatness"?

Personally, my yardstick was etched with musical notes.

All of my life, I wanted to be a singer. My brother is a singer and a songwriter and I was always compelled to be the female version of him. To me, he had achieved "greatness"... to him, it's hard to say if he felt



the same. (I doubt it, since he in his perspective had his own personal concept of "greatness", I am sure). Anyways - I always wanted to be a singer - in my younger days I would perch myself in front of a mirror and mouth the words to my favourite "45's" - Carley Simon, Janis Ian, Linda Rondstat - pretending it was me singing. I really thought that I could be great - I had the facial gestures down "pat" - I even started playing the guitar at nineteen, perfecting the only Janis Ian song I knew - "Seventeen" — "I learned the truth at seventeen, that love was meant for beauty queens and high school girls with clear-skinned smiles who married young and then retired..."

And I would sing -

loud and strong... to my mirror. Yes - I was a "closet entertainer" perceiving that one day, my "greatness" would be somehow remarkably discovered and shared by the world at large - even if quite by mistake.

Several years passed... I had to seek a profession that was safe and provided me with a steady income - which I did. Still, the closet entertainer lurked inside of me, waiting, waiting, waiting - for that opportunity to burst out in song. I would sing to my children, my reflection (still), my dog - anyone, anything, any inanimate object that would appear to be listening - I was limbering up my vocal chords (still twenty years later) to achieve what I perceived to be "greatness".

Then, at the age of 36, I had a stroke. My reflection suddenly changed. I could no longer carry that tune that I had been singing for three decades. My gait could hardly carry me across a room; let alone hum a happy little ditty and "kick out" in my previous "Ann Margaret" fashion. The world as I had known it, was gone forever; a new one - without song - was about to emerge. Initially I was devastated; not because I had truly thought I would achieve "greatness" as a singer, but because it was something that I simply loved to do.

Something I loved was gone.



I suddenly had to face the harsh realization that I could never REALLY sing; if I could have ever REALLY sung, that's what I would have done long before I'd had my stroke. My thirty-year misunderstanding smacked me head-on:

I had achieved "greatness"!

I am great to my two girls - I am their mother - I live to make their lunches; have tea parties; kiss their "boo boos", hug the life into them and pray them safe each night —

I am "great" to my husband, for conceiving and nurturing two of his finest achievements; for remaining on this earth with him and not taking "until death do us part" to a literal plateau when I had my stroke; and for laughing with him for (hopefully) another lifetime;

and

I am "great" to my friends, not because I chose them, but because they loved me long and hard enough for us to create a "history" with each other —

And what of my accomplishments?

I am still alive — there's a large, colour-filled diploma on my office wall and next to my name, it states "STILL LIVING — B.A., MTC (More to Come)".

There's also a gold plated plaque (from Insight University) that is deeply inscribed:

"No greater tune could have been sung, even if you had come out of the closet."





Common Terms

Aneurysm	An abnormal swelling in a blood vessel which may rupture.
Anoxia	The lack of oxygen causing damage to the brain.
Anterograde amnesia	The inability to make new, conscious memories.
Aphasia	The loss of ability to express oneself or understand language.
Arousal	The ability to be alert and take in information.
Ataxia	Uncoordinated muscles
CAT Scan / CT Scan	A series of x-rays taken at different levels of the brain to determine if surgery is needed or how the brain is recovering.
Catheterization	A tube inserted into the bladder through the urethra to empty the bladder.
Coma	Being unconscious more than briefly.
Contracture	Abnormal shortening of a muscle.
Contrecoup	A type of injury in which the brain bounces back and forth inside the skull, injuring both sides of the brain.
Contusion	A bruise.
Dysarthria	Difficulty with speaking.





E.E.G. Electroencephalogram	A test measuring electrical activity in the brain which helps diagnose a brain injury or seizure disorder.
Emotional lability	Rapid and drastic changes in emotions.
Encephalitis	Inflammation of the brain, often caused by a virus.
Glasgow Coma Scale	A scale showing the severity of the injury. It includes motor responses, eye opening and verbal responses.
G-Tube	A tube leading into the stomach through the abdomen for liquid food and medicine. A GJ tube also has an extension into the small bowel.
Hematoma	A swollen area of tissue that is filled with blood.
Hemiparesis	Weakness on one side of the body.
Hemiplegia	Paralysis of one side of the body.
Hemorrhage	Bleeding from a ruptured vessel.
Heterotopic Ossification	Extra bone formed around joints.
Incontinence	The inability to control the bowel or bladder or both.
Mobility	The ability to move without restriction.
Paralysis	The inability to move a part of the body due to damage to the nervous system.
Post-Traumatic Amnesia	The loss of memory for events occurring immediately after the injury that may continue for weeks or months.
Rancho Rating Scale	An observation scale of behaviours used to describe the person, from coma to near complete recovery.
Retrograde amnesia	The loss of memory for experiences that occurred before the injury.



Seizure	Uncontrolled discharge of nerve cells in the brain. Seizures may cause tremors, change in behaviour, loss of consciousness and loss of bowel and bladder control. There are 2 types of seizures; grand mal and petite mal seizures.
Spasticity	Abnormally high tension in muscles making them resistant to stretching.
Stroke	Damage to a part of the brain due to a blockage in the blood flow to that area.
Tracheostomy	A tube inserted into the trachea through the neck to let air pass or remove secretions.
Tumor	The uncontrolled growth of cells, causing an enlargement or mass.
Ulcer	An infected open sore on the skin.
Unilateral neglect	The inability to respond to things on one side of the body.
Visual Field Deficit	The inability to see objects in a specific area of the visual field.



A Handbook for Families about Brain Injury

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and

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