



# ABI TOOLBOX



Saskatchewan  
Brain Injury  
Association

WWW.SBIA.CA

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# INTRODUCTION

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## **ACKNOWLEDGEMENT**

We thank all those people who so graciously gave their time and talents in helping us prepare this TOOLBOX. Many people, in varying aspects of the medical profession, survivors, and families of survivors, were asked to review our material and make suggestions for improvements. We thank you all for your time, input, and expertise.

We, as family members, offer this information in the spirit of support and solidarity. The information contained here should not be taken as medical advice or prognosis. We sincerely send good wishes to you and your family members on your journey of rehabilitation.

This TOOLBOX has been prepared for you by the Saskatchewan Brain Injury Association (SBIA). We have chosen the name TOOLBOX in the hope that you will pick and choose the information that you can use, much as you would choose tools from a 'toolbox'. We sincerely hope the information will be helpful.

We invite you to contact us. Our contact information is listed on page 1.

Watch for related links on our website to other organizations and information. There are Support Chapters in various communities in the province. Do you need someone to talk to who has been there or just somebody to join you for coffee? Let the local Support Chapter know how they can help – contact our office to get the number of the Support Chapter nearest you.

### **SASKATCHEWAN BRAIN INJURY ASSOCIATION**

The Saskatchewan Brain Injury Association is dedicated to the prevention of brain injury and to improving the knowledge, services, and quality of life for people living with acquired brain injury, their families, and their service providers.

# SOMETHING YOU SHOULD KNOW

Dear Friend,

Things are happening very quickly right now! It can be overwhelming trying to keep up with all the new information that keeps coming your way. Know that you are not alone. This TOOLBOX was developed to help you sort out some of the confusion, organize some of your thoughts, provide answers to some of your questions or, at least, tell you where to go to find some of the answers, and record the happenings.

We offer this material simply as an aid, pick and choose what will be useful to you. Most of the information here has been prepared by parents of survivors and we offer it not as medical experts, but as people who have experienced a lot of what you are going through right now. The information contained in these pages had been gained through experience and research and is not meant to suggest, in any way, that we have all the answers. Every brain injury is unique, as you will hear so often during recovery. Some of our experiences will be common to each of us, some experiences will not.

We offer this TOOLBOX as a tool that you can pick up and read when you have time and need support. We wish to share some of what we have learned from our experiences and trust you will find some information that is useful.

We realize you may not have the energy to read through all this material at this time, but we hope that you will find some time to look through the material and pick out the information most useful or interesting to you.

Many people who have gone through what you are experiencing have found it helpful to obtain as much information on acquired brain injury as possible. You can do that in many ways: read as much as you can, check the internet and libraries, don't be afraid to ask questions, and don't feel ashamed to say, "I need help".

We would like to draw your attention to the area of the TOOLBOX where there are numerous pages on which you can list important items. These include diary pages, pages for listing the names of those you will be dealing with in the medical field, pages for listing appointments, medication, and questions you need answered by the medical staff. Note particularly the section called SAVE ALL YOUR RECEIPTS on page 11 – this may be helpful to you when it comes time to file your income tax.

Our association is always present to give you support in many ways and we have many and varied services. Our goal is to help you along this pathway of changes.

Some of the services we can provide include:

- Support for individuals and families coping with the effects of ABI
- Regular programs for survivors and their supporters in six cities
- Educational programs for the public as requested
- Retreats to gather survivors and their supporters provincially
- Referrals to and support of peer Support Chapters

Our address appears throughout this TOOLBOX. Our telephone number is 1-888-373-1555 (toll free); and in Saskatoon (306) 373-1555.

Included in this TOOLBOX is the phone number and address of the Saskatchewan Health Authority (page 43). The Saskatchewan Health Authority can put you in touch with the resources in your area and tell you of the services available to you.

Also included in the TOOLBOX are a number of links to additional information and recommended reading/viewing that we feel will complement what we have written. We hope you will find them helpful.

Your Friends,

Survivors, families, and friends

# Take Care Of Yourself Too

At this time your first thoughts go to the person injured, and you may be trying to be many things to many people. However, you must remember to look after yourself too. Your journey has just begun on the 'road to recovery' and sometimes it can be a very, very long road. You may, at times, feel very tired and overwhelmed; so you must get enough sleep, eat well, exercise, and try not to be overly worried about this situation, one over which you have no control.

Stress is normal at a time like this, but by understanding the ways in which stress can affect you, you may be able to reduce some of the problems extreme stress can cause. Watch for weight loss, over eating, inability to sleep, high blood pressure, stiffness in neck and/or shoulders, and anything that is out of the ordinary, then see a doctor if you have some concerns.

If you have health problems such as diabetes, heart problems, blood pressure, etc. then be sure to pay attention to them. Do medications need to be adjusted? Even when you are not hungry and food tastes terrible it is important to 'eat healthy'. Try some fruit, nuts ,or a piece of cheese. It is important to keep up strength and stay healthy. It is helpful to get outside in the fresh air and just go for a walk (even a short one). Be sure to take the time to sleep or just lie down, take a warm bath – whatever you need to do reduce your stress. Some good advice might be to avoid alcohol and reduce caffeine.

We realize you are worried about the person who has been injured. Will they 'wake up' from the coma, what will they be like when they do 'wake up"; these and related thoughts are questions that are emotionally draining. The doctor cannot tell you exactly what to expect because no two injuries are the same, however, by asking questions you will get some of the answers and some of the stress may be relieved. You might find it helpful to sit down and make a list of the things you are worried about, then study that list keeping in mind the following poem a very wise person once wrote:

**Grant me the SERENITY to accept the things I cannot change;  
The COURAGE to change the things I can;  
And the WISDOM to know the difference.**





Are you worried because you really don't understand the situation or the implications of the injuries? Who can you ask? How do you go about asking? Where do you find the answers? List the questions you have for the nurses and doctors. Come prepared with questions to which you really need answers. Perhaps sit down with other members of your family and ask what questions they need answered. Then ask one of them to accompany you on your visit to the doctor or nurse. To alleviate confusion for both the family and the medical staff, it is best if you appoint one person in the family as the spokesperson, but they may wish to have someone accompany them to serve as a recorder. Write down the answers as you get them, because in times of stress our memory often is taxed. See page 13 for a sheet to get you started on listing your questions.

Next, you may want to look at ways of relieving your stress by allowing others to assist you with some of the responsibilities. Share your feelings and concerns with other loved ones; don't try to take on all the responsibility for the care of the person with the injury yourself. You can allow others to help you; they too are feeling the stress of worry, and by allowing them to help, you will empower them to feel useful. Perhaps giving them a choice of tasks they could do for you, such as going to the store, or staying with your loved one while you go for a walk. Many people really do want to help. Having someone sit with your loved one while you get some well-deserved rest is very helpful. It is easy to get caught up in the situation and not realize just how tired you really are getting. Sometimes you just need to be alone.

It can be very lonely sitting by the bedside of a loved one. You feel you have to give your 'all' to them and there is not energy left for other relationships. It is important to take the time to make the acquaintance of others around you – other patients and their families, staff, and volunteers in the hospital. This is particularly important if you are in a strange city without family or friends as support.

Most hospitals have a Volunteer Service, Social Worker or Chaplain who would be available to speak with you, just ask a nurse how to get in touch with them. They may be able to give you advice on low cost housing while your loved one is in the hospital (some facilities have housing attached to the hospital for just a situation as yours), or where you can find a really good bowl of home-style soup. A few moments in the chapel can be very comforting for some people.

This is a time when you need support from your family and friends. Some people like to have a phone in the room to 'keep in touch'; others don't want the intrusion. You be the judge. It is easy to let the stressful situation overtake you. Try to choose your words carefully in times of stress; the tension can sometimes lead to words spoken in anger or frustration that would not normally be uttered. It might be better to take a little walk and get away from the situation for awhile. Right now the best thing is to pull together to support the individual with the brain injury.

# OTHER FAMILY MEMBERS



Be careful not to neglect the other members of your own family, they still need you in their world too. Others in the family may not understand what is going on or may not understand why you are so preoccupied. Try to spend some quality time with other family members, they need you too and you need that time with them as well. Perhaps another person in the family has a baseball or hockey game they would like you to attend.

It might be wise to keep the principal of the school updated on the facts, if the injured person is a student. That way the school can stop rumours from starting and the teachers will know the facts to enable them to be supportive of the other children in the family.

Be careful not to neglect your relationship with your spouse or significant other. You need each other now, perhaps more than ever before. Take time for each other, even if it is a very short time – you need to keep in touch. Inform the hospital how to reach you, then relax. Your loved one is going to be well looked after in the hospital – you can relax and have time with the other members of the family.

You may experience confusion, denial, anger, guilt, helplessness, fear, frustration, and more – you have experienced a shock; a shock for which you had no time to prepare. There are social workers available to help cope with these very common emotional responses; common in that they affect many people. Don't be frightened by these emotional responses, but also don't be afraid to ask for help.

# HOW CAN I HELP MY LOVED ONE?

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## WHAT CAN I DO NOW?

- While they are not able to “look out for themselves”, they depend on you to “look out for them”, you become their advocate.
- You can offer the best support because you know them best.
- Besides support, you will need patience for the recovery process.
- Due to the brain injury, they may have lost knowledge of themselves; they may not remember what they were like as a person before the injury. You can help them rebuild their memories, their self-knowledge, and self-worth.
- You will find that the things the brain knows the best are those least likely to be affected by the injury, that is if the survivor was an accountant prior to the injury they will likely still be good with numbers. Sometimes you'll be surprised by what the person with a brain injury knows, and sometimes you'll be surprised by what they do not know.
- Have some familiar objects in the room, for example a favourite blanket, stuffed animal, trinket, football, pictures on the wall, etc.
- Display pictures of themselves, family, friends, and pets. Familiar items help them regain their 'sense of self'.
- Because the patient may appear fine, others may assume they are fine. The less visible the condition, the harder it may be for others to understand. You may need to explain that the brain injury has affected various aspects of the patient's life. It is easier for someone to understand the pain and recovery of a broken leg, because they can see the condition. A brain injury is sometimes referred to as the hidden injury.
- Consistent schedules and routines are less tiring and confusing.
- While in a coma, they are still affected by what is going on around them. Try to keep the noise and confusion in the room down to a minimum.
- While in a coma, they may appear to be unresponsive, but they still may be able to hear. Talk to them in a quiet, loving, and reassuring manner. Perhaps, at times, play softly some of their favourite music, try to pick pieces that aren't too fast or busy.
- Remember that healing occurs with rest and sleep and these must be regulated closely.

## HOW DO I TREAT THE PERSON WITH THE INJURY? WHAT DO I DO? WHAT DO I SAY?

Never forget that the person with the brain injury has feelings, hopes, and dreams. Always treat them with respect, love, and acceptance. Treat them the way you would like to be treated if it were you in this situation. Strive to rebuild their self-esteem and self-confidence. Encourage their efforts in striving to reach new goals. If the individual is an adult, treat them as an adult. Do not belittle them by 'talking down' to them but give them positive feedback when appropriate.

You may have a tendency to want to do everything for them. DON'T! Encourage them to do as much for themselves as possible – you might be surprised at just how much they can do. It will take time, and yes, you probably could do it faster if you did it for them, but will that help them to grow and to regain self-esteem? Doing for themselves will help to promote their self-esteem and independence. Incorporate extra time in your schedule that will allow enough time for him/her to do a lot of the dressing and personal hygiene by themselves. Introduce some simple tasks that they are able to accomplish – for with risk comes progress and success.

The person with the brain injury may go through many different emotions. Some emotional behaviour may be due to the injury itself. Some people do experience deep depression because of the loss they have experienced. A full evaluation of depression may be called for in some situations. As strange as it may seem, the better the person becomes, the greater the possibility of depression setting in, for they become more aware of what they have lost. Self esteem and self worth may suffer. Be supportive and encourage continued involvement in their recuperation.

The family is a very important part of the rehabilitation process. It is important for the family to be part of the rehabilitation team. Family members often know best how to encourage and stimulate the person.

Trust your instincts, most of the time they will lead you in the right direction. Stand up for your rights as a caregiver and advocate for the person with the brain injury as they are unable to do so.

## **COMMUNICATION**

POINTS TO REMEMBER: (these suggestions come from our varied experiences)

- Ask the doctor for an assessment by a Speech Pathologist, if it has not already been done
- The person with the injury will be thinking in slow motion. They will need a longer period of time to understand what you are saying and to formulate responses. Give them time to search for a word, but give them the word if it is causing frustration. Remember too, that if you wait too long, because of the short-term memory deficit, they may have lost their train of thought. You then could repeat the question.
- Break task down to simple steps and speak in simple sentences remember NOT to 'talk down' to the patient.
- Include the person in conversation, even if they can't respond. Do not talk 'about' them in their presence
- Try not to change the way you treat the person, do not treat an adult as a child
- It is not necessary to speak loudly to the person; generally hearing problems are not caused by a brain injury.
- Do not make your conversation complicated. Speak in simple sentences and ask simple questions. Ask one question at a time, and then give them enough time for an answer.
- Ask questions in a positive way. For example, "Would you like to go for a walk?" rather than, "Don't you want to go for a walk?"
- Respect their likes and dislikes regarding food, clothing, entertainment, music, etc.
- Let the person make decisions. Ask appropriate questions, such as, "Do you want to go to bed now or would you rather stay up for another 15 minutes?" Make sure either choice is appropriate.
- Praise them when it is appropriate to do so.
- Remember always that they will take their cues from you. They will pick up your mood very quickly whether it be happy, sad, content, or angry.
- Support and encourage them to initiate a conversation. They might start a sentence and then stop – seemingly lost in thought. Repeat the part of the sentence they said to encourage them to continue. For example, they could say, "I saw the ..." wait for a moment for them to search for the word, then repeat the words, "I saw the ..." Don't make an issue of it as the thought may simply be gone.
- Ask them to describe actions or name objects. Such as "spoonful of ..." or "brush your..."
- Encourage gestures and talking with their hands to help find the right word to communicate a meaning.
- They may repeat themselves in word or an activity because of the loss of their short-term memory. You can mention it, but don't make an issue of it.
- You may have to repeat information to them, because of their short-term memory loss.
- Be prepared for inappropriate language (swearing) and the use of wrong words. Accept this without anger or laughter (never ridicule) and try to help them by giving them the correct response.
- Discourage exaggeration of facts or made-up stories. One of the effects of a brain injury is that there may be time when they 'fabricate' a story or 'fantasize'. They honestly believe these 'stories' to be true. Correct without ridicule and point out that sometimes their mind plays tricks on them. Be sure you have your facts straight.
- Say what you mean as the person will take what you say for the literal truth.
- Orient the person as to time, day, month, and year.
- Ask for a Speech/Language Pathologist consultation if you have concerns about communication and swallowing issues.

## **OTHER POINTS TO REMEMBER:**

- Do not tease or encourage the person to say inappropriate things.
- Do not use sarcasm or ridicule speech or pronunciation.
- Do not put them on display and force them to talk to others, but encourage them to join in conversations.
- Do not over or underestimate their ability to understand. Ask questions to see if they comprehend.
- Do not pretend to understand them when you do not. They may be asking for help.
- Do not talk for the person, unless absolutely necessary.

## **ATTITUDES:**

- Be honest about the injury and the person's abilities.
- Praise appropriate behaviour, without belittling the person.
- Look to the present and future; do not dwell on the past and past abilities.
- Your happy demeanor can influence the survivor in a positive manner.
- Keep a positive outlook and end each visit in a positive manner. They will take their cues from you.
- Redirect the person to another activity when he/she feels embarrassed or uncomfortable or has exhibited inappropriate behaviour.
- Remember that no two people with a head injury recover at the same rate.
- Remember that their emotions are very close to the surface. Protect and correct them if they have misinterpreted comments or actions.
- Help the person relax by being calm and patient. Give them hugs and tell them you care. They need to know you still care for them.
- Allow them to enjoy success in new activities and assure that the 'risk' activity has a good chance of success.
- Above all: always keep them SAFE.

## **WHAT'S NEXT?**

What happens next? After the patient is stabilized to the point where they can be discharged there is often a dilemma as to what to do next. Do we take the 'survivor' home? Do we ask to have them placed in a rehabilitation setting? Do we place them in a setting that is far from home but has a good reputation for rehabilitation? Or do we keep them near or at home to keep the family support near the survivor? Do they require a long term care facility? How do we go about locating the right facility? There are no cut and dried answers. Sometimes it becomes necessary to advocate for what we feel is needed for our loved one. Don't give up in advocating for the rights of your loved one, often times persistence pays off.

Certainly the goal of many facilities is to have the injured person become, once again, fully integrated in society and living with family or on their own with the help of supports and services. Unfortunately, that is not possible for all survivors and we do not have the number of facilities in the province required for the number of people with a brain injury. There are many people working as advocates for more appropriate facilities to be made available in our province.

# SAVE YOUR RECEIPTS

It may be wise to START TODAY and save ALL YOUR RECEIPTS. Your expenses can accumulate very quickly, especially if your loved one is in a hospital or institution that is not in your hometown. Save everything: gas receipts, receipts for meals, lodging, medical expenses, child care expenses, anything incurred due to the brain injury. These can be used as medical expenses on your income tax (check with your accountant). START NOW, many of us did not find this out until we went to fill out our returns a year later!

Also, for income tax purposes, keep track of all out-of-town doctor appointments you may have, noting distance, meal receipts, and overnight accommodations (you can claim for the injured person plus his/her assistant). We have included a sheet for appointments on page 14 of this TOOLBOX. As verification of the appointment, request a note from the receptionist stating you were in attendance at the doctor's office that day OR at the end of the year you can request a composite sheet listing all the visits for the year.

## Sample Receipt Log Book

<b>DATE</b>	<b>DESCRIPTION</b>	<b>AMOUNT</b>
<b>M/D/Y</b>	<b>Medical</b>	<b>\$0.00</b>
<b>M/D/Y</b>	<b>Travel</b>	<b>\$0.00</b>
<b>M/D/Y</b>	<b>Hotel</b>	<b>\$0.00</b>
<b>M/D/Y</b>	<b>Meals</b>	<b>\$0.00</b>

## Sample Mileage Log Book

<b>Date</b>	<b>Purpose</b>	<b>From</b>	<b>To</b>	<b>Start (odometer)</b>	<b>Finish (odometer)</b>	<b>Mileage</b>
<b>M/D/Y</b>	<b>Appointment</b>	<b>Home</b>	<b>Hospital</b>	<b>17,145</b>	<b>17,160</b>	<b>15</b>



















# WHEN YOU ARE READY

Family members of individuals with an acquired brain injury have prepared the following pages. They have experienced some of what you are going through. We DO NOT present this material as MEDICAL EXPERTS, but as family members who have gained some experience in the area of acquired brain injury. That does not make us experts, but we wanted to share with you some of what we have learned from experience, reading, observing, reflecting, and doing.

We know too, that no two brain injuries are the same and that different therapies and reactions to therapies will vary from one person/situation to the next. Your medical care team members are the experts in the field and are to be consulted when you have questions.

This material is a very simple overview of the brain and how it works, and an explanation of some of the reactions and situations you may come across with your loved one. There are many 'in depth' books available and of course you can ask people on your medical team for suggested reading material. This is just to help you begin the process of educating yourself.



## HELPFUL FOR MEDICAL STAFF

Helpful for the medical staff is information about your loved one. There, of course, is the pertinent medical information (what medications they are on and dosages, diseases and conditions they may have), but also such things as:

- Is the person hearing impaired, does he/she have a hearing aid?
- Is the person vision impaired, does he/she require glasses at all times?
- What language(s) does the person speak, what is his/her strongest language?
- Did the person have any physical conditions before the injury?
- Does he/she have any allergies to food, medications, materials (flannelette, latex, etc)?

# WHAT IS AN ACQUIRED BRAIN INJURY?

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An injury to the brain occurs when the brain is damaged due to a trauma to the head (blow to the head, a fall, surgery, Shaken Baby Syndrome, etc.). Another cause of damage to the brain is due to an internal influence (tumour, lack of oxygen to the brain, infection, substance abuse, etc.). The effects an individual will experience will depend on which areas of the brain are injured and how severely the brain is damaged. Damage to the brain is permanent, however the effects of the damage may vary. The effects of brain damage may be temporary or permanent.

Few illnesses, injuries, or diseases result in the devastating and overwhelming life changing effects which accompany a brain injury. One is never prepared for the tragedy of a severe brain injury and the challenges such an injury will present. In an instant your entire focus in life changes from one of limitless possibilities to adjusting for immediate survival. The entire family is influenced by the changes caused by a brain injury to one of its members. Your loved one is no longer the same; they may behave and think differently than they did prior to the injury. It is often said, that to the family it seems as though it is a 'roller coaster ride' of uncertainty.

At first glance the patient may appear the same and yet have sustained an injury to the brain. A brain injury attacks the emotions, personality, way of thinking, mobility, and the person's sense of 'who' they are. While it is a very personal disability to the patient, it affects others too. It attacks the person's sense of self with far reaching ripple effects.

Since an injury to the brain is not something you can see, it is sometimes hard for the individual who has had the injury to recognize that they have suffered any impairment due to the injury. This is not necessarily a psychological defense, but can represent a true inability to realize the physical, cognitive, or behavioral impairments that may be obvious to others. It can be especially hard for children and teens to understand what has occurred to them as a result of the injury. As a family member you may be more aware of the changes than the person with the injury.

## **INJURY MAY OCCUR IN DIFFERENT WAYS:**

1. Injury may occur directly where an object hits the skull; this can create an open wound or a closed head injury.
2. The brain may be injured by disease, lack of oxygen to the brain, or invasion by surgery or a tumor.
3. The brain may bounce against the opposite side of the skull, resulting in further damage.
4. The brain may twist and turn on its axis, the brain stem, causing tearing or shearing of delicate brain tissue.
5. Injury occurring in all or many areas is called a diffuse brain injury.



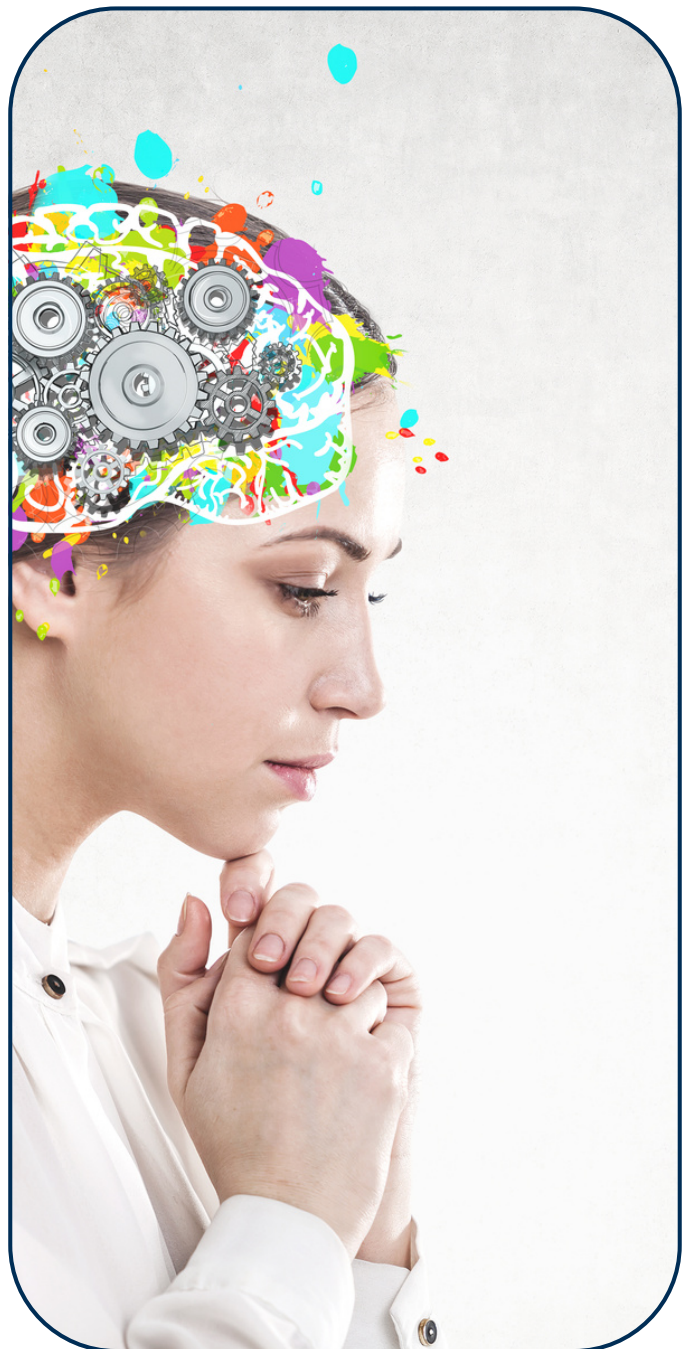
# HOW DOES THE BRAIN WORK?

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Parts of the brain operate much like a computer; other parts are responsible for intuition, emotions, planning, etc. The brain controls all body actions and functions. It is the control centre for movement and for how a person thinks, acts, and feels. It receives and interprets messages through the five senses (sight, sound, smell, taste, and touch), and directs the body to respond, move, or react. If injured, the brain affects the body's system in unpredictable ways.

When there is a traumatic blow to the skull or a sudden acceleration or deceleration of the brain as when the head strikes an object, the brain continues to move in the skull, like jelly in a bowl. It slams against the inside of the skull at the point of impact and bounces back and forth causing repeated blows on all sides of the brain. The movement of the brain inside the rough skull causes laceration and/or tears. The damage is then more widespread. It is common to hear such comments as, "he hit the left side of his head on the steering wheel so that is where the brain is injured". In reality, the brain may have suffered from the impact at multiple sites. Problems with one part of the brain may cause problems with other parts as well.

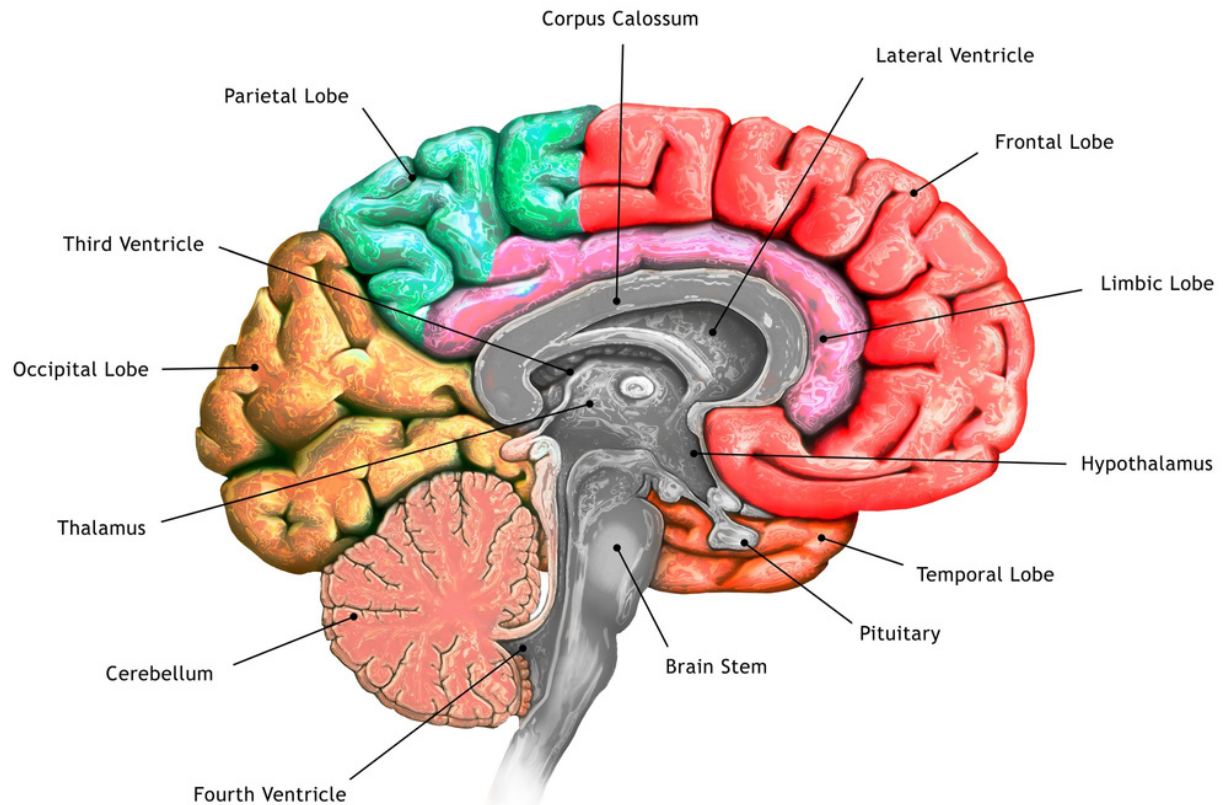
A recently injured brain is particularly susceptible to damage from subsequent trauma to the head, particularly in the first year after injury. Generally, the injured person should be excluded from all contact sports or activities involving the risk of a blow to the head. The people involved in contact sports at a professional level are starting to look more seriously at the risks of concussions.



## PARTS OF THE BRAIN

We have included in this portion a brief (and simplified) overview of the anatomy of the brain. For further information consult your doctor, medical books found in most libraries, online, etc.

The brain is covered by a thick, protective bone structure called the skull. Fluid surrounds the brain allowing it to float within the skull. This fluid acts as a shock absorber to cushion the brain against injuries.



The brain is made up of three main structures:

1. The Cortex – most thinking occurs here  
The cortex is the largest part of the brain and is divided into four lobes.
  - The Frontal Lobe which is the center for speech, emotional control, motivation, problem solving, reasoning, insight, movement, and behaviour.
  - The Temporal Lobe is the center for hearing, memory, organization, and musical awareness.
  - The Parietal Lobe takes in information from the surroundings and sorts it out. This includes thinking, moving, and positioning of the body.
  - The Occipital Lobe is the center for vision and recognition of things seen previously (people, objects).
2. The Cerebellum – coordinates movement and balance.
3. The Brain Stem – controls consciousness, alertness, and basic bodily functions such as breathing and heart rate. It connects the brain to the spinal cord.

The brain is divided into two hemispheres; right and left. Usually, the right half of the brain controls the left side of the body and the left side of the brain controls the right side of the body.

# WHAT HAPPENS TO THE BRAIN DURING AN INJURY

The brain is a very delicate organ with a texture similar to gelatin. In the skull, the brain is surrounded by cerebrospinal fluid which helps to cushion it.

## **Traumatic Brain Injury**

A closed brain injury, such as a forceful blow to the head, causes the brain to bounce around, colliding with the ridges inside the skull. This contact can stretch, tear, and destroy connections between brain cells or blood vessels.

The same occurs in a penetrating brain injury, where an object enters the skull and pierces the brain, tearing the cells and vessels. A penetrating brain injury can also cause the brain to move around and connect with the ridges of the skull, further injuring it.

## **Non-Traumatic Brain Injury**

Non-traumatic injuries such as infections, tumors, or clots may injure the brain by increasing intracranial pressure (the pressure inside the skull), blocking the flow of blood or cerebrospinal fluid, or damage cells as a result of toxins. There are many other ways non-traumatic injuries may harm the brain, but they all involve putting stress on the cells and structures of the brain. For example, a tumor may prevent blood from reaching certain cells, thereby not allowing an area of the brain access to the oxygen and nutrients it needs to function.

Just like any other body part, the brain swells when hurt, but cannot expand past the skull. This causes the brain to push on the skull (increased intracranial pressure), putting strain on the cells and damaging them further. This is an example of a secondary injury, discussed further on page 27.

Whether it is a traumatic or non-traumatic injury, almost all injuries cause some sort of pulling, stretching, tearing, or other force on the cells, which greatly effects how they function. They may also prevent blood and cerebrospinal fluid from reaching the brain reducing the cells' access to oxygen and nutrients, or trapping fluids in certain areas causing swelling.

# BRAIN INJURY CAN AFFECT THE ENTIRE BODY

## **Changes in MOVEMENT may appear as:**

- Poor balance (they lose their centre of gravity)
- Paralysis or weakness on one or both sides of body
- Easily fatigued or may lack energy to move
- Difficulty planning motor activity (apraxia)

## **Changes in the SENSES:**

- Loss of vision, blurry vision, double vision
- Difficulty judging how far away things are
- Decrease in what is seen and/or heard
- Increased sensitivity to movement or sound
- Loss of sense of smell or taste
- Difficulty recognizing objects and faces

## **Changes in SPEECH and LANGUAGE:**

- Difficulty understanding what is said or read
- Difficulty speaking or writing
- Slurring of words

## **Other ways the body may be affected:**

- Easily tired and may sleep most of time
- Change in sleep patterns
- Changes in ability to control body temperature, blood pressure, or breathing
- Uncontrolled appetite or thirst
- Loss of bladder and/or bowel control (incontinence)
- Difficulty swallowing
- Acne may appear (oil glands in the skin can overwork)

## **Changes in COGNITIVE ability:**

Cognition is a person's ability to think and make sense of what is happening around them. Depending on the damage done to the brain there may be different types of cognition (thinking) difficulties. Some difficulties which may arise are:

- Attention span
- Sequencing (in what order to do things)
- Short and long-term memory
- Problem solving
- Finding the correct word or phrase
- Beginning a new task (initiation)
- Abstract thinking
- Safety awareness
- Retaining new knowledge

It is more difficult to recover from cognitive changes than from physical changes. The patient may not be aware of the cognitive changes and may try to do things they are unable to do. While it is important to allow the survivor the opportunity of 'risk and challenge', it is also important to keep them safe and protected. Family members may find this challenging, as the survivor may want to do most things for themselves. Close supervision is often called for with the person with a brain injury.

Changes in cognitive thinking can range from mild to severe and may be permanent, may improve somewhat, or change over time.

# LEVELS OF CONSCIOUSNESS

## **DURING THE COMA:**

- They will not open their eyes, talk to you, or follow commands
- They seem to not be aware that you are there. It is important to talk to them in a supportive manner as they may be able to hear you
- There is no medication to shorten the coma
- The doctor cannot tell you when they will come out of the coma, as every case is different
- One of the first signs of coming out of a coma is occasional eye opening or movement; these are encouraging signs. They may begin to say the odd word or follow a simple command

A brain injury is usually described as mild, moderate, or severe. The length of time that a person is in a coma is one of many factors that will determine the severity of an injury. The length of a coma is different for each person, because each brain injury is different. Professionals cannot predict how long a coma will last and this can be frustrating for families. Much is still unknown about what really happens to the brain when it is injured.

The individual generally does not recall the early stages of recovery. It is not because they do not wish to remember, it is because information is not stored in the brain. It is important to note that the patient may not be able to remember material that was learned just before the injury.

## **GLASGOW COMA SCALE:**

This helps professionals evaluate the level of consciousness. It is based on three measures:

1. Eye opening
2. Verbal or spoken responses
3. Motor or physical responses

Each measure has a numbered score. An overall score is developed with a high of 15. When the score is 13-15, the brain injury is considered 'mild', 9-12 indicates a 'moderate' brain injury, and 3-8 reflects a 'severe' brain injury.

The Glasgow Coma Scale is used for children aged four and up to adults. There is a modified scale for younger children.

## **RANCHO LOS AMIGOS SCALE:**

This is a more detailed scale that describes the behaviours and abilities of a person who is gradually coming out of a coma. It is often referred to as the Rancho Scale and includes eight levels of responses that describe the person's awareness and response to light, sound, touch, and commands.

The basic Rancho Scale is for patients aged 14 years and older.

## **AFTER THE COMA:**

- Confusion is common. There may also be some behaviours that were not typical of that person before the injury
- No one can predict the rate of recovery. Recovery is a continuing process, rather than something that reaches an end
- Although progress does occur, the rate can be frustratingly slow at times
- Remember that the patient will tire easily, both mentally and physically
- Memory after trauma is like Swiss cheese; there are definite holes in it
- Recovery and learning continues throughout ones lifetime

# SYMPTOMS DOCTORS MAY WATCH FOR

## Primary Injury vs. Secondary Injury

When a brain injury occurs, there are two components: the primary injury and the secondary injury.

The primary injury is the direct physical injury on the brain, such as a blow to the head or a hemorrhage.

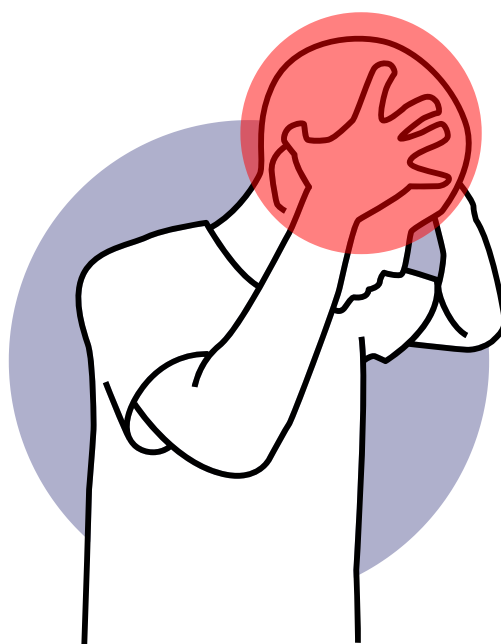
The secondary injury is damage that occurs to the brain afterward as a result of the primary injury. This can include increased intracranial pressure, an infection, hypoxia, etc.

## Possible Symptoms

While your loved one is still in the hospital recovering from the primary injury, there are warning signs of secondary injuries that doctors will watch for, as secondary injuries can lead to further damage.

Some of these signs include:

- Headache
- Nausea and vomiting
- Convulsions or seizures
- Confusion
- Weakness or numbness
- Decreased coordination
- Restlessness
- Unusual behaviour
- Vision changes



These are all possible signs of increased intracranial pressure, blood vessel damage, infection, and other significant changes occurring in the brain. These secondary injuries may lead to further injury by restricting blood flow to the brain or straining brain cells and structures.

# COGNITIVE AND BEHAVIOURAL CHANGES

THE FOLLOWING TWO PROBLEM AREAS ARE OFTEN EVIDENT WITH BRAIN INJURIES:

## Changes in the person's ability to think:

- Confusion as to who they are, where they are, and who is present
- Easily distracted (short attention span)
- Difficulty concentrating
- Difficulty with memory (both short term and long term)
- Poor judgement (a safety concern)
- Difficulty planning, making decisions, and problem solving
- Repeat themselves
- Difficulty with changes to daily routine – they like structure/routine
- Difficulty with sense of direction
- Difficulty doing things in the correct order (sequencing – such as getting dressed)

## Behavioural problems:

- Lack of interest
- Unable to start a task or once started unable to stay with task
- Mood swings
- Crying or laughing at inappropriate time
- Difficulty controlling emotions, temper flare-ups, aggression, cursing, frustration
- Depression
- Irritability
- Inappropriate sexual behaviour
- Change in sex drive – increased or decreased
- Social immaturity
- Focuses on self (self-centred)
- Lacks sensitivity to others
- Confusion
- Impulsiveness
- Restlessness, agitation
- Not aware of physical and cognition difficulties
- Believes they will return to former job or lifestyle sooner than reasonably possible
- Does not like to accept help from others (which may bring in safety factors)

Keep in mind that the person may not remember the problems the next time the situation occurs.

Some behaviours that might be exhibited by people who have sustained a brain injury have been listed above. There are some things you can do to help handle those situations. Talk to a health care professional for additional information.

## OTHER BEHAVIOURS

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### **IMPULSIVENESS**

Impulsiveness (action done without thinking of consequences) can be a problem as the person usually has no concern for their own safety; they may move or talk without thinking about the consequences.

Suggestions:

- Discuss the situation with the person and point out the possible negative effects of their actions
- Give positive feedback to the person when they show good judgement

### **DENIAL**

Denial (refusal to accept the situation as it is - this may be a good thing, in some instances) often accompanies brain injuries – the person may not be aware that things have changed. They simply deny or are not aware of the effects of the brain injury. The person may refuse to try to do certain tasks because it is 'too childish', or 'they've done that a thousand times' or they may make excuses for not being able to accomplish the task. Then again, they may simply not remember.

Suggestions:

- Supervise in order to keep person safe
- Guide the activities in a gentle manner
- Provide encouragement

### **AGGRESSION**

Aggression (hostile or destructive behaviour) will occur if agitation continues. Aggression may decrease during recuperation. The injured person may bite, hit, spit, pull out tubes/IV's, try to get out of bed when it is unsafe to do so, curse and make abusive remarks.

Suggestions:

- If possible, allow personal space
- Keep eye contact and speak in a calm voice
- Restrain the person as little as possible, restrain only if safety is a factor
- If necessary, call for help keeping the person in sight
- Provide a safe environment (remove objects that might be thrown)
- Sedation may be required



## **AGITATION**

Agitation (constant anxiety) can involve physically striking out, not being able to pay attention, outburst of temper, and restlessness.

This is an expected and generally a temporary stage of the brain's recovery. The length of time the patient will be in this stage will vary from patient to patient. It is important to remember that the injured person's life is no longer 'normal' and this itself can cause confusion and fear.

The patient may exhibit almost constant movement whether in bed, wheelchair, or while walking. They may ask for help, then turn on the person who offers that help.

Suggestions:

- Control their environment
- Keep lights and noise levels low
- Limit number of visitors and length of visitations
- Keep to a routine
- Establish a scheduled rest period (no visitors during rest period)
- Avoid noisy situations (crowded malls, cafeterias, etc.)
- Give simple directions
- Respect the person's right to space and privacy
- Exhibit calm behaviour yourself

Once agitated it may be helpful to:

- Direct the person to a quiet area
- Direct the person's attention away from source of agitation
- Avoid quick movements or abrupt changes in activities (unless unsafe to continue)
- Do not confront or scold, this may increase the agitation

## **IRRITABILITY AND FRUSTRATION**

Irritability and frustration (quick to anger) may arise during recuperation. The person may have less control over emotions, overreacting in some situations, and may have difficulty accepting change.

The person may show frustration when unable to do tasks that they were able to do easily before the injury or even tasks that they were able to do yesterday. They may become unreasonably irritated when kept waiting by someone else.

Suggestions:

- Irritability can increase with fatigue. Encourage frequent rest periods
- Ask person to suggest possible solutions and acknowledge effort
- Do not challenge or confront
- Try for a structured environment and stick to a schedule, this causes less confusion and irritability
- Do not take this aggression and irritability personally
- Show some understanding of the frustration

## **INABILITY TO CONTROL EMOTIONS**

Inability to control emotions (expression and moods may change suddenly) such as sadness and happiness are very common.

Sometimes the expressions of emotions may seem inappropriate. Praising a person for a job well done may cause them to begin to cry. The person may begin to laugh for no apparent reason.

### **Suggestions:**

- Ignore inappropriate emotional outbursts
- Change the topic
- Ensure the person is getting enough rest periods
- Praise the person when they have been able to control emotions
- Remember they will take their cue from your behaviour and response

## **IMMATURITY IN A SOCIAL CONTEXT**

Immaturity in a social context may seem apparent because social skills can be lost due to a brain injury. The person may seem unaware of the needs and feelings of others. They may interrupt a conversation with something totally unrelated. They may rebel with an outburst or tantrum because they do not get their own way.

### **Suggestions:**

- Tell the person that this is an inappropriate time or topic without embarrassing them.
- Change the subject.
- Be direct and clear.



# CHANGES IN DAILY LIVING

We have listed here some changes that may occur at various stages of recovery. We want to stress to you again that we offer this information from our own experience and we are not offering this information as medical advice. We also wish to mention that we do not offer this information to alarm you, but merely to reassure you that if these changes do occur and it is not unusual. You will not have to deal with any of this information in the early stages of recovery, but we offer it as a basis of reference for later on in the recovery process

## **NUTRITION AND APPETITE**

Good nutrition is very important for recovery, it is important to eat a balanced diet. After a brain injury, eating habits and nutrition needs may change. Extra calories and protein may be needed for a few months following a brain injury and can sometimes be supplied by supplemental drinks and snacks. Seek advice from a nutritionist/dietician.

A brain injury can affect the ability to swallow. Often a therapist will be consulted to determine what type of food is appropriate at different stages of recovery.

Some eating behavioural problems, that may occur, are:

- Constant urge to eat (may have forgotten that they just ate). They may have no sense of satiation (no sense of hunger being satisfied and will continue to eat as long as there is food available). It may become necessary to limit snacking. Direct attention away from food to another activity.
- May eat only from one side of the plate. In this case turn the plate for them so that they will eat the other portions of food.
- May pick up anything and start to eat it (drinks left by other people on counters, may chew on a Styrofoam cup, etc.). Protect the person when you are out in public as they may see a discarded cup and begin to drink from it.
- They may lose their appetite. Do not make eating a major issue. You could bring some small portions of their favourite foods from home. Also, work with the dietary staff to make them aware of the patient's food preferences prior to injury.
- They may become confused and/or distracted during mealtime. Some suggestions are to alter the environment (turn off TV/radio); or you could serve one food at a time.
- Acts impulsively while eating. They may put too much food in their mouth at one time, may not chew their food well.
- There may also be a loss of appetite, particularly for those with a loss of smell. This can also be caused by depression. It is important to monitor food intake to be sure that nutritional needs are met.

# CHANGES IN DAILY LIVING

## **CONTINENCE/INCONTINENCE:**

After a brain injury the injured person may no longer have the ability to control their bowel and bladder. They do not feel the urge to use toilet facilities until it is too late.

In a case such as this, it is often advisable to toilet the person approximately every two hours or set a schedule, such as right after meals and upon rising from sleep. In some cases it may be necessary to use products on the market such as incontinence pads or 'Attends'. Keep in mind their human dignity and assist them to keep clean at all times.

## **MENSTRUAL CYCLES:**

Menstrual cycles often become irregular because of the trauma to the body. It is often not unusual for a female to stop having her monthly cycle for a few months, stop completely, or to have prolonged or frequent cycles.

## **SLEEP PATTERNS MAY CHANGE:**

The person with a brain injury generally requires more sleep. They may need to go to bed much earlier and require one or more naps during the day. They tire easily from physical tasks and mental tasks (concentration takes a lot of energy). If they don't nap during the day, it is a good idea to at least have a rest period with no visitors, TV, or other distractions.

Schedule their sleep for as long as their body requires.

The patterns of sleep may also vary:

- Some people seem to be sleepy all day and unable to sleep at night, in this case try to keep them from sleeping during the day with exercise and fresh air or other activities, allowing for rest/quiet periods as needed.
- It is often difficult to get them up in the morning. Start early enough in the morning to allow for delays. Be cheerful, as the person with the injury will take their cue from your attitude.
- It is important to remember that the injured person may require much more sleep than before the injury. Be sure to allow them to schedule their sleep for as long as their body requires.

## **SEXUAL HABITS:**

Sexual habits can be affected following a brain injury; therefore, sexuality should not be overlooked. A person who sustains a brain injury may experience a loss of closeness to their partner, decreased social interaction, and decreased ability in dating skills.

There are different forms the changes may take:

- Changes in body image
- Changes in sex drive (either decreased or increased)
- May lose interest in sex, display inappropriate sexual activity such as making sexual advances to those around them
- Fatigue may lead to lack of interest or lack of stamina
- May lose self-esteem and feel they are unattractive
- Spousal interest/fatigue may be involved as well

# CHANGES IN DAILY LIVING

## **CAFFEINE:**

Caffeine is a stimulant. As was mentioned previously, over stimulation can cause difficulties for an individual with a brain injury. Stimulant increases physical and mental activity in a person. The doctor may recommend that the injured person reduce their intake of caffeine.

### **The injured person may be requested to reduce some of the following:**

- Regular coffee and tea
- Coffee-flavoured drinks
- Foods with chocolate
- Soft drinks with caffeine

### **Some things that might take their place are:**

- Fruit juices
- Water
- Decaffeinated soft drinks
- Milk
- Decaffeinated coffee or tea
- Fruit based drinks

## **ALCOHOL:**

In general, the effects of alcohol and other psychoactive drugs are much more unpredictable on the injured brain. The effects are usually much more pronounced and therefore the best policy is abstinence. Remember that alcohol kills brain cells. Obviously, the person with the brain injury must not suffer any further loss of or damage to brain cells. There is always the danger that the use of drugs and/or alcohol will be a dangerous combination with the drugs the person is being prescribed by the physician and may cause further injury.

A good reference on this topic is Acquired Brain Injury (ABI): Alcohol and Drugs, produced by S.G.I and Saskatchewan Health.

The physician should be made aware of any past or present abuse of either alcohol or drugs.

## **SEIZURES:**

Seizures can be brought on by a brain injury.

When a person is having a seizure it is important to remember:

- Do not place anything in the mouth of the individual
- Do not restrain the individual
- Move furniture and other objects away so they will not hurt themselves
- Be sure the airway is not blocked. Turn the individual onto their side and the head to the side to allow saliva etc. to drain from the mouth
- Observe what happens during the seizure so you can accurately report this to the doctor
- Reassure and offer help to the individual after the seizure
- Call their doctor and be sure to inform the doctor that the individual has sustained a brain injury previously
- Call an ambulance if the seizure lasts more than a few minutes.

A seizure may be brought on by the use of illicit drugs, alcohol, or lack of sleep and can often be controlled by prescribed drugs.

## **FATIGUE:**

Fatigue will play a large part in how much the person with the brain injury will be able to do different tasks. Be understanding and try to add routine to their daily life that incorporates rest periods and a regular bedtime.

# CHANGES IN DAILY LIVING

## **POST-TRAUMATIC AMNESIA:**

Amnesia is a loss or impairment of memory

There are two types of Amnesia:

1. Retrograde Amnesia: a loss of memory of events before the injury. Events immediately prior to the trauma may never be recalled.
2. Anterograde Amnesia: a loss of memory for events following the injury. The person cannot store new information, therefore information is lost and cannot be learned and remembered. At times they may be able to do things they used to do, at other times they may not remember how to do those same things.

Here are some suggestions to help those with post-traumatic amnesia:

- A calendar in their room
- A clock on the wall and a wristwatch to wear
- A daily schedule of events, showing time and place – posted prominently in their room
- Labels on drawers as to what is in each
- Labels on pictures to identify the people and places in the pictures
- Name tags on those around them
- A day book/journal to record the days events and visitors. Either the individual, or if they are unable to write, someone on staff or at home can record events. Therapists can also make notes as to what was done and how the individual responded in the therapy session that day
- A list posted in their room to show sequencing regarding personal hygiene and dressing

## **MOTIVATION:**

The survivor may not show much interest in certain tasks or activities. They may also need a lot of encouragement and prompting to begin a task or activity. Try to encourage participation without intimidation. Give them choices (just a couple to prevent confusion) don't always decide for them. Be careful not to confuse them with too many suggestions. Perhaps you could start a project by doing the first step and encourage them to finish the task.

They may not want to finish a task (dressing, finishing an activity, or job related task); explain why the task needs to be completed. Be sure to encourage and give positive feedback on a job well done.

## **DISTRACTIONS**

You will find that the survivor is easily distracted. They may start to do a certain task and be distracted by the simplest thing: a sound, a sudden movement, or the sight of their own hand as it moves. Gently bring them back to the focal point and help keep them on track.

Distractions can work to your advantage, too. Sometimes he/she may become quite determined about not doing something that has been asked of them. It may be something that they do all the time, but this time they've decided not to cooperate. A momentary distraction from the situation may relieve the tension and you can approach the subject again with entirely different results.

# CHANGES IN DAILY LIVING

## **STIMULATION/OVER-STIMULATION:**

In the very early stages of recovery, over-stimulation can be a problem. The injured brain can only process so much information at one time. At first it may be wise to use subdued lighting, keep the noise level to a minimum, and limit the amount of activity near the person. This can be difficult in a hospital environment, but do the best you can to keep the activity level and noise down near the individual. Closing the hospital door can reduce a great deal of noise. There may be times when the number of visitors, even family members, may need to be limited. Remember he/she may find noise and activity to be very disturbing and distracting. If it is possible, a private or semi-private room may be the best.

Throughout the rehabilitation process keep a balance between stimulation and quiet times. Follow activities with a quiet time. Follow rules for visiting periods and don't allow the patient too much TV time as this can be too much stimulation for the brain. Remember that the person with the brain injury is thinking in 'slow motion'. Over stimulation can be detrimental to the patient.

## **REST:**

Rest is paramount to the recovery of a person with a brain injury. It is not unusual for a patient to require 12-14 hours of sleep at night and still require a number of sleep/rest periods throughout the day. Do not be alarmed by this, the body protects itself by demanding sleep.

You will also find that the mind will often be very slow to 'wake up' after sleep. It may be some time before the individual is fully awake and aware of what is going on around him/her. It may take hours for their mind to be fully alert. Some days will be better than others.

Even after the individual seems well along on the road to recovery, you will find that he/she will require more sleep than he/she did before the injury.



# RECOVERY AND REHABILITATION



## **WILL THE PERSON WITH THE BRAIN INJURY GET BETTER?**

It is important to remember that every brain injury is different and it is impossible to predict how far a person will progress. Recovery can continue for years; even after a mild brain injury a person may still have changes in thinking and behaviour.

Many things affect recovery from a brain injury:

- Age at the time of injury
- Length of time that individual is unresponsive (in coma)
- Location and severity of injury
- Other injuries at time of accident
- Length of time before medical help was received
- Skills and behaviour before injury
- Availability of rehabilitation
- Substance use and/or abuse
- Past brain injury or concussion
- Family support
- The list can go on...

## **GOALS OF REHABILITATION:**

- For the person with the brain injury to become as independent as possible
- To work with the family and other caregivers regarding how to help the individual

## **THE REHABILITATION TEAM WILL:**

- Test and evaluate the effects of the brain injury
- Help set realistic goals
- Put a plan into action which will help achieve the goals

It is important to set short-term goals and accept small improvements until the person is emotionally and physically strong enough to face larger and long-term goals.



# HELPFUL TOOLS FOR PATIENTS

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## **CREATE A FAMILIAR ENVIRONMENT**

Have family, friends, and pet pictures around

Speak of familiar names, places, experiences, and interests such as hobbies and favourite past times

Talk about what is happening at home with their family and friends

Encourage family and friends to visit after the acute stage of recovery, but try to limit the number of people so it is not overwhelming. It may be necessary to restrict the number of visitors. Educate family and friends about the injury and be aware that friendships may change because of limitations and interests that change

Have a clock and calendar in the room, and if they are used to wearing a wristwatch have one for them to wear (one without a "second" hand might be best, to avoid confusion)

You may need the assistance of family and friends to fill in the gaps in memory and in developing relationships (old and new)

## **A PATIENT JOURNAL**

The use of a journal is encouraged. It is a journal where therapists, visitors, and family members will record what they have observed that day. It can include therapies attended, activities, reactions to different stimuli, changes in condition and attitudes, and comments made by the patient. It can be very helpful tool in plotting progress.

We also suggest YOU use a diary (see page 16). Do not confuse the Diary and Patient Journal, they are meant to be two different tools.

## **AN ORIENTATION BOARD/SHEET**

An orientation board or sheet of paper listing the day, month, and year, the days activities, nurses, therapists, the facility they are in, etc. can be very helpful. Many patients with a brain injury will have difficulty with their orientation to time and place. Often 'chunks' of memory are missing or misplaced and having a board to refer to occasionally may be helpful.



## WHERE TO TURN?

Contact the Saskatchewan Abilities Council for equipment and aids needed to support the survivor. A health care provider (physical therapist, occupational therapist, physiatrist, doctor, nurse, etc.) may need to order specialized equipment if your loved one with the injury will be returning home.

There are various agencies available to assist in the rehabilitation of your loved one; The ABI Outreach Teams can provide you with information and addresses. For the number of the ABI Outreach Team in your region, please see the 'Services' directory starting on page 43 of your TOOLBOX. It is often up to you as a caregiver to seek out the services available to you. By advocating for the needs of those with a brain injury, we can improve the availability of services.

REMEMBER, YOU ARE NOT ALONE. Contact our office for information on brain injury, and for contact numbers for support people in your area. Our contact information is located on Page 1.

# PATIENCE

One of the most important tools you will need is patience. You will need patience in:

- Watching your loved one getting over physical problems
- Understanding that recovery takes time
- Understanding all the new terms
- Keeping straight the names and duties of all the health professionals
- Waiting for the brain to heal
- Most of all you will need patience when dealing with the person who has received the brain injury

Your loved one will be slow to respond and may not be the same person you used to know in some or in many ways. Their mistakes are not intentional. Allow them the opportunity to push themselves towards achievement – it will give them a great sense of accomplishment to complete some of the tasks they set for themselves and experience success. Obviously, safety issues are always of prime concern and must always be considered when something new is tried. Be patient, for the journey can be very long, but take comfort in every improvement – you are part of the progress. NEVER GIVE UP HOPE! What you think is impossible today, may be second nature six months from now. Your loved one is ALIVE, that is the first step, just build from there.

# HOPE

One of the sweetest words in life is HOPE. How very hard it is to sit and wait in the hospital, whether or not your loved one is in a coma. Doctors come in and out, but can't tell you what is going to be the outcome. Still you must maintain hope; it gets you through day by day, week by week, month by month. It helps you to 'carry on' and helps your loved one recover.

Some families have found that the emotions experienced by the family members following a brain injury to one of their own, can serve an important and positive function in moving forward. These emotions can allow the family members to build strength, as they prepare to deal with the uncertainties of the future that were brought on so suddenly. It may be of some comfort for families to know that this journey can eventually result in continued family growth and personal development, and can add strength to the family bonds.

Recovery takes time and will vary with each person. There will be ongoing changes as the healing continues. These changes will appear in your life and also to your role in the life of the person with the acquired brain injury. Recovery time will vary as well. Physical recovery is more visible and often more immediate than psychological recovery and personality changes. These last changes are often more difficult to measure.

# ACCEPTANCE

It is important to accept the reality of the injury. IT HAS HAPPENED, but that doesn't necessarily mean that there will be no improvement in the condition of the survivor. If the brain has been injured, there may be some long-term effects from that injury. That does not mean that the extent of the injuries you see in the beginning will always be the same. Through therapy, stimulation, and the passage of time you may see many improvements. The brain will not heal at the same rate as a broken bone will heal – there are more factors than just physical.

You will experience a mixture of emotions – firstly, you are thrilled that the person has survived the injury, but you must still face the changes that are occurring. Time will make a difference, but it is going to take a lot of hard work for everyone involved to get the person with the brain injury to reach his/her highest potential. At least the person has survived the injury, that is the first step.

Depending on who in the family has received the brain injury, there may be a need for a change of roles in the family. This change can cause a lot of stress. Don't feel you have to carry this all on your own shoulders - find a professional who can help you get through this period of adjustment. Try not to allow yourself to become overwhelmed by all the changes, there are people to help you. Always remember “just one step at a time”, you will make it.

Don't deny your emotions. You may face denial, disbelief, guilt, anger, sadness, and a sense of being overwhelmed. Try to keep a positive outlook, for the most part.

Humour can be a good ally at this time. This statement is not meant to make light of the situation, but is meant to encourage you to look for the positive side of things in your conversation and actions. Your loved one is looking to you for guidance and if they see fear in your eyes it may frighten them, but if they see love and caring it will reassure them. Enjoy a light hearted video or joke book together with your loved one, if they are up to it. Work at bringing happiness and joy to the situation, as best you can. Some people have found it helpful to recall humorous events from the past and enjoy them all over again. It is okay to laugh and smile at a time like this. A smile can be infectious – pass it on!

You can gain support from others who have or who are facing the same kind of difficulties. Many people receive comfort from support groups. You will find our phone number on page 1 of this TOOLBOX, please contact us for the number of the support group nearest you.

ATTITUDE is the key to accepting and dealing with life's changes. By working at having a pleasing disposition we can positively affect those around us.

# IMPORTANT INFORMATION

1. If this injury is the result of:
  - a. **MOTOR VEHICLE COLLISION:** Contact Saskatchewan Government Insurance (SGI). They may be able to assist with financial matters.  
Call toll free: 1-800-667-8015
  - b. **INJURED AT WORK:** Ensure that your employer has filed the appropriate reports with the Workers' Compensation Board (WCB).  
Call toll free: 1-800-667-7590
2. As a close family member, you may wish to stay overnight in the hospital room with your loved one. The hospital will sometimes make those arrangements. Remember though, that you too need your rest to be able to cope with the challenges that lie ahead. After your loved one is out of danger, it may be wise to 'touch base' at home for a couple of days.
3. Don't be alarmed if your loved one becomes agitated when you are present. Do NOT take this personally or see this as a failure on your part. It just happens sometimes.
4. You may wish to request permission from the hospital to bring in some of the injured person's favourite items such as: music, family photographs, even food.
5. Some families take pictures of their loved one while in hospital, at various stages of recovery. The survivor sometimes wants to know what it was like at the differing stages of recuperation. It can be a very positive experience to see how far they have progressed and can encourage them to work even harder on their rehabilitation. This, of course, is a personal choice you and your family can make.

# DIRECTORY OF SERVICES

Saskatchewan Brain Injury Association (SBIA)

Mailing Address:

P.O. Box 3843

Regina, SK S4P 3R8

Saskatoon Office:

230 Avenue R South, SPH Residence

C-Wing, Room 422

Saskatoon, SK S7M 2Z1

Moose Jaw Office:

322 – 310 Main St. N.

Moose Jaw, SK S6H 3K1

Phone: (306) 373-1555

Toll Free: 1-888-373-1555

Email: [info\\_sbiam@sasktel.net](mailto:info_sbiam@sasktel.net)

Website: [www.sbiam.ca](http://www.sbiam.ca)

SBIA provides support and information for survivors of acquired brain injury (ABI) and their families. It also promotes public awareness and prevention, houses a general information resource center, and connects individuals to local Support Chapters, organizations, and Outreach Teams.

There are Support Chapters located throughout the province. Please contact our office for the number of the Support Chapter near you.

Saskatchewan Abilities Council

Provincial Services

2310 Louise Avenue

Saskatoon, SK S7J 2C7

Phone: (306) 374-4448

Saskatchewan Health Authority

Saskatoon City Hospital

701 Queen Street

Saskatoon, SK S7K 0M7

Phone: (306)-655-0080

Toll Free: 1-833-445-0080

# ABI OUTREACH TEAMS

The Acquired Brain Injury (ABI) Outreach Teams are an initiative of Saskatchewan Government Insurance. It is a three year program to coordinate services for ABI survivors across the province.

The aim is to assist and empower the survivor of brain injury toward successful integration or interdependence within the community. They have information on educational options, re-training, return to work/school, recreational opportunities, sexuality, equipment options, and much more.

## **Saskatchewan North**

Prince Albert Health  
Contact: Outreach Team Coordinator  
Prince Albert Parkland Health Region  
1521 6th Avenue West  
Prince Albert, SK S6V 5K1  
Phone: (306) 765-6630  
Toll Free: 1-866-899-9951  
Fax: (306) 765-6657

## **Saskatchewan Central**

Saskatoon  
Contact: Outreach Team Coordinator  
Saskatoon City Hospital  
701 Queen Street  
Saskatoon, SK S7K 0M7  
Phone: (306) 655-7743  
Toll Free: 1-888-668-8717  
Fax: (306) 655-8454

## **Saskatchewan South**

Regina  
Contact: Outreach Team Coordinator  
Wascana Rehabilitation Centre  
2180 23rd Avenue  
Regina, SK S4S 0A5  
Phone: (306) 766-5617  
Toll Free: 1-866-766-5617  
Fax: (306) 766-5144

# GLOSSARY OF NAMES

## **Audiologist**

An audiologist is available to perform hearing assessments

## **Dietician**

The dietician will assess nutritional needs and plan appropriate meals

## **Intensive Care Doctor**

The attending doctor while the patient is in Intensive Care that specializes in acute care medicine

## **Medical Social Worker**

Provides counseling for both the patient and the family, and also helps in locating a receiving facility when the patient is ready for discharge from the hospital. They can also help with other practical problems

## **Neurologist**

Medical specialist trained to care for all types of nervous system problems

## **Neurosurgeon**

Physician specialist trained to care for all varieties of brain problems and perform brain surgery as needed. He/she is primarily concerned with coordinating the medical treatment of the head injured, and deciding whether or not there is need for surgical treatment

## **Neuropsychologist**

The psychologist assesses the patient's intellectual, emotional, and social functioning and may provide recommendations for further treatment

## **Occupational Therapist (O.T.)**

Assess and treat patients in activities relating to dressing, eating, hygiene, household and domestic activities, and fine motor coordination. May be involved in assessment of cognition and safety

## **Physiatrist**

A rehabilitation specialist who may be consulted and/or provide inpatient and outpatient treatment

## **Physical Therapist (P.T.)**

The physical therapist is a therapist who assesses and provides treatment to improve strength, range of motion, coordination, balance, and mobility.

## **Recreational Therapist (R.T.)**

A recreational therapist is a therapist who promotes independence and assists with community integration. The goal is to help the patient develop skills, knowledge, and to help find resources to allow for the patient to take part in activities that add quality and meaning of life.

## **Resident Doctor**

A fully qualified doctor who is specializing in a particular field of study

## **Speech-Language Pathologist (S.L.P)**

A speech pathologist is a therapist who assesses and treats patients with communication, language, or hearing problems, and develops non-verbal communication systems as required. They may also assess and assist with swallowing and cognition.



# GLOSSARY OF TERMS

**A.D.L.**

Activities of daily living, e.g. feeding, dressing, grooming, domestic chores

**A.F.O.**

Ankle-foot orthosis, short leg brace

**Ambulate**

To walk

**Amnesia**

Loss or impairment of memory

**Anoxia**

A lack of oxygen which may cause damage to the brain

**Antibiotic**

Medication used for treatment of bacterial infections

**Anticonvulsant**

Medication to decrease the possibility of seizures; also used to prevent or relieve convulsions (Dilantin, Phenobarbital, or Mysoline)

**Aphasia**

Inability to express or understand ideas in any form

**Expressive Aphasia**

Inability to express oneself even though one knows what to say

**Receptive Aphasia**

Inability to comprehend spoken language

**Global Aphasia**

Both expressive and receptive aphasia

**Apraxia**

Inability to plan motor movements

**Arterial Line**

A thin tube inserted into one of the patient's arteries (usually in the arm) to allow direct measurement of the blood pressure and to measure the concentration of oxygen and carbon dioxide in the blood. The arterial line is attached to a monitor

**Aspiration**

A swallowing problem when food, liquid, or secretions enter the lungs

**Ataxia**

Failure of muscular coordination; irregularity of muscular action

**Attention Span**

The length of time a person can concentrate upon a task or event

**Bed mobility**

Ability to move oneself on a mat or bed, as by rolling, sitting, or lying down

**Bilateral**

Pertaining to both sides of the body

**Brainstem**

The lower portion of the brain which connects it to the spinal column

**Brain Stem Evoked Responses**

Auditory brainstem responses provoked by stimulation to the brainstem with painless sound waves using headphones. The brain received these sound waves, and a machine is used to test whether the brainstem has received the signals. The quality of the brainstem's functioning in a comatose patient is thought to be an important indicator of the degree and site of brain injury

**Catheter**

A tube for draining urine inserted into the bladder (Foley) or external over the penis (condom)

**Intermittent Catheterizations**

On a regular schedule, a catheter is inserted into the bladder to empty it. The catheter is then removed

**Central Venous Pressure (CVP) Line**

A thin tube into one of the patient's veins to allow direct measurement of the venous blood pressure (the pressure of the blood as it returns to the heart). CVP lines are inserted into veins in either the patient's arms, the chest just below the shoulder, or occasionally on the side of the neck. The CVP catheter is connected to a monitor

**Chest tubes**

Tubes inserted into the patient's chest between the lung and ribs to allow fluid and air to drain from the area surrounding the lungs. Removing this fluid and air from the lungs allows them to more fully expand. An accumulation of fluid and air in the lung capacity can cause the lung to collapse there may be one or more of these tubes and they drain into a large plastic container near the foot of the patient's bed

**Cognition**

Understanding and reasoning, the mental faculty or process by which knowledge is acquired. It includes all aspects of perceiving, thinking, remembering, and problem solving

**Cognitive Retraining**

Developing or relearning the processes involved in thinking

**Coma**

Unconsciousness lasting for more than a brief period of time. A state of unconsciousness where the person cannot be aroused or does not respond

**Communication System**

Any approach designed to support, enhance, or supplement the communication of individuals who are not independent verbal communicators. i.e. sign language, picture boards, technical aids.

**Concrete Thinking**

The individual is unable to understand the similarities between situations, seeing each situation as different; language is interpreted literally

**Concussion**

An injury to the brain resulting from a blow or violent shaking. Producing temporary impairment of consciousness, vision, or balance. A mild form of brain injury, which can cause serious problems with repeated occurrences

**Contracture**

Loss of joint motion; stiffness

**C.T. Scan**

Computerized radiography which shows sections of the brain at different levels

**Decerebrate**

Abnormal response characterized by extension of extremities to painful stimuli

**Diplopia**

Double vision

**Drug Levels**

Test giving level of medication (e.g. Anticonvulsant) in blood

**Dysarthria**

Unclear slurred speech due to disturbances of muscular control which results from damage of the central or peripheral nervous system

**Dysmetria**

Errors in range of movement

**Dysphagia**

Inability to swallow or difficulty in swallowing

**Dysphasia**

Impairment of speech or written language resulting from a brain injury

**E.E.G.**

Electroencephalogram (brain wave test). Electrodes are placed on the scalp to detect electrical charges produced by brain activity

**E.K.G. (E.C.G.)**

Electrocardiogram. Electrode pads are placed on the patient's chest to monitor heart rate and rhythm

**Endotracheal Tube (E.T.tube)**

Tube that serves as an artificial airway and is inserted through the patient's mouth or nose and passes through the throat (vocal chords) and into the air passages to help breathing. It is the tube that connects the respirator to the patient

**Extension**

The act of straightening a joint

**Fine Motor Activities**

Activities involving small complex movements such as writing and manipulating small objects

**Flaccid**

Lacking muscle tone, flabby

**Flaccidity**

Abnormal decrease in muscle tone resulting in less resistance to passive and active movement

**Flexion**

To bend a joint

**Gait**

The manner or style of walking

**Gait Training**

Instruction in walking, with or without equipment; also called ambulation training

**Gastrostomy Tube**

A feeding tube passed directly into the stomach from a surgical opening in the abdomen

**Glasgow Coma Scale**

Classification of level of coma. Evaluation of verbal, motor response and eye opening abilities

**Gross Motor Activities**

Large movements of body parts, as those involved in rolling, sitting up and standing

**Halo**

A metal ring used for patient's with spinal cord injuries, which encircles the patient's head to allow for proper alignment of the neck and spinal column

**Hematoma**

A localized collection of blood, usually clotted, in an organ, space, or tissue, due to a break in the blood vessel wall

**Hemiparesis**

Lack of muscle control on one side of the body (see Paresis)

**Hypertonia**

A condition of excessive tone of the skeletal muscles; increased resistance of muscle to passive stretching

**Hypotonia**

A condition of abnormally diminished tone of the skeletal muscles

**Hypoxia**

A decrease in oxygen to the brain

**I.C.U.**

Intensive Care Unit

**Incontinence**

Inability to control bowel and bladder functions

**Intention tremor**

Tremor most evident at the end of a fine motor movement

**Intra-cranial pressure (I.C.P.)**

Pressure within the skull

**Intravenous**

A tube inserted into a vein enabling the administration of fluid solutions and medications

**Intubation**

Insertion of a tube, especially the introduction of a tube into the wind pipe to improve respiration

**Memory**

The mental faculty by which sensations, impressions and ideas are recalled

**Motor planning problem**

Difficulty starting, continuing and stopping movements when there is no actual muscle weakness or damage. May affect speech or movement of the arms or legs. Also referred to as Apraxia

**M.R.I.**

Magnetic Resonance Imaging. A study using magnetic and radio frequencies to produce a picture of the brain or any other body part

**Muscle Spasm**

A sudden, violent, involuntary contraction of a muscle or a group of muscles, attended by pain and interference with function, producing involuntary movement and distortion

**Muscle Tone**

The tension present when a muscle is at rest or with movement

**N/G tube**

Nasogastric tube. A tube which is passed through the nostril and into the stomach to carry food directly to the stomach

**Neurological Vital Signs**

Neurological responses, which are followed to determine improvement or deterioration of a patient, such as motor responses, etc.

**N.P.O.**

A medical abbreviation for a physician's order that the patient is to receive 'nothing by mouth'

**Nystagmus**

Involuntary movement of the eyeball

**O.R.**

Operating room

**Orientation**

Awareness of self, other people, time and place

**Orthotics**

Braces for various parts of the body

**Paralysis**

Inability to move a muscle or group of muscles voluntarily

**Paresis**

Lack of muscle control/weakness of the body; partial paralysis

**Perception**

Ability to recognize and distinguish objects in the environment, including size, shape, color, and distance and the integration of sensory impressions into meaningful information

**Perceptual Motor**

Interaction of vision with motor (muscular) activities, such as eye-hand coordination, eating, picking up objects, etc.

**Plateau**

Stabilization of condition at certain level of impairment

**Post Traumatic Amnesia**

Loss of sequential memory for events since the injury. This leads to severe impairment of learning ability

**Premorbid**

The patient's condition before the injury

**Pressure Area**

A sore or discoloured area of skin caused by continued pressure, which could eventually develop into a decubitus ulcer or bed sore

**Prosthetic**

An artificial limb

**Quadriplegia**

Lack of control of all four limbs of the body resulting from an injury to the brainstem or cervical spinal cord

**Range of Motion (ROM)**

The range of motion available in a joint, measured by degrees

**Reality Orientation (R.O.)**

Reviewing with the patient names of familiar persons, places, things and time

**Reflex**

An involuntary response to a stimulus, such as a knee jerk

**Rehabilitation**

A system of organized treatment that enables an injured person to regain the highest possible degree of mental and physical ability

**Respirator/Ventilator**

A mechanical device used to assist the patient's respiration

**Retrograde Amnesia**

Lack of memory of things that happened just before a head injury

**Sedative**

Medication given to achieve a calming effect

**Seizure**

Disturbances of the electrical activity to the brain that may cause impairment or loss of consciousness, abnormal motor movement, psychic or sensory disturbances of the autonomic nervous system. Symptoms are due to the disturbance of the electrical activity of the brain

**Selective Attention**

Ability to focus attention upon a specific thing or task for a given amount of time

**Sensation**

Information received by the brain through the senses of touch, sight, hearing, smell and taste

**Sensory Stimulation**

Arousing the brain through any of the senses

**Spasm**

A sudden, abnormal, involuntary muscular contraction

**Spasticity**

Abnormal increase in muscle tone or stiffness, resulting in more resistance to passive and active movement (also called hypertonicity)

**Splint**

A support used to position one or more joints properly to reduce muscle tension, increase movement and/or allow greater use of the body part

**Stimulation Program**

Set of exercises, activities or maneuvers designed to facilitate the recovery of the patient

**Strabismus**

Uncoordinated movement of the eyes, usually resulting in double vision

**Structure**

(used as a verb) to simplify a task, activity, information, or surroundings by giving information in a uniform manner (repetition)

**Suction**

Removal of gas or fluid by use of a catheter and/or suction device

**Tone**

Tension in resting muscles and the amount of resistance that is felt when the muscle is moved

**Trach (Tracheotomy)**

A surgical opening at the front of the throat providing access to the trachea or windpipe

**Transfer**

Refers to methods of getting to and from a wheelchair, bed, toilet, etc. using a stand-pivot movement or a sliding board, for example

**Unilateral**

Affecting only one side of the body

**Void**

To urinate

**Walker**

An aid utilized to provide support while walking

**Wheelchair Tolerance**

The amount of time a person can sit in a wheelchair, determined by the skin's response to the pressure of sitting and the ability to maintain a sitting posture without excessive fatigue

# RECOMMENDED READING & VIEWING

## RECOMMENDED READING

Meeting the Housing Needs of Brain Injury Survivors  
<https://www.sbia.ca/s/SBIA-Housing-Book-FINAL.pdf>

Statistical Information on Acquired Brain Injury  
<https://obia.ca/resources/brain-injury-information/statistical-information-on-acquired-brain-injury/>

### Books

The Brain That Changes Itself by Dr. Norman Doidge

The Brain That Heals Itself by Dr. Norman Doidge

The Woman Who Changed Her Brain by Dr. Barbara Arrowsmith-Young

Gabby by Gabrielle Giffords and Mark Kelly

Livewired by David Eagleman

Fallen: A Trauma, a Marriage, and the Transformative Power of Music by Kara Stanley

Fiction – Left Neglected by Lisa Genova

## RECOMMENDED VIEWING

You Can't Predict a Brain Injury (Part 1)  
<https://www.youtube.com/watch?v=TDHJgnVn6L4>

The Same But Different (Part 2)  
<https://www.youtube.com/watch?v=UWHDfrhghns>

Support is Key (Part 3)  
<https://www.youtube.com/watch?v=tAlr58dJ2ro>

Heading Into the Future (Part 4)  
[https://www.youtube.com/watch?v=m\\_4IUNB11-0](https://www.youtube.com/watch?v=m_4IUNB11-0)

You Can't See a Brain Injury: Emilia's Story  
<https://www.youtube.com/watch?v=i5C7rGkKcp0>

Neuroplasticity  
<https://www.youtube.com/watch?v=ELpfYCYa87g>

## RELATED LINKS

SBIA Website  
<https://www.sbia.ca/>

BrainLove Website  
<https://www.brainlove.ca/>

ABI Partnership Website  
<https://www.abipartnership.sk.ca/index.php>

Understanding the Intersection of Intimate Partner Violence and Traumatic Brain Injury  
<https://abitoolkit.ca/>

Mindfulness & Meditation After ABI (research and training by Melissa Felteau)  
<https://www.semanticscholar.org/author/M.-Felteau/11295474>



# RESEARCH MATERIALS

Brain Injury, Coping with the Results of Brain Injury. Glenrose Rehabilitation Hospital. (1993) Edmonton, Alberta. ISBN 0-9695567-2-1.

The Concise Oxford Dictionary. (1985) University Press, Oxford, England, UK.

Head Injury Manual. (1992) Regina Qu'Appelle Health District, Wascana Rehabilitation Centre, Regina, SK.

Learning to Help Yourself. (1986) Saskatchewan Head Injury Youth Association.

Patient Education and Discharge Planning Manual. (1995) Aspen Publishers, Inc.

Pathways to Recovery: A Handbook for Volunteers Working with Brain Injured Adults. (1994) Association for the Rehabilitation of the Brain Injured, Calgary, AB. ISBN 0-9692477-1-0.

Various Pamphlets:

Craig Hospital, Englewood, Colorado, USA.

Saskatchewan Government Insurance (SGI)





# Saskatchewan Brain Injury Association

## **THIS TOOLBOX HAS BEEN PREPARED FOR YOU BY THE:**

Saskatchewan Brain Injury Association  
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# Saskatchewan Brain Injury Association

## **MISSION**

The Saskatchewan Brain Injury Association strives to prevent brain injuries and to improve the lives of brain injury survivors and their families.

## **VISION STATEMENT**

Brain injuries are reduced and there exists a provincial continuum of support informed by those with lived experience that encompasses all those affected by brain injury.