MANITOBA BRAIN INJURY ASSOCIATION

We've been there, we can help

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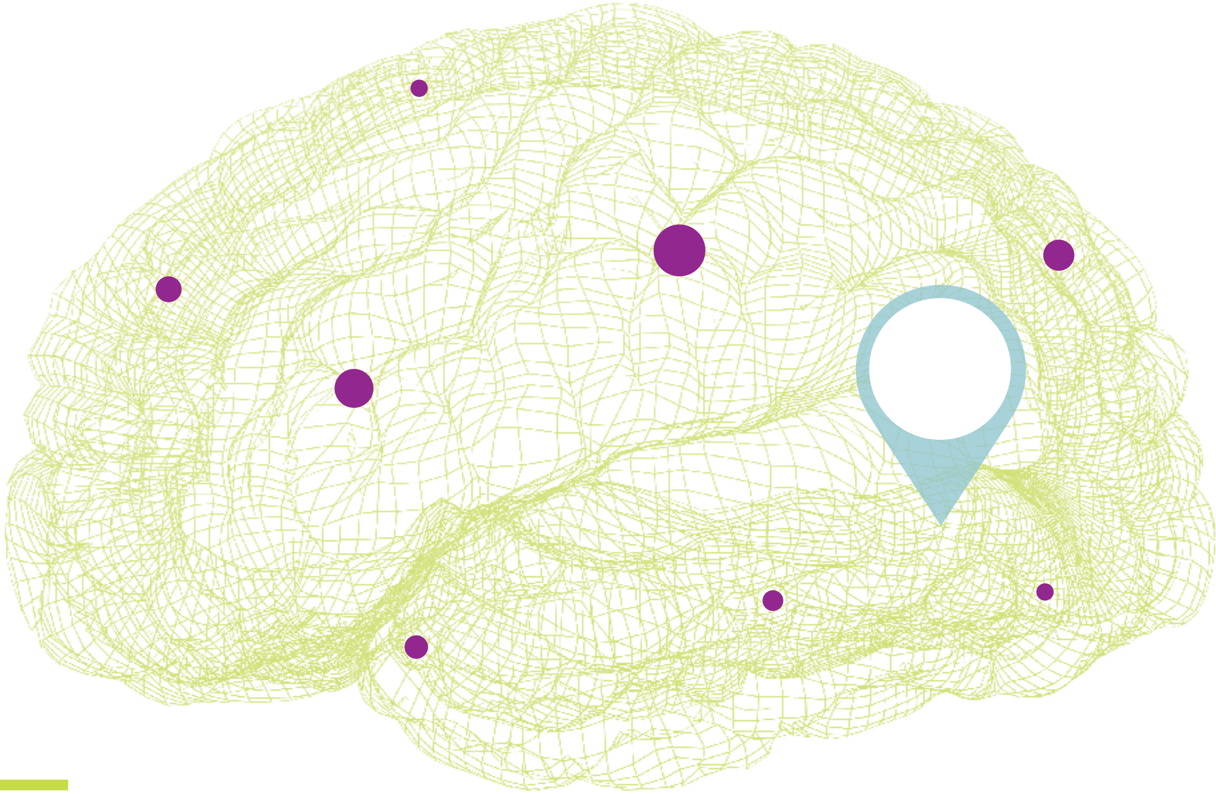
PREFACE

There are no magic solutions to the anxiety and fear that brain injury survivors, their families, and friends go through following diagnosis. We hope that this booklet will provide some guidance and insight. We wrote it with a deep sense of empathy and a desire to help you and your loved ones now and throughout the journey of recovery.

Knowledge is empowering and liberating and makes rational decision-making possible. A lack of knowledge leads to fear, misconception, poor decisions, and stress. The more we know and understand about acquired brain injury generally and our own brain injury in particular, the greater the possibility of making a full recovery and achieving the quality of life we seek. Knowledge is more than simply receiving information. Its value comes when we are able to think through and understand the information, and then take action based on that.

We've organized this booklet so that you and your loved ones can find needed information easily. If you come across unfamiliar terms, check the glossary in the last chapter for explanations. Keep this booklet handy as you progress through the journey of recovery and refer to sections as they apply.

Keeping a journal can be very helpful. The nature of recovery often involves very small, slow steps. Because of this, it's easy to feel as though there has been no progress. At these times, caregivers and other family members can look back in the journal to show you the progress that you have made. We have included an outline of a journal for the first 10 days of the journey of recovery to help you get started.



INTRODUCTION

The brain is a spectacular organ. It monitors and manages our entire body, storing all the knowledge we have ever gathered. It receives, processes, and interprets all the external stimuli our various senses collect. The brain then meshes this together to create the thoughts and perceptions that become our reality.

Each year 50,000 Canadians suffer a brain injury and more than 11,000 Canadians die from one. In Canada and the US, acquired brain injury (ABI) is the 3rd leading cause of death and the leading cause of disability. An estimated 1 in 26 Canadians are living with ABI, ranging from mild concussion to more severe trauma that leaves the survivor in a life-long coma. On average, hospitals admit 46 people a day due to a traumatic brain injury (Canadian Institute for Health Information, 2006).

Acquired brain injury has many forms. Traumatic brain injuries (TBI) occur as the result of an external force to the head such as in motor vehicle collisions, assaults, falls, sports concussions, or shaken baby syndrome. Nontraumatic injuries occur as the result of body malfunctions such as strokes, aneurysms, brain tumours, or heart attacks. Others are due to long-term action or inaction such as drug or alcohol abuse or uncontrolled diabetes or high blood pressure.

DAILY JOURNAL

(In Hospital)

Recorded by:

Date:

AM

Observer:

The best thing that happened today

PM

Observer:

The best thing that happened today

Doctor came to visit.

DAILY JOURNAL

(In Hospital)

Recorded by: ____________________

Date: ____________________

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How we can help

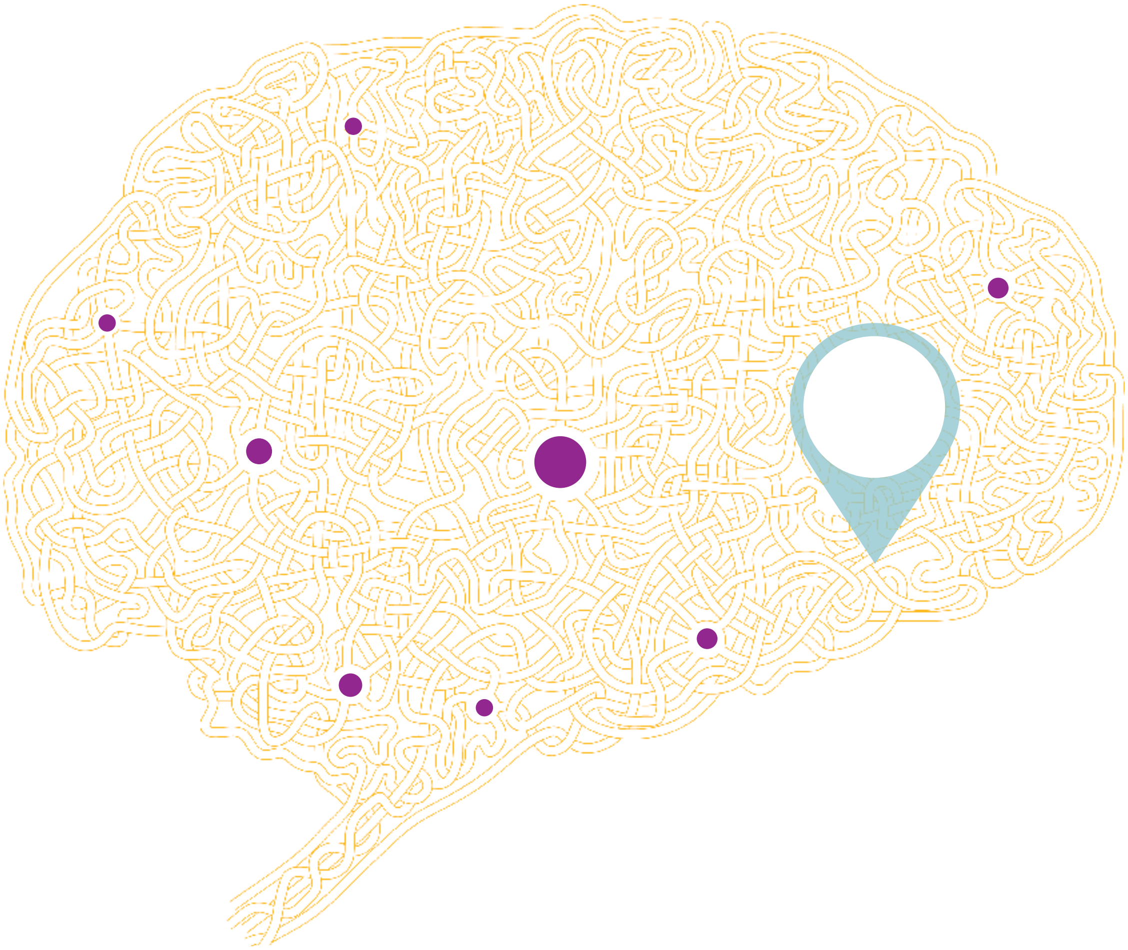
Following a brain injury, the injured person as well as his or her family can feel confused and uncertain. Education is important during each phase of recovery. It helps improve functioning and self-care, prevents complications, and restores independence. The Manitoba Brain Injury Association (MBIA) is your ally during this difficult time.

We began as a group affected by brain injury who came together to share personal experiences and offer support to one another. MBIA's mission is to offer help and hope to individuals and families living with the effects of brain injury. We do this through direct services, education, and advocacy. We work to promote independent living and a sense of community among those affected and to educate all Manitobans in an effort to prevent ABI.

We provide support to those living with a brain injury, as well as their families, through group meetings as well as social and recreational programs. We provide education about the causes and effects of brain injuries for our members, the public, professional organizations, and private industry. We raise awareness of the unique needs of people living with the effects of brain injury. We also advocate for our members who often need help to access government agencies, health services, and rehabilitation centres.

SUPPORT

CHAPTER 1



The Basics of Brain Injury

WHAT IS ACQUIRED BRAIN INJURY?

Acquired brain injury refers to damage to the brain that happens because of an event after birth. It does not refer to brain defects present at birth or to degenerative brain conditions such as Alzheimer's disease or Parkinson's disease.

CAUSES AND TYPES OF BRAIN INJURY

Generally, there are two types of brain injury: **traumatic** and **nontraumatic.**

A ***traumatic brain injury*** *is an injury caused by a force outside of the brain.*

Closed traumatic brain injury

This type of injury is the result of a blow to the head. The force of a strong blow will cause the brain to move or shake within the skull. The sharp and hard parts on the inside of the skull itself can cut and bruise the brain. It can happen in many ways such as the following:

- impact from a motor vehicle accident
- a fall
- when hit with a blunt object such as a fist or weapon

Sometimes the brain bounces against the sides of the skull resulting in more damage. This is called a **coup-contrecoup injury**.

Open traumatic brain injury

This type of injury happens when an object enters the brain through the skull, such as bullets, knives, debris from an explosion, or pieces of bone or metal. Damage to the brain tissue is seen mostly in one area—the area of penetration.

Nontraumatic brain injuries *are caused by changes or problems within the brain itself. Some examples of this kind of injury are as follows:*

Spontaneous bleeding

Bleeding within the brain can happen due to weak or malformed blood vessels. Another term for bleeding is hemorrhage. This type of injury can happen with high blood pressure, arterial venous malformations or rare bleeding disorders.

Infections or metabolic disorders

There are many types of infections (which is when a virus attacks the brain) as well as metabolic disorders (caused by events such as an overdose of drugs, loss of oxygen due to heart and lung failure, or a sudden change because of the failure of a body organ).

Tumours

A tumour is an abnormal mass of tissue that can cause injury to the surrounding brain tissue. After surgery has removed the tumour, the surgical process may result in changes to the brain.

HOW BRAIN INJURY IS DIAGNOSED

When you or your family member is injured, the first questions that come to mind are, "How bad is it?" and "Will I be normal again?" This is difficult to answer because there is no way to predict how a person will recover. However, the severity of brain injury is based on the indices of neurological and neuroradiological tests. In the case of a traumatic brain injury (TBI) resulting in a coma, health practitioners gauge severity of that injury based on the Glasgow Coma Scale (GSC).

> *A coma is a state of unconsciousness lasting longer than an hour. Unconsciousness means no speech and no meaningful response to touching and talking.*

Glasgow Coma Scale

The Glasgow Coma Scale is used in the emergency room and intensive care.
It measures level of awareness, how bad the brain injury is, and coma level.
This is used to rate the following:

- ability to open eyes
- ability to respond when asked to move
- ability to speak

Scores can range from a low of 3 to a high of 15. A score of 9 or more means the person is no longer in coma.

HOW BRAIN INJURY IS RATED

Brain injuries are rated by their severity at the time of the injury. Ratings range from mild to severe.

A concussion is a mild form of brain injury. In most cases those who have had a concussion exhibit the following physical signs:

- Loss/altered consciousness
- Balance problems
- Seizure
- Poor concentration
- Inappropriate emotions
- Vomiting
- Slurred speech
- Personality changes
- Sleep disturbance

Some individuals may have one symptom, some may have all. Having only one can still constitute a concussion.

Upon the patient's release from the hospital, the physician will give instructions on how to provide care and explain the symptoms or behaviour changes that should be reported to the hospital.

WHAT HAPPENS RIGHT AFTER THE INJURY

The fastest recovery tends to happen in the first six months after the injury. When other issues (such as other bodily injuries) are present, the recovery becomes more complicated. The pace of recovery tends to be slow, steady improvement with further smaller gains over time. Progress can feel a bit like riding a roller coaster. No one can be certain about the outcome of the journey of recovery or to what level of functioning the survivor will advance.

After the initial injury, there could be brain swelling (also called cerebral edema). In the days and weeks after injury, the tissue in the brain may swell or bleed. In some cases, small amounts of fluid are removed from around the brain to relieve the pressure in an effort to improve its functioning.

COMMON COMPLICATIONS FOLLOWING BRAIN INJURY

Here are some of the common complications that can happen as a result of a traumatic brain injury:

Increased intracranial pressure: This is when pressure inside the skull increases, affecting the brain tissue.

Edema: This is also called brain swelling, which happens when the brain contains more fluid than normal.

Hydrocephalus: This happens when there is too much water (cerebrospinal fluid) on the brain. If the condition becomes severe, doctors place a shunt in the brain to drain the fluid.

Low blood pressure: Blood carries oxygen to the brain. Low blood pressure means a decrease in blood flow to the brain.

Fever: Injury to the brain may cause high fevers especially in the first few hours or days after injury.

Pneumonia: Injury increases the risk of pneumonia; the doctors and nurses will make sure to monitor breathing and lungs.

THE STAGES OF RECOVERY

"If my brain is injured, how will I ever recover?"

This is a question many who suffer a brain injury ask. Our mission is not only to provide you with information, but also to give you hope. And there is hope for recovery.

Every brain Injury is unique to each individual, as is his or her journey of recovery. Much depends on the location and extent of the injury. Recovery is a slow process and it's best to view it as a marathon rather than a sprint. The recovery process can take weeks, months and even years. Sometimes it's longer than friends and family expect.

Recovery begins immediately following the event. Generally, acute care hospitalization is necessary until the survivor is strong enough for three hours of rehabilitative therapy a day. Most of the time, rehabilitative inpatient therapy is provided until the survivor is able to function safely in the community. For many survivors this takes six to eight weeks.

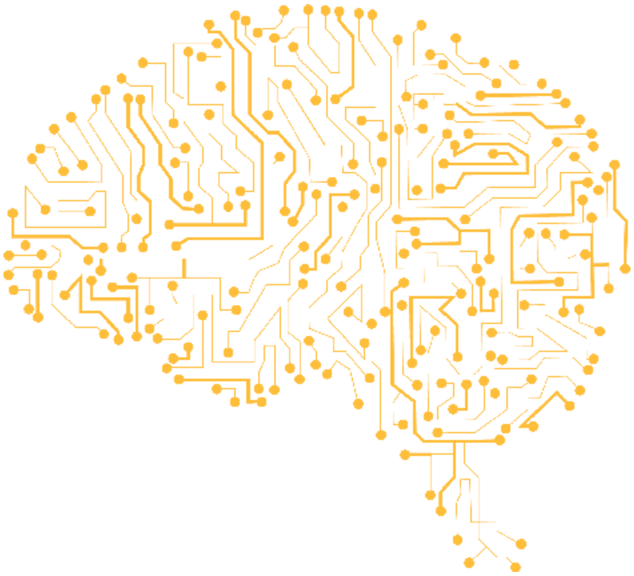
Upon return to the community, recovery will continue until the individual reaches a quality of life that is meaningful and satisfying.

HOW THE BRAIN RECOVERS OVER TIME

The journey of recovery following a brain injury is a long-term process. It is a journey of small steps taken slowly over time. Recovery happens as the brain tissue and other body organs heal. There are many factors that could affect the pace of the recovery process. The following are just some of the factors:

- age
- area and extent of injury
- time since the injury happened
- motivation to recover
- substance use and abuse
- previous brain injury or concussion

When the brain suffers an injury, areas responsible for certain functions are damaged. But the brain has the incredible ability to adapt to this damage by using another part of the brain to perform the same function. In response to an injury, the brain's structure can also change and adjust though learning. This ability to adapt and learn is called brain plasticity or neuroplasticity. In the rehabilitation phase, you will be guided through specific experiences and practices that aid neuroplasticity. Rehabilitation will focus on the functions of the brain that need improving.



RECOVERY IS A MARATHON RATHER THAN A SPRINT

The brain controls how we perceive, understand, and interact with the world around us. When the brain is injured, the ability to do these things may change. You may need to relearn tasks that you had previously mastered, such as talking, walking or writing. Things may be harder to remember than they used to be. This can be frustrating, and it is understandable to want to work hard to regain function as fast as possible. The fact is, recovery takes time! **A successful recovery is not measured by how fast it happens.** If you broke your leg, it would be in a cast for weeks or months. Even when the cast is removed, your leg would still require time to adjust. Nobody would expect you to be able to run a marathon the moment the cast comes off. The same is true for the brain.

As part of the recovery process, you may need to accept that you will not be the same person you were before the injury and you may experience grief over this loss. This is a normal process and is no cause for shame. Often, it is necessary to grieve the loss of the "old self" before embracing the "new self." Keep in mind that your brain is resilient and has the ability to learn new ways of functioning. At any time in life, we are the sum total of all our development and experiences to that point. Recovery does not mean going back to what you were. Rather, it's a continuation of life that involves making adjustments based upon present functioning.

As a family member, it can be heartbreaking and frustrating to watch a loved one recover from a brain injury. You might feel hopeless not knowing how to best help your loved one during the recovery process. It is equally important for you to keep in mind that recovery takes time.

Dr. Jill Bolte Taylor (2006), who suffered a brain injury due to a massive stroke, makes the following recommendations for you to consider during your loved one's recovery process:

- I am not stupid, I am wounded. Please respect me.
- Come close, speak slowly, and enunciate clearly.
- Be as patient with me the twentieth time you teach me something as you were the first.
- Approach me with an open heart and slow your energy. Take your time.
- Be aware of what your body language and facial expressions are communicating to me.
- Make eye contact with me.
- Please don't raise your voice – I'm not deaf, I'm wounded.
- Honour the healing power of sleep.
- Stimulate my brain when I have any energy to learn something new, but know that a small amount may wear me out quickly.
- Introduce me to the world by touch. Let me feel everything.
- Ask me questions with specific answers. Don't rush me for an answer, allow me time to think and formulate my answer.
- Speak to me directly, not about me to others.
- Trust that my brain can always continue to learn.
- Break all actions down into smaller steps of action.
- Look for what obstacles prevent me from succeeding on a task.
- Clarify for me what the next level or step is so I know what I am working toward.
- Celebrate all of my little successes.
- Please don't finish my sentences for me or fill in words I can't find. I need to work my brain.
- Focus on what I can do rather than bemoan what I cannot do.
- Introduce me to my old life. For example, don't assume that because I cannot play like I used to play that I won't continue to enjoy music or an instrument, etc.
- Keep me familiar with my family, friends, and loving support. Build a collage wall of cards and photos that I can see. Label them.
- Be protective of me but do not stand in the way of my progress.
- Remember, a person has to walk before they can run. These recommendations will assist you in helping your loved one during the recovery process. But do not be discouraged if this process takes time. Your patience and support will be a powerful force for their recovery.

Survivor's Story:

The Power of Support

In September 1981, my wife Val, who was 26 at the time, was shopping at St. Vital Centre when she felt a sudden and intense explosion in her head. She became very ill and required emergency transport to St. Boniface Hospital. A blood vessel in her brain had ruptured and was bleeding within her skull, causing potentially life-threatening pressure on her brain. This is what is medically referred to as a ruptured aneurysm. I am an athletic therapist by profession and am trained to recognize and treat athletic injuries including those to the head. Ironically, on the day of her accident I was testing a student therapist on his ability to handle emergency head injuries.

When I arrived at the hospital, a neurosurgeon (whom I knew very well) gave me the facts in very cold and non-emotional terms. I was very shocked and angry at this response, but later learned to appreciate that this person delivers a similar message to other families on an almost daily basis. It must be particularly difficult with people you know and this was likely his way of coping with the emotions.

Val was hospitalized for three weeks and thankfully recovered to the point where she could be released. No surgery was suggested at the time. Our family and friends were our primary source of support. Perhaps people assumed that because I was aware of the medical issues involved I didn't need any other support. Fortunately, we were young and we did not have children in need of our attention.

Two months later, to help with her recovery, Val volunteered at the school where she had been teaching before her brain injury. In September 1982, Val's strong will, determination, and perseverance enabled her to recover well enough so that she could return to full-time teaching. We thought we were back to normal again.

In January 1984, Val and I were anxiously awaiting birth of our first child due that April. One evening Val had a severe headache and I rushed her to the emergency room. She had suffered a second bleed. This time she was six and half months pregnant. Special precautions were required leading up to and during the birth of our daughter Erin. Val required surgery following the birth.

Something very different happened this time.

I was waiting in the hospital waiting room for Val to be transferred up to the ward. When I sat down, I saw a young man flanked by an older couple. They were sitting in the very same seats where wife's parents and I sat in the first time. I looked at their faces and knew then that they were facing the very same problem we had encountered three years earlier.

Once Val had been transferred up to the ward and was stabilized, I walked out of the room and saw these same three people clinging to each other in the small waiting room on the ward. I stopped and told them that my wife and I had been through this once before and asked if there was anything I could do. They immediately started to ask me a million questions. As it turned out, this was a young couple who, like us, were expecting their first child in six weeks. The older people were the woman's parents.

I spent a lot of time with the husband and his family helping them to understand the medical aspects of his wife's head injury. More importantly, I think, I listened to him talk about the emotions he was feeling. In some ways it was therapeutic for me and helped me deal with our situation as well. I had to be strong and maintain a positive attitude for all of us. Both of our wives were in the same room. They also talked to each other offering support, strength, and hope whenever the other was in need. Both of our wives delivered healthy babies and required surgery a short time later.

Our relationship extended beyond the hospital stay. Because this family was from out of town, much of our contact was by telephone, short visits when they came to Winnipeg to see the doctor, or when we travelled to their home to visit. Both of our families are now "back to normal."

This experience demonstrated to me the importance of a support group. People experiencing this crisis situation are totally overwhelmed by fear, anxiety, and the sudden change in their lives. The medical personnel, who must focus on the medical needs of the patient, may not have adequate time to provide a compassionate ear or tend to the emotional needs of both the patient and the family.

Helping others is also empowering to those of us who have experienced the crisis. It helps us to reaffirm that we have been strong enough to overcome our own problems thus far and will continue to do so in the future.

- Glen Bergeron

JOURNAL

Describe the injury as best as you can, in your own words.

Strongest fears or concerns at this moment in time.

What impact have these fears or concerns had on you?
On your family members?

The Brain

The more you know about the brain, the easier it is to understand your brain injury.

The brain is a complex organ that acts as the control centre for all of the body's actions and functions. Billions of nerve cells in the brain respond to messages that allow the person to perform bodily processes such as emotions, judgment, movement, and thought processes.

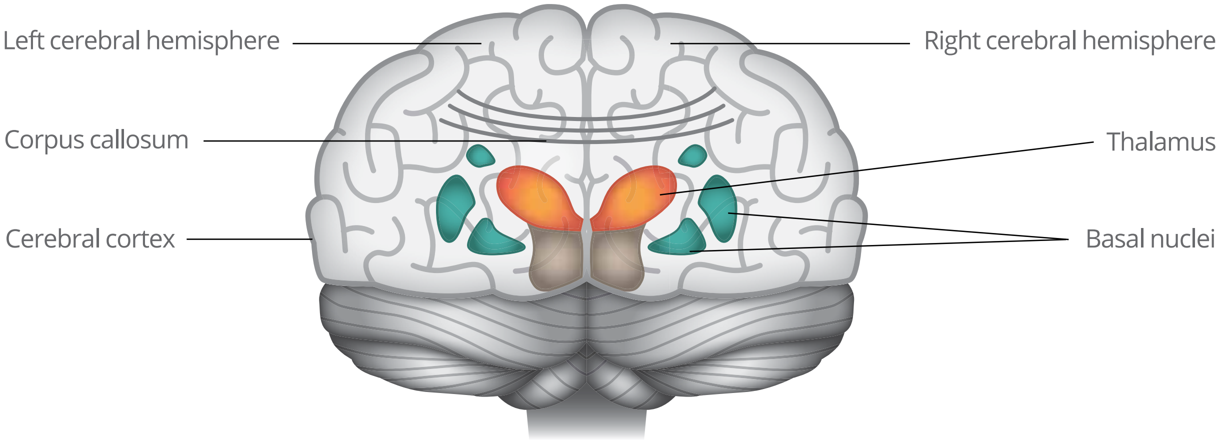
The brain has six parts: the frontal lobe, parietal lobe, temporal lobe, occipital lobe, cerebellum and the brain stem. Each part has different functions and links to other parts of the brain to perform specific tasks. However, when a brain injury occurs and one or more of these areas is affected, normal functioning may be altered depending on the location and the severity of the injury.

ANATOMY OF THE BRAIN

The brain weighs about 1-1.5 kilograms (2-3 pounds) and is located inside the skull. Just inside the skull, the brain is surrounded by a clear fluid called **cerebrospinal fluid (CSF).** This fluid allows the brain to float within the skull, which provides it with protection by acting as a cushion.

The cerebellum is the largest part of the brain. Its function is to coordinate movement. Damage to this area can result in **difficulties with balance.** Movements may be slow and uncoordinated. It may seem as though the person is "missing their target" due to difficulties with judging distance and coordinating hand-eye movements. The cerebellum is divided into a left and right hemisphere.

Figure 2. Cerebral Hemispheres

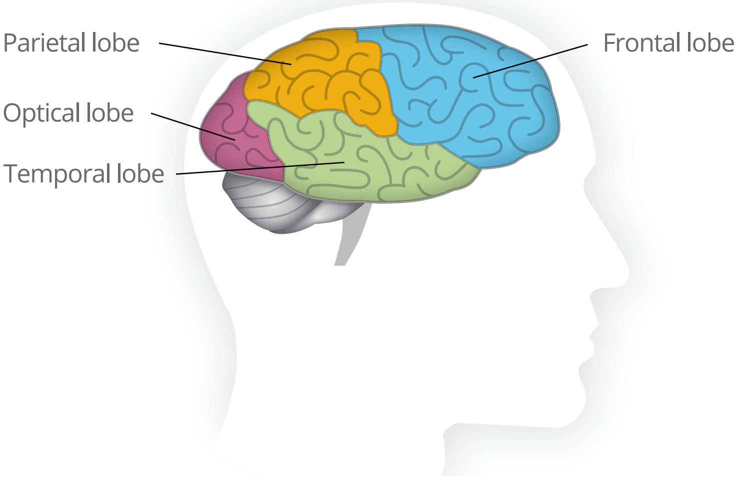


Lobes of the Brain

The brain is divided into four lobes:

- frontal
- occipital
- temporal
- parietal

Figure 3. Lobes of the brain



Frontal lobe

The frontal lobe is the largest of the four lobes. This lobe is responsible for executive functions, which refer to higher level, more complex thinking. Injury is common in the frontal lobe area because it is located in front of the brain and sits inside the skull near its bony ridges.

The frontal lobe is also responsible for the following:

- problem-solving
- planning and anticipation
- organizing and sequencing
- understanding abstract concepts
- attention and concentration
- memory
- judgment
- impulse control
- social and sexual behaviours
- self-awareness and insight

Temporal lobe

The temporal lobe is involved in memory and in the primary organization of sensory input. Other functions of this lobe include:

- organization and categorization
- learning
- concept of time
- understanding verbal language
- emotion
- hearing
- visual perception

Damage to this area of the brain can result in **memory problems and difficulties learning new information.** This happens when damage results in difficulty committing new information to memory. The person may also experience difficulties understanding spoken or written language. This is known as **receptive aphasia.**

Parietal lobe

The parietal lobe, being near the back, is more protected from traumatic injury, but it can also be injured. Functions of this lobe include:

- sense of touch
- identification of sizes, shapes, colours
- spatial awareness
- visual attention
- integration of senses

Damage to this area of the brain can result in **difficulties with perception, such as recognizing objects and a sense of one's body in relation to space.** It can also result in difficulties with mathematics, writing, and telling the difference between right and left. This area of the brain plays a role in putting together the information received from different senses. Therefore, damage to this area can significantly affect the way the individual understands and interacts with his or her environment.

Occipital lobe

The occipital lobe is involved in processing and interpreting visual information. Damage to this area can result in **difficulties with vision**. Damage to the left occipital lobe may cause problems with seeing things on the right side. For example, the person may only eat food on the left side of the plate due to not seeing the food on the right. Damage to the right occipital lobe may cause problems in seeing things on the left side.

BRAIN STEM

This part of the brain is basic to the body's core functions because it is the link between the brain and the spinal cord. The spinal cord communicates information between the brain and the body. The deeper structures of the brain also include the cerebellum, thalamus and hypothalamus.

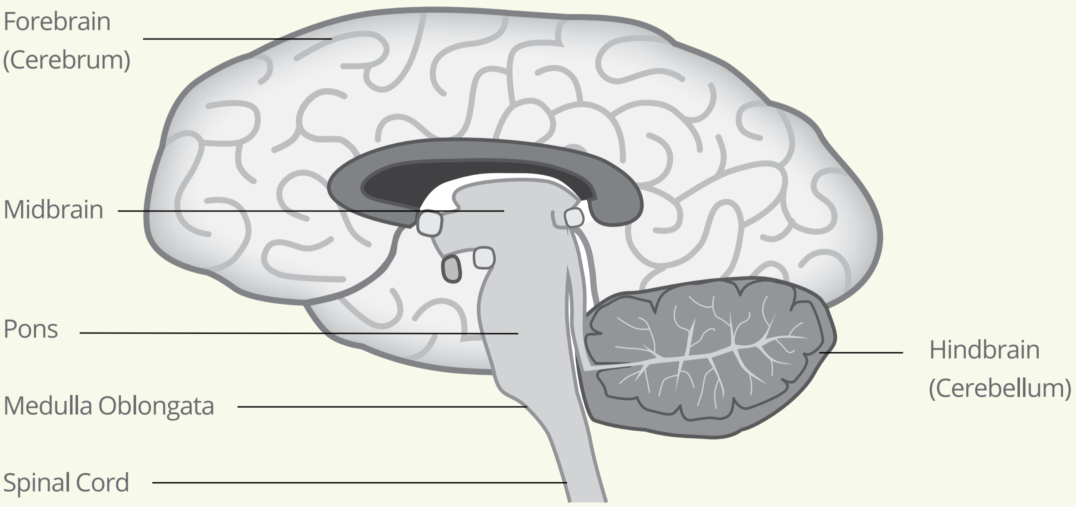
This part of the brain controls:

- breathing
- blood pressure
- consciousness
- sleep cycle
- swallowing
- temperature regulation
- heart rate

Damage to this area can **interrupt communication between the brain and the body**. In addition, the body may have a hard time regulating vital functions such as heart rate, breathing rate, and body temperature. Other effects may include difficulties paying attention or staying awake.

There could be other effects of damage to this area that aren't listed here. The nature and the extent of the effects will depend on how many areas of the brain have been injured.

Figure 4: the brain stem



"Another important thing I have learned is how to look at how valuable I am."

Survivor's Story:

Watch the Train

My name is Charlie Coleman and I live in rural Manitoba. I am a middle-aged male and a survivor of a brain injury from a motor vehicle accident in June 2003.

I was hit by a train locomotive at an uncontrolled level crossing. The train was going 100 kilometers per hour. I was driving a dangerous-goods semi-truck and when I looked I did not see the train. It may have been hidden by the large truck mirror. The impact ripped the cab of the truck off the frame. I am told that I was not left unconscious in the accident. I suffered many broken bones and have had a few surgeries to get most of things back in place. I am finally able to walk again.

The doctors were able to put steel pins, plates, and rods on and in my bones to get my body healed back together. I have not found or heard of any doctors that could just fix up the internal brain injury I suffer from daily, like they fixed my broken bones.

I am far better now with my brain injury than I was two years ago. I still walk with a limp, but the doctors have not been able to figure out if the limp I have is from steel rods, plates and pins in my leg, the stroke I had in the accident, or from the brain injury I suffered. All I know is that I have a limp that cannot be fixed so it does not matter what caused it.

I still suffer from a few of the things that most brain injured people suffer from, like limited smell and taste, little if any patience, vision problems, hearing problems, poor memory, loss of hope, and many more. I used to have an instant anger problem. When I was confronted by a person or with a problem I would instantly blow up and lose it. After a couple of years, I now have a long fuse length before I get upset. I feel an important point here is that I now control the length of time it takes me to get upset. It has not been easy to get to this point of control.

Another important thing I have learned is how to look at how valuable I am. After my accident, I was upset with myself and believed I was useless, just a waste of skin, and breathing valuable air that other people could be breathing.

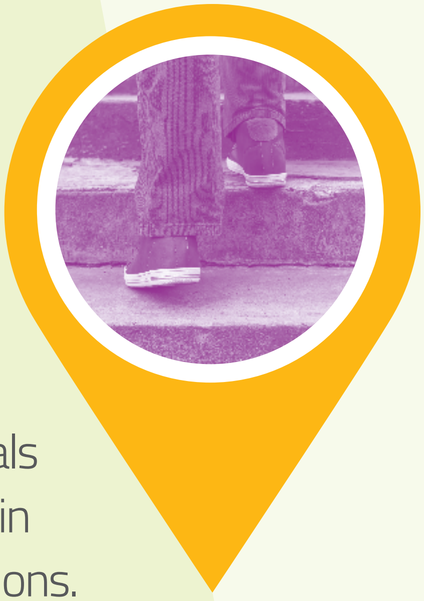
In my recovery process, I came across a doctor that asked me that dreaded question, "On a percentage basis, what percent of work could I do now as compared to before my accident?" I told him I used to work at over 90% every minute of the day, and now I would be lucky to do 10%. This was before I got control of my fuse length, and he knew that I was upset. He told me that I could look at it like I was 10% of what I used to be, and be mad all the time or I could look at it like I had a new job. The old job that I used to do and was very familiar with had ended. I now had a new job that I did not know much about so I was learning every day. As I learned what I was doing, I was 100% efficient. I have always forced my brain to work overtime and feel I have tripled my thinking capacity. I live with the thought everyday, "DON'T EVER GIVE UP."

- Charlie Coleman

CHAPTER

3

Physical Changes



The brain receives the signals from all the nerves in the body. By reacting to the signals the brain controls physical functions. A brain injury may disturb one or all of these functions.

The following are a variety of ongoing physical problems survivors of a brain injury may experience while recovering. Along with some examples of the problems, we offer suggestions that may help you understand and deal with them.

COMMON PHYSICAL EFFECTS

Fatigue

Fatigue (being extremely tired) is very common during the journey to recovery. The body needs time and energy to heal after the injury.

In addition to one's body feeling tired, a survivor can also have cognitive fatigue because of a brain injury. This affects thinking, causes irritability, and bad headaches.

Fatigue can slow down the return to normal life activities such as school and work. Over time, energy will improve and last longer and fatigue will lessen.

Tips for reducing the effects of fatigue:

- Recognize the signs of fatigue and take breaks as needed.
- Set a schedule that includes regular rest breaks or naps.
- Avoid evening naps as this can upset regular day/night sleep patterns and result in increased fatigue the next day.
- Start practicing simple activities that you can complete easily without fatigue.
- Over time, practice more complex activities taking breaks as needed.

Headaches

Headaches are another common physical effect following a brain injury. Some people have a headache all the time while others have headaches that come and go.

Tips for minimizing headaches:

- Get enough sleep as rest can help relieve a headache.
- Avoid alcohol.
- Cold foods, aged hard cheeses or chocolate can trigger headaches. Avoid if possible.
- Stress can increase headaches. Breaks during activities can help manage stress. Take the approach of "small steps slowly," which can be less stressful.
- Keep track of headaches and share the information with your doctor, who may be able to help.

Sleep Changes

Sleep problems are very common in the first few months after a brain injury. This problem can sometimes occur because survivors sleep during the day from fatigue and then have difficulty falling or staying asleep at night.

Tips for reducing sleep problems:

- Work with your doctor to set healthy sleeping patterns. Schedule a regular late afternoon nap followed by enough activity to help you feel tired by bedtime.
- Avoid caffeine after noon.
- Get regular exercise.
- Go to bed at the same time every night. It doesn't matter what time, what's important is the amount and quality of your sleep.

Dizziness

Dizziness is a term used to describe feeling faint, lightheaded or weak.

As other parts of the body are affected after injury, a number of signals to and from the brain are disrupted. These signals control sense of balance so you may feel dizzy.

Dizziness often happens in the first few weeks following injury. If you feel dizzy, be careful as there is an increased chance of falling. If dizziness does not go away, tell your doctor.

Tips to minimize the effects of dizziness:

- Remove items that you could slip on such as rugs and electrical cords.
- After lying down sit upright a few moments before standing.
- Use a cane, walker or other assistance.
- Avoid driving a car when feeling lightheaded.
- Before walking, give your brain time to adjust by sitting for a few minutes.

Seizures

After a brain injury, there may be scar tissue in the brain. This scar tissue may cause you to have seizures.

Seizures are most common in the first year after injury. It happens when the electrical system in the brain misfires as is common with a brain injury.

Although seizures can be frightening, it's important to know the following:

- You cannot swallow your tongue.
- You will not die.

Grand Mal seizures (tonic-clonic seizures) are the most common type of seizure and likely the most commonly experienced by those who have an acquired brain injury. This type of seizure has the following signs:

- It usually lasts about 40 seconds.
- The person is unconscious.
- It affects the whole body with jerking movements.
- The person may bite cheeks or tongue and have foamy saliva.
- Loss of bladder and bowel control can happen.
- Skin might turn slightly blue.

Following a seizure, the person will likely feel very tired, have sore muscles, and be confused. It is common for the person to rest for a few hours after a seizure to regain strength.

Tips for helping someone who is having a seizure:

- If the individual is standing or sitting, help them to the ground and place something soft under the head (pillow, jacket, or your lap).
- Clear the area surrounding the individual to reduce harm to jerking limbs and body.
- Do not try to restrain movement during a seizure as this can lead to injury.
- Do not put objects in the mouth to stop the biting as this could cause choking.
- Once the seizure is over, stay with the individual. They will have little or no memory of the event. Calmly explain what happened.
- Clear any crowd that has gathered to reduce anxiety and embarrassment.

Seizures come and go. Some things that trigger seizures include the following:

- stress
- alcohol and other drugs
- fatigue
- flashing lights
- emotional upsets
- poor nutrition and low blood sugar

Seizures can happen over the short or long term. It is very important to control them and medication is the most common way to do this. It usually takes about two weeks to adjust to a new medication or dosage change. Let your doctor know if you have any side effects.

Sensory Changes

When a person has a brain injury, each of the five senses is at risk of a change. Typically, this lasts for about a year following injury. For some, these changes may not go away. In these cases, therapy and rehabilitation will help.

Examples of changes you might see:

- blurry vision, double vision or sensitivity to light
- hearing problems including ringing in the ears
- changes in taste and smell

Tips for minimizing effects of sensory changes:

- See a neuro-ophthalmologist to evaluate visual problems.
- Avoid alcohol.
- Check hearing and use hearing aids if necessary
- Seek further evaluation and treatment as needed.

LESS COMMON PHYSICAL EFFECTS

Apraxia

Apraxia is the inability to carry out movements even though muscle strength, coordination, and sensation are normal. This happens when messages from the brain to the part of the body involved in the task are disrupted.

Someone with apraxia may have trouble with the following:

- writing
- folding
- putting clothes on correctly
- putting a letter inside an envelope
- using cutlery for eating

Tips for minimizing the frustration of those with apraxia:

- Allow the individual as much time as needed to do the task.
- Offer to guide the person to do the task step by step.
- Write instructions for the person to follow.
- To support independence, help only if the person asks for it or accepts your offer to help.
- Work with the physiotherapist and the individual to develop more helpful ways to carry out daily routines.

Bladder/Bowel Changes

The brain controls bladder and bowel function. The health care professionals involved in your care will be the first to assess these functions following injury. Do not assume that all bladder and bowel changes are a direct result of the brain injury. Have your doctor verify that they are not the result of other issues. After assessment, there will be a plan set to meet these main goals:

- Maintain dry and healthy skin.
- Establish a regular elimination pattern suited to the individual.
- Manage constipation, incontinence (no control), and diarrhea.

Tips for minimizing the effects of bowel and bladder changes:

- Try to set a regular schedule to empty bowels, which you can adjust to fit needs and activities.
- Seek help from healthcare professional to teach bladder retraining and to provide medications that may help.
- If caring for an individual unable to ask for assistance, try to learn to recognize signs of discomfort leading to a bowel movement.
- Be aware of the location of bathrooms when on outings.
- Get enough fiber and fluids in diet to avoid constipation.
- Use an adult diaper.

Spasticity

Spasticity refers to an abnormal increase of muscle tone throughout the body. This occurs when the part of the brain that controls movement is injured. You may be unable to move your muscles when stretched. Instead, they remain stiff and interfere with your ability to perform regular daily tasks (e.g., getting dressed).

The degree to which an individual experiences muscle stiffness varies from slight to severe and recovery can be a lifelong process.

Tips for minimizing the effects of spasticity:

- Seek help from a physical therapist to develop a stretching program.
- Have someone help you do the recommended stretches.
- If you use splints, monitor the skin area for redness, blisters or open sores, which can lead to pressure ulcers.
- Ask your doctor for other treatment options if spasticity gets worse.

FIND HELP

Swallowing

Problems swallowing can happen after a brain injury. Whether this happens and how much of a problem it is depends on the location of the brain damage. The frontal lobes of the brain are responsible for the muscle action in swallowing and the brain stem is responsible for relaying the message to swallow to the frontal lobes. Tracheostomies or tube feeding may also cause problems with swallowing. The technical term health care professionals use to describe this is dysphagia.

Swallowing problems can cause food to go into the lungs instead of the stomach. When food or fluid gets into the lungs it often causes pneumonia.

Following a brain injury there can be many factors that can contribute to difficulty swallowing. Examples include the following:

- decreased strength in muscles used for swallowing
- decreased concentration level
- poor control and strength in the upper body and head

Tips for minimizing the effects of swallowing problems:

- Seek help from a speech or occupational therapist to figure out the best types of liquids and foods to eat.
- To avoid weight loss due to appetite changes, see a dietician to review what you're eating and learn how to have a balanced diet.
- Write meal times in a day planner and check them off when finished.

Visual Spatial Problems

Visual spatial problems can include blind spots and changes in the brain's ability to understand what the eyes see. The ability to be aware of where you are in space and in relation to other items surrounding you can also be affected. This is called spatial relations syndrome, which includes difficulties judging distance between two or more objects.

Examples of visual spatial problems:

- bumping into things on the affected side
- confusion between right and left
- difficulties seeing
- difficulty finding your way around
- ignoring things on one side of the body

Tips for minimizing the effects of visual spatial problems:

- Have a place for everything and keep everything in its place.
- Arrange your house to make tasks easier.
- Slow down and carefully look and feel for things around you.
- Avoid going to new places alone.
- Seek professional advice about whether it is safe to drive.

Survivor's Story:

Falling through the cracks

Brian and I were married December 1998. Brian had one operation regarding his shunt a few months before our wedding. He and the shunt[1] seemed fine and everything was as we were told it was going to be.

In February 2002, Brian's headaches were so bad he would hide in our bedroom trying not to cry. He could barely open his eyes because the light or movement bothered him. The next two years would be the worst that we could imagine. Doctor after doctor wanted MRI's, CAT scans, X-rays, and EEGs. Doctor after doctor told us that there was nothing wrong with the shunt and that the headaches were his own doing. Doctors told us that Brian was depressed and should be on medication.

My Brian is a major tease and through all of this he could still tease me and I knew he wasn't depressed. We went to two mental health workers and then a psychologist who told us after an hour that Brian wasn't suffering from depression, but frustration. He took Brian off the antidepressants saying they wouldn't do anything for him. Brian left his office smiling. Although he was off the antidepressants his GP (general practitioner) later put him on two types of morphine, pill form and liquid. They would help for about 1-2 hours then the pain would come back. He went into the hospital very sick. When I confronted the doctors that something was terribly wrong they bluntly stated he had the flu and that was all.

The day he doubled over with pain in his abdomen was a prayer answered. All those important tests taken earlier were done on his head or chest area; they neglected his abdomen where the trouble was hiding. He had a small blockage that was enough to cause a problem. The relief that we felt was tremendous. It gave us solid ground.

Brian had an operation and was out of the hospital within 46 hours. He felt great. He was so happy to be with our 1-year-old daughter Monica again. I was working full time and able to leave Brian with Monica and not worry. Then in November, we were watching TV while Monica was in bed. Brian got up, fell down, crawled back to the couch and started retching and vomiting.

Back to the hospital we went, but this time we were angry and knew something wasn't right again. He was in hospital overnight when the GP consulted the neurosurgeon who told us to get back into the Health Sciences Centre (HSC) fast. When we got to the HSC, he was almost in delirium with nausea and pain took over. When we got to see a doctor he actually listened to us and he did a simple test. With a syringe, he withdrew liquid from Brian's shunt reservoir. It should have been clear like water, but it looked like milk, which suggested an infection. The doctor put him in intensive care. Nothing could be done till the infection was cleared up.

I was granted a leave of absence from work; I would stay in Winnipeg all week with Brian then go home to our daughter on weekends.

The infection was bacterial meningitis and was almost a death sentence. It left Brian with a brain injury on top of everything else happening to him. Brian had hallucinations of being abducted by aliens, and semi-trucks parking beside him with Christmas lights on. He thought that one of the nurses was me. He grabbed her trying to get her to stay with him, almost breaking her arm. He became incontinent and had to wear diapers. He would eat (when he was awake and somewhat alert) then vomit it all back up. After weeks of this routine the infectious disease doctor told us they were going to try yet another drug.

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[1] a **shunt** is a hole or a small passage which moves, or allows movement of fluid from one part of the body to another

> "... we have to live each day not dwelling on the past, but concentrating on today and the tomorrows with our kids."

Two and half months after we entered the HSC for the second time I left the hospital and Brian was with me. He had two weeks of intense antibiotic treatments in a much closer hospital. He was finally released and for four weeks we drove back and forth for out-patient treatments.

At his check-up appointment with the neurologist, the doctor apologized. He informed us that the last year should not have happened, especially the last six months. He knew Brian had the start of an infection after the first operation six months earlier. He told us that Brian should have had a prescription for a strong antibiotic when he left hospital for the first time. He believed that was why Brian had got so sick the second time.

I was shown X-rays of Brian's brain. The silent stroke he had, along with the scarring tissue, is why they believe he lost some of his eyesight. We finally got some truth and were happy about that, but the fact that a lot of this could have been avoided was maddening.

Brian is on medication for grand mal seizures that he did not have until he got bacterial meningitis. He cannot drive because of his loss of eyesight. He has difficulty with memory, comprehension, and concentration; he is moody along with a few more things I could mention. We have since had another child. We can only live day by day. Sometimes, it's hour by hour.

We have come to the conclusion that because he will more than likely have to have another operation in the future, we have to live each day not dwelling on the past, but concentrating on today and the tomorrows with our kids.

- Georgina Wood

JOURNAL

What are some of the physical effects you have?
How severe is the effect?

Is there a particular physical effect that stands out for you?
Describe it.

What are the impact(s) these physical effects had on you?
On your family?

What are some of the strategies you've used to deal with this physical problem? How well have they worked?

What strategies you want to try in the future?

CHAPTER

4

Cognitive Changes

Cognition refers to the way we think. Thinking involves our ability to pay attention and process information, remember that information, and then use that information to function in daily life. Following a brain injury, these processes may be interrupted making day-to-day functioning a challenge. Cognitive changes may require adaptation in order to compensate for them. You, your family, and friends can use specific strategies to deal with how cognition is affected by your brain injury.

COMMON COGNITIVE EFFECTS

Attention and Concentration

A brain injury can affect a person's ability to pay attention to things going on around them. The survivor may not be alert enough to communicate and he or she may not be fully aware of the environment. It can also affect the survivor's ability to focus attention for long periods.

The following are examples of attention and concentration problems:

- easily distracted by sights and sounds that would not have pulled attention away before
- trouble concentrating while reading because it requires focus in order to absorb information
- trouble paying attention to more than one thing at a time (multitasking)
- trouble switching from one task to another because it takes so much effort to focus

Tips for minimizing effects of attention and concentration problems:

- Eliminate distractions in the environment.
- Limit attention to one task at a time.
- Avoid interrupting if the survivor is speaking to someone else.
- Avoid changing topics or tasks quickly.
- Take rest periods to avoid overload.

Confusion

After a brain injury, most people experience some confusion. This could last minutes or days or even weeks.

The following are signs of confusion problems:

- disorientation
- staring blankly
- confusing times or tasks in schedule of activities
- confabulation (making up stories to fill memory gaps)

Tips for minimizing effects of confusion:

- Have a calendar, clock, family photos, and location signs nearby as reminders.
- Use notebooks to plan for and log events.
- Have a daily routine and avoid making abrupt changes to it.

Decision-Making and Problem-Solving

Making decisions and solving problems can be hard for someone with a brain injury. The survivor may have trouble analyzing information or making a change in thinking. When problem-solving, there may be difficulty deciding on the best solution or the person may get stuck on one solution and not consider other options.

Signs of difficulties with decision-making and problem-solving:

- extreme frustration when not able to perform a task
- doesn't listen to all information before making a decision and viewed as stubborn at work

Tips for minimizing effects of difficulties with decision-making and problem-solving:

- Avoid making decisions when tired, hungry or under stress.
- Limit the number of choices as too many are often overwhelming and can increase indecisiveness.
- Practice problem-solving by evaluating the options.

Memory Problems

A problem with memory is one of the most prominent features of a brain injury. Long-term memories or past memories are often not affected. Loss of the ability to make new memories or short-term memory can be the most disabling. Memory problems range from mild, such as occasional difficulties with remembering names, to severe post injury amnesia where the survivor cannot remember events that happened just a few seconds ago.

Confabulation is a very common memory problem in which the person produces false memories. When someone confabulates, they either report remembering events that never happened or remember events as having happened at an incorrect time or place. This is a direct result of the injury to the brain, but may go away on its own. It is important to remember that the person is not intentionally doing this.

Slowed Speed of Processing

Brain injury survivors may experience slower information processing speed, which means they require more time to think. This affects decision-making even in emergency situations.

Signs of slowed speed of processing:

- takes longer than usual to coordinate two-handed activities with household objects (e.g., opening cans, making coffee)
- not able to complete tasks at work
- may not be as quick or witty as before injury

Tips for minimizing the effects of slowed speed of processing:

- Slow down and simplify information.
- Allow more time to respond to questions and to understand new information.
- Avoid overstimulating situations (e.g., noise, crowds).
- Encourage family and friends to slow down and repeat information when talking.

Reasoning and Judgment

The ability to solve problems is the height of other cognitive skills. It involves the ability to attend to a situation, understand all components of a problem, recall possible appropriate alternatives, and then make the correct choice among the alternatives. However, reasoning and judgment may be impaired in persons with a brain injury. The survivor may have difficulty determining the action that should logically come next in a sequence. The survivor may also show poor judgment as a result of difficulties predicting and evaluating the possible consequences of actions. The person's thinking style may be inflexible. Because of poor judgment, a frequent outcome of brain injury is that the survivor may not make sound decisions.

COMPENSATION STRATEGIES

The cognitive effects of a brain injury differ for each person. Compensation strategies can help you build on your strengths and improve your cognitive skills.

Cue Strategy

Cueing means someone giving a signal to you to prompt a specific action. A therapist can teach this strategy to enable the person with a brain injury to act and do things independently.

Types of cues:

Direct cue - asking a specific question (e.g., "Did you look in your calendar?")

Indirect cue – a non-verbal signal such as pausing or nodding head

Self-cue - asking yourself the question (e.g., "Where could I find that information?")

5W Strategy

This strategy involves teaching you to focus and then pick out the main points of what you are learning.

Read and Remember:

1. **who**
2. **what**
3. **where**
4. **when**
5. **why**

Problem-Solving Worksheet

Below is a sample problem-solving worksheet that you can use to break a problem down into manageable solutions.

The Problem	Possible Solution	How it Worked
I can't remember what my doctor told me to do.	Next time, I will bring a planner and write down instructions.	Now I can look at my notes if I forget something the doctor said.
1.		
2.		
3.		
4.		

Survivor's Story:

My new reality

On or around the 23rd of August 1972, I awoke to some unfamiliar surroundings. Because I could not seem to verbally communicate with any of the people I thought were around me at the time, I counted to one hundred in my head in an attempt to determine whether I was dreaming. I then lapsed back into what had been the lengthy coma that I had just started to come out of. Unfortunately, as time went on, I learned that NONE of this had been, or was ever going to be a dream!

It turned out that ever since late in the evening of June 21, 1972, which had been some six weeks earlier, I had been somewhere within New Westminster's Royal Columbia Hospital in a comatose state after having undergone corrective brain surgery. I was informed that in the late afternoon of June 21st I had been riding a friend's ten-speed bicycle and I had fallen off. After that fall, I had apparently walked back to that friend's home in White Rock, B.C., where I was visiting from my home in Winnipeg. I then ate supper, which I eventually brought back up. Because of that incident, I went to White Rock's Hospital for observation. While there, it was determined that the afternoon's fall from a bicycle had ruptured a minor artery on the lower left inside portion of my skull or my head.

It was still bleeding, creating an ever growing blood clot and thus more and more pressure on and displacement of the brain. I was then taken to Royal Columbia Hospital by ambulance for corrective neurological surgery.

I spent 1972's Labour Day weekend flying back to Winnipeg with my wife, followed by a three-month term in the Rehabilitation Hospital. Those three months were the start of my own education about my "new" reality. People told me I was doing rehabilitation, but I would never refer to it as that. Fortunately, in spite of that experience, I rapidly recovered most, if not all, of my mental functions, such as engineering, higher mathematics, logical and reasoned thought, plus speech. My reading and spelling took a bit longer to come back in what is for me their "full" function.

From what I've been told, one's memory returns in the reverse order to which it had been laid down. And even though I had only temporarily lost my abilities to do all those mundane things like design engineering, reasoning, planning, reading, writing and speaking, it seems that I have permanently lost the ability to do most of those things our North American society really seems to value, like dancing, football or hockey. In part I can only surmise that this has something to do with the fact that walkers and/or wheelchairs are just not vogue—I use a motorized cart.

Similarly, I have had more than my share of problems accepting the typical North American reclassification my former employer, the City of Winnipeg, has given me as "permanently disabled". However, I eventually used this in the best ways that I could. Even though I would have preferred to continue doing electronic design in the position I had with the Water and Waste Department, I ended up using a portion of the permanent disability pension I continue to get to setup, equip, and run my own in-house engineering office. Over this time, I have successfully developed around 8-10 different electronic ideas. I even applied for, and eventually got, a couple of patents on some of these ideas. Unfortunately, patents and the world's markets are not directly interconnected! On three or more other occasions, I have also been re-employed or contracted by one of several different companies to successfully complete several electronic design ideas.

Even though from time to time it seems like all my wife's and my efforts have only permitted us to take an occasional federal income tax write-off on a portion of our total engineering expenses, we have not given up trying to accomplish more than that, at least so far. Regrettably, it also took me about 20 years before I finally went for and got my current driver's licence. I did this in part to relieve my wife of the entire highway driving on any of our business trips or vacations. So now that I have successfully retained this licence for the past four years, I do not intend to let it or any other skills lapse from lack of use.

JOURNAL

What cognitive problems are you experiencing?
How severe is the effect?

Is there a particular problem that stands out? Describe in detail.

What impact have these cognitive problems had on you?
On your family members?

What strategies have you used to cope with this problem?

Strategies in the future?

CHAPTER 5

Communication Changes

The ability to understand (receptive language) and communicate (expressive language) the spoken and written word are two of the most complicated cognitive functions. People make many judgments about others by the way they communicate. A brain injury can change all rules of communication because the exchange of information happens in a new context, complicated by a range of factors that likely seem mysterious to you and your family caregivers.

Communicating in the context of these changes, along with changes to physical abilities and thinking patterns, is like playing a board game with a new set of rules. The goal is the same yet the obstacles to clear communication are different. A message sent may not be clearly received.

The brain controls the ability to use and understand words. Also, the muscles that we use to speak are controlled by the brain. A brain injury can cause changes in a person's communication skills. However, these changes vary from person to person.

As a social being, a person's communication skills are very important in everyday life. Brain injury can affect the following abilities:

- knowing and understanding words
- communicating thoughts
- paying attention
- remembering what was said or heard
- forming ideas into words
- writing, spelling, and reading

A speech-language pathologist can give you more information as well as treatment for specific problems.

COMMON COMMUNICATION EFFECTS

Speech and Voice Difficulties

After a brain injury, damage to certain areas of the brain can interfere with messages to the muscles of the tongue, lips, jaw, larynx, and other areas. The result may be the following difficulties with talking:

- slurred speech
- speaking too loudly or softly
- speaking too quickly

As with other communication difficulties, family and friends can use signals or gestures to tell the person with a brain injury to adjust his or her speech. For example, a finger to the ear could signal the need to speak up, while a finger to the mouth could signal the need speak more softly. If speech is hard to understand because of slurring, family and friends need to be patient and emphasize their desire to understand the survivor when asking him or her to repeat what was said. If difficulties understanding persist and the survivor is able to write, a note might help with the words that are difficult to say.

Expressive Language Difficulties or Word-Finding Problems

Expressive language can take many forms. Occasionally, we all have trouble finding the "right" word for something. Usually the word eventually pops into our heads. For those with a brain injury, this problem can be more frequent and disruptive to their ability to communicate. It is not that they don't know the word, they will understand the word if it is said to them. The difficulty is in retrieving the word in the moment it is needed. For example, the person may be able to describe a pair of shoes with wheels on them, but cannot think of the term "roller skates".

Another aspect worth noting is nonverbal language or body language. A person with a brain injury may have difficulty establishing a match between what he or she is saying and what he or she is doing. Most of the time, communication is lost because of this. For example, a person may be saying something positive, but display a negative stance (e.g., folded arms and crossed legs).

Tips for minimizing effects of expressive language and word-finding problems:

- If the word is a noun, describe the object, person, or place. If the word is a verb, describe the action.
- Explain the meaning of the word if it is an abstract concept (e.g., love, happiness).
- Picture the word and its meaning in your mind.
- Family members should be patient and set up a cueing system.
- Use many words instead of a single word. This is called circumlocution and is a strategy speech-language pathologists will often teach.

Problems Following a Conversation

A person who has survived a brain injury will often find it difficult to follow a conversation. He or she might experience the following:

- difficulty paying attention to what is said
- misinterpreting what is said
- being "off topic" compared to others in the conversation

Difficulties following a conversation may be severe or may affect the person only at certain times, such as when very tired. Usually, if a person has problems understanding he or she will also have trouble reading.

LESS COMMON COMMUNICATION EFFECTS

Dysarthria

Dysarthria is a speech difficulty resulting from the inability to use muscles to form words and produce sounds.

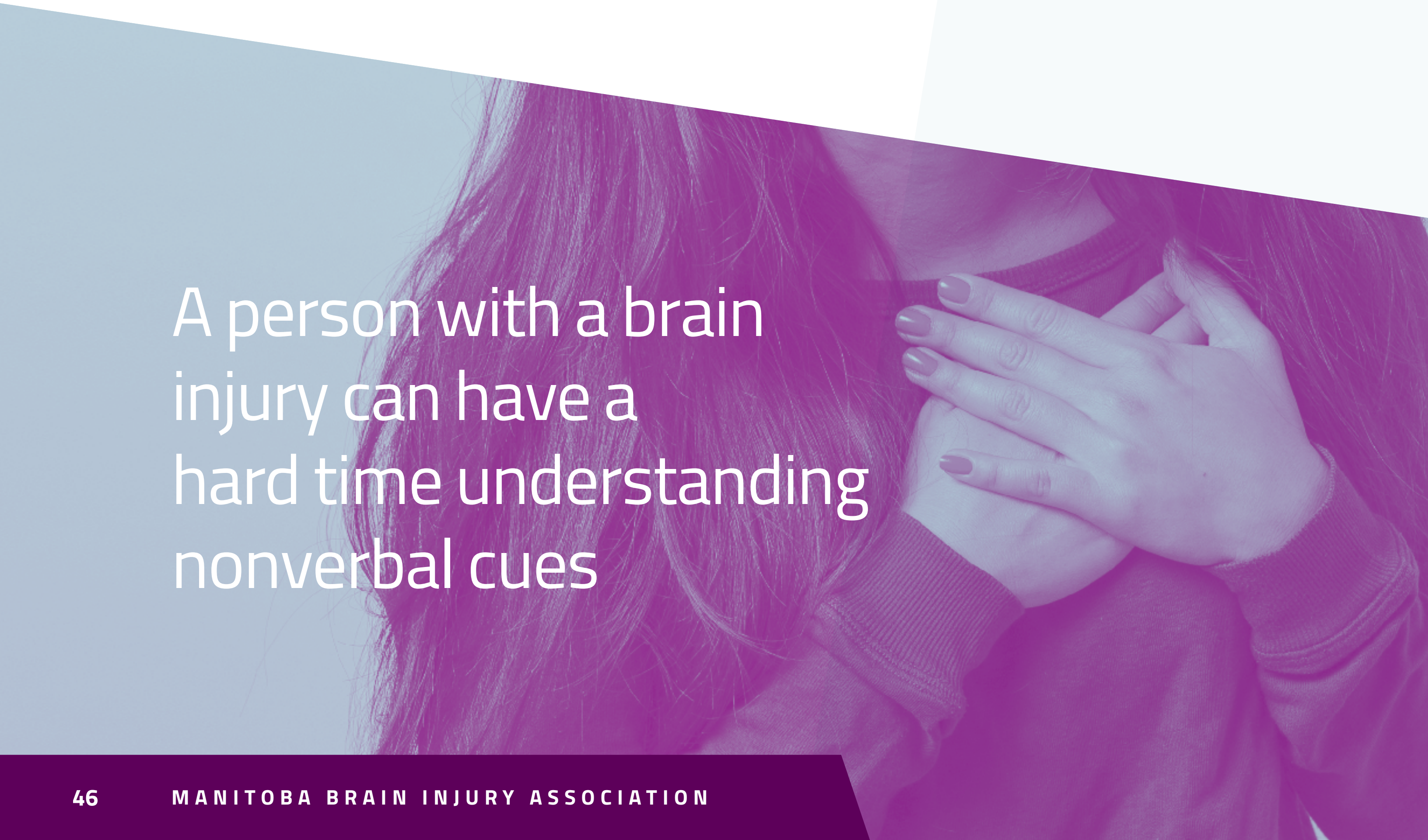
The following are signs of dysarthria:

- speech is often slow, slurred, and garbled
- problems with intonation (varying tone) or inflection (e.g., ending a question with an upturn of voice)

If you are experiencing dysarthria, the speech-language pathologist will give you exercises to improve the muscles used in speaking. Family members can also help you to exercises properly and regularly.

Nonverbal Communication Issues

Language problems can lead to miscommunication and confusion. But nonverbal communication can also be affected by injury. A person with a brain injury can have a hard time understanding nonverbal cues such as facial expressions and hand gestures. The survivor's language and facial expressions might not match what he or she is saying and there may be poor eye contact or staring at others during conversation.



A person with a brain injury can have a hard time understanding nonverbal cues

Survivor's Story:

Miracles Do Happen

> "... my neurologist informed my wife and daughter that miracles do happen"

What I remember is waking up (actually regaining consciousness following a 24-hour coma) to find that my left arm had turned to lead (my left side was paralyzed). I was unable to speak, unable to swallow, and extremely confused. I thought, "Maybe this isn't really happening." For some reason I had the most aggressive case of the hiccups. I could not hear my wife when she asked if I was trying to say something.

I tried to tell her, "No, it was only a hiccup." The only word that would come out of my mouth was "burp". Despite my confusion and the mental fog that I was in, I somehow knew that was not the correct word, but no other words would come out of my mouth. I was aware that I was in hospital due to a broken right hip so I wondered why was I having problems with my left arm and head?

I became even more befuddled when a few minutes later I looked up to see the arrival of five family members from Winnipeg. "GEEZ THIS CAN'T BE GOOD!" I strained to understand what was being said as all five plus my wife and daughter seemed to be speaking at the same time except for my youngest son. He was humming the theme song from the *Six Million Dollar Man* TV series while making booming statements such as, "We will rebuild him; we will make him whole again."

As the din subsided somewhat I struggled to say, "What are you doing here?" Despite the garbled nonsense that came out of my mouth, my oldest son recognized what I was attempting to ask and replied "This is what family does."

Slowly, I later learned that during surgery blood clots had developed in my right leg. Some of these clots travelled to my brain causing two massive strokes. That afternoon my doctors had informed my wife and daughter that there was very little likelihood of my survival. My daughter had made a phone call to Winnipeg where most of my family was gathered for Christmas Eve dinner.

My daughter told my sons that they had to get to Victoria as soon as possible, which resulted in five family members catching a flight at 6 a.m. that Christmas morning. Later that evening my neurologist informed my wife and daughter that miracles do happen. I had my miracle and thus began my journey through three months in hospital (four hospitals) and years of rehabilitation and recovery.

- Jim Sinclair

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What communication problems are you experiencing?
How severe is the effect?

Is there a particular problem that stands out? Describe in detail.

What impact have these communication problems had on you?
On your family members?

What strategies have you used to cope with this problem?

Strategies in the future?

CHAPTER

6

Behavioural and Psychosocial Changes

A brain injury often affects a person's social and behavioural responses. These changes can show up in areas related to self-care skills, cognition (thinking), and interpersonal skills. These changes can be the hardest ones for family caregivers. The majority of acquired brain injuries result in some kind of behavioural change. It is important to remember that problem behaviour is often because of a person's brain injury and the resulting frustration and anger that the survivor feels.

COMMON BEHAVIOURAL EFFECTS

Irritability

Many survivors feel more irritable and have less patience. This may relate to feelings of frustration because of difficulties in doing things that he or she was able to do before the injury.

Examples of problems with irritabilty:

- nothing pleases the survivor; he or she complains about everything
- friends find the survivor difficult to get along with
- quick to react negatively to loud music or children playing, getting worse when fatigued

Tips for minimizing the effects of irritability:

- Establishing a daily routine so the survivor may feel more secure and in control in his or her environment can help.

Impulsivity/Lack of Self-Control

An individual with a brain injury may be acting on impulse or acting without thinking. He or she might say the wrong thing, drive a car when told several times not to do so, or engage in unsafe work behaviour even when warned about his or her limitations. Impulsivity is hard to deal with because it applies to so many situations.

Frustration and Anger

After a brain injury, many people become frustrated more easily than before. The survivor may not be able to do things as easily as previous to the injury. Sometimes he or she may not know what others expect. This can be frustrating. Most survivors have the tendency to get angry and lash out easily.

Examples of frustration and anger difficulties:

- wants to get up and leave the doctor's office after waiting short time
- fires case worker for not returning call the same day

Tips for minimizing frustration and anger:

- As a caregiver, come to terms with the fact that you are interacting with a person who has little patience.
- Remind the survivor that there are steps necessary to achieve what he or she wants to have happen.

Foul Language and Outbursts

It is common for brain injury survivors to use foul language or rude body language. This can sometimes be very embarrassing in social situations. At times, outbursts can be physical rather than verbal.

Examples of a foul language/outburst difficulties:

- survivor rarely swore before injury, but now happens daily
- has begun to get physically abusive
- young survivor threatens to kill his or her teacher

Tips for minimizing foul language and outbursts:

- Anticipate the events that might trigger the survivor in this way and try to avoid them
- Point out the tone and kind of language the survivor is using.
- Explain this change in behaviour to family and friends.
- Don't let the behaviour escalate to abuse. Know when to ask for professional help.

Lack of Self-Awareness

Self-awareness means understanding one's own strengths and weaknesses. It is very common for a person who has survived a brain injury to lack insight into what tasks they can do. The survivor may even be unaware that he or she has any deficits as a result of the brain injury.

Tips for minimizing effects of lack of self-awareness:

- Build self-esteem by encouraging the person to try a non-dangerous activity that he or she feels confident doing.
- Use visual or verbal reminders to improve confidence.
- Give realistic and supportive feedback.

Less Effective Social Skills

A survivor of a brain injury may not behave appropriately. He or she may have lost social skills. This can make it hard to fit in, get along with others, and read and understand people and situations.

Examples of less effective social skills:

- interrupting conversation with something unrelated to topic
- revealing personal details about self or others to staff or strangers
- having an outburst if can't do a task or get own way

Tips for minimizing the effects of less effective social skills

- React calmly.
- Role-play (practice) responses to social situations.
- Use redirection (get the survivor interested in something else going on).
- Praise and encourage appropriate behaviour.

Repetitive Behaviours (Perseveration)

Perseveration means getting stuck on one idea or one behaviour and repeating it over and over again.

Examples of perseveration:

- talks constantly about daughter's terrible husband
- speaks daily of getting driver's licence renewed
- writes several letters to social worker complaining about not being helpful

Tips for minimizing perseveration:

- Use redirection (get the survivor interested in something else going on).
- Engage the survivor in a physical task if verbally "stuck" on a topic.
- Be firm and refuse to discuss the topic anymore.

Sexuality

Many people who have survived brain injury experience cognitive and psychological changes that can cause problems with sexual relations. Problems can include impulsivity, loss of sexual interest, sexual hyperactivity, and sexual dysfunction. In most cases, brain injury can also produce heightened sexual drive, which can disinhibit the survivor and make him or her more demanding when it comes to sex.

Examples of difficulties in the area of sexuality:

- takes every opportunity to grab or touch other people
- takes a very assertive approach to sexual relations that tends to scare people off
- talks constantly about wanting a spouse

Tips for minimizing difficulties in the area of sexuality:

- Repeat often that the behaviour is inappropriate.
- Warn those in the brain injury survivor's company to stay at arm's length so they are not vulnerable.
- Engage a trained professional to provide the survivor with a way to express sexual feelings and frustration.

COMMON PSYCHOSOCIAL EFFECTS

Depression

Some healthcare providers view signs of depression as part of a survivor's progress. Often, it means the person has come to realize his or her disability and difficulties. The person may begin to grieve in a way that is similar to when a friend or family member has died. This grief follows the familiar progression of feelings including denial, anger, depression, and acceptance. At first the survivor may not recognize the loss. Once he or she does recognize it, anger and frustration usually follow. Depression can set in after this stage.

Signs of depression:

- low activity level
- sleep problems
- difficulty controlling emotions
- lack of initiation

It may be helpful for families to recognize the symptoms and provide support and reassurances. In cases where depression interferes with rehabilitation, medication can help.

It is important to know that there are gender differences in the symptoms of depression as well as the ways of coping with the symptoms. Men are more likely than women to use alcohol and drugs while women are more likely to talk about depression to others.

In severe cases, both men and women may experience suicidal thoughts. If you notice symptoms of depression, seek professional help (see last chapter for resources).

Mood Swings (Emotional Lability)

Emotional lability is a term for sudden mood swings. The person with a brain injury often shows feelings in an extreme and inappropriate way. Expressions and moods may change suddenly. This is caused by physical damage to areas of the brain that control emotions. It is important to understand that the person has lost some degree of control over emotional responses.

Examples of emotional lability:

- someone passing gas causes laughing fit
- very emotional when talking about grandmother who died 10 years before brain injury
- viewing pictures from past is a very emotional experience

Tips for minimizing emotional lability:

- Keep a "matter-of-fact" attitude.
- Ignore inappropriate emotions, but be nonjugmental.
- Change the topic.
- Have the survivor take regular rest periods as fatigue may make these problems worse.

EMOTIONAL

Fear and Anxiety

A brain injury can create stressful and unfamiliar circumstances, creating emotional responses such as fear and anxiety for the survivor. These are normal emotional responses to unknown and uncomfortable situations. Fear and anxiety often go along with depression.

Signs of fear and anxiety:

- constant physical tension
- excessive worry
- irritable, jumpy and restless
- panicky

Tips for minimizing fear and anxiety:

- Help the survivor to recognize the reasons for feeling fear and anxiety.
- Writing about fears and anxieties can often help to reduce them.

Changes in Self-Esteem

Self-esteem refers to a person's view of him or herself. A brain injury can mean a loss of status in significant areas of people's lives. This loss of status often impacts an individual's self image.

If the survivor has full recall of how life used to be before the injury, his or her new status in the family may be very discouraging. This decrease in self-esteem takes a very long time to rebuild. As a survivor, focusing on what you can do rather than what you cannot do may be the most effective way to help restore a positive self-image.

"As we sat in this tiny room with most of our family, the feelings we felt overpowered us—numb, hopeless and scared beyond words."

Survivor's Story:

A Mother's Love

We were a normal family—a dad, mom, and two kids named Chris and Courtney.

We thought that we had normal ups and downs: not enough money, and lots of issues with raising two kids, learning how to be good parents, loving the craziness of our life, being with friends, feeding everyone, and keeping our kids safe.

Chris and Courtney are three years apart and very close. As a 22 and 19-year-old, they still loved to do things together, and one spring night they decided to meet after Chris's work shift was over.

We never knew who was home. It was only in the mornings, counting shoes at the door, that knew who was there. We woke the next morning to get ready for work and suddenly our phone rang. It was 6 a.m. It was the Concordia Hospital and I was told that our daughter Courtney had been in an accident. She was bumped up and shaken, but wanted us to come and get her. That was all they told us and at that point, we didn't know who else was involved.

We decided to go to the hospital together in one vehicle. As we were driving, we heard on the radio that there was an accident that closed the road that we would have taken. When we arrived, we stopped at the nurses station to locate Courtney. As we stood at there waiting, I glanced at a room thinking that someone looked familiar. As the nurse explained that Courtney was ok I got this bad feeling. I asked who was involved, she said three occupants were in the vehicle, two were admitted at this hospital, one was sent to HSC with a head injury, but was stable as well. I asked the name, but she didn't know. She only knew that he was a male, 22 years old. I knew right then, that it was our son Chris. She quickly called the Health Sciences Centre (HSC) and confirmed that Chris had been admitted to the intensive care unit.

We found Courtney in a room, crying and sobbing uncontrollably, telling us that there had been a horrible accident that Chris had been knocked out and she thought it was really bad. We quickly made arrangements for grandparents to come to be with Courtney, before leaving for the HSC to be with Chris.

We weren't prepared for what we found when we got there. They ushered us into a private family room, doctors arrived, they looked serious and told us that Chris had received a devastating brain injury and the next 24-48 hours were critical.

As we sat in this tiny room with most of our family, the feelings we felt overpowered us—numb, hopeless and scared beyond words.

My next memory is finally being able to see Chris for the first time, down a long hallway, scary, going through security doors and seeing Chris, tubes, monitors, ventilator and finally settling on Chris. As I watched him, I just knew despite what we had been told, he was fighting a battle that I had never experienced in my life, but he was still with us. I just knew.

Everything was a blur—family, friends; I was overwhelmed with the outpouring of support. I believe at one point there were 37 people sitting with us on that first day. Our life had changed so much in that day; we became sheriffs of our son's care, and keepers of well-being.

Every day, I would call the hospital before I would leave the house to see how his night was. We had rotating family and friends staying with Chris, trading off with them sometimes three times a day. I wish I could tell you that Chris woke up fine one day, but the reality is he woke up and was in a vegetative state for about four months.

We were with him most of the time, fighting for him, talking to him, telling him he was so loved.

Eight months later they transferred Chris to a long-term care facility, telling us he would not get better. We asked to bring him home, but were told he was too sick, and his needs were too high for us to handle.

There were lots of nightmares, two transfers to other hospitals, and one day, I looked in the mirror and thought, Chris would never choose to live like this, we're going to bring him home!

It's been three and half years since we brought Chris home and we've seen lots of changes. Chris can laugh, joke, and walk with a walker. We're so proud of him and I know that his story will continue. One day his voice will return, one day he will march into those hospitals and tell them, here I am, and I made it.

We are so thankful to so many people that have been with us since that awful day. There is so much more to do and tell people.

- Tammy Kehler

JOURNAL

What behavioural/emotional problems are you experiencing? How severe is the effect?

Is there a particular problem that stands out? Describe in detail.

What impact have these behavioural/emotional problems had on you? On your family members?

What strategies have you used to cope with this problem?

Strategies in the future?

CHAPTER 7

Life After a Brain Injury

A brain injury affects the entire family and those people around them. Whether it is good or bad, any experience can change our lives. Living with a brain injury takes a lot of adjustment. However, there are many things that you can do to help yourself and your family members.

There may be interruptions and changes in usual family roles, routines, and responsibilities. Take time to identify how your brain injury changed the roles in your family, the new responsibilities that have been added to your daily routine, and how these changes have affected your life.

Going Home

Planning for a return home should begin once your healthcare team has determined your short- and long-term needs.

Planning tips:

- Ask for planning assistance from your social worker or nurse.
- Contact the professionals, associations or agencies you will need depending on the services you require such as: home care and support services, respite care, insurance coverage, therapies (physiotherapy, occupational, and speech), transportation arrangements, making follow-up appointments, and educational assistance.
- Contact the Manitoba Brain Injury Association for a list of agencies that provide the above services.
- Basic equipment such as wheelchairs, grab bars, toilet and bath seats are provided to persons at no cost through the provincial government.
- Make a list of things that you will need upon discharge from the hospital.
- Maintain contact with professionals that are already involved in your care.

The process of rehabilitation continues at home. Having realistic goals and expectations is very important in the recovery process.

Home Care Services

The Manitoba Home Care Program is a community-based service that provides home support to any eligible Manitoban, regardless of age, who requires health services or help with daily living activities. Families or individuals may have the opportunity to manage their own home care services through family-managed or self-managed care options. For general information, visit: www.gov.mb.ca/health/homecare/guide.pdf.

Available Support Services

The following are support services available to assist people and their families:

Respite offers families short-term alternative care for adults living with disability.

Day service transportation may be provided through public or specialized services for people attending approved day services.

Crisis intervention ensures the immediate physical safety and well-being of people in crisis while long-term plans are developed.

Clinical services provide a range of behavioural and psychological supports, including clinical assessment, therapy, and consultation with community programs.

HOUSING

Survivors who are unable to return to the community or their family usually remain in the hospital until they are eligible to be placed in a personal care home or chronic care facility (nursing home). However, there is a long waiting list for these facilities. the Province of Manitoba determines the fees for these accommodations according to income. If you are receiving benefits from Employment and Income Assistance, these fees will be paid.

New programs for community-based housing with support services are always being developed. Check with your social worker or the Manitoba Brain Injury Association to find out what is available in your area.

Transitional Housing

Transitional housing resources offer short-term or temporary residence for persons with disabilities learning to live independently in the community with limited, moderate or extensive support from home care attendants and/or equipment aids.

One resource is Ten Ten Sinclair Housing Inc., which is an apartment complex managed by staff who provide support, guidance, and information to help the tenants achieve their goals. The length of tenancy varies from three months to two years.

EMPLOYMENT

Returning to work after a brain injury is not easy. Sometimes returning to work is not an option. Other times, when somebody returns to the same position they are not successful because of the changes from the brain injury. Some have found returning to work on a part-time basis is the best answer. Survivors should give themselves lots of time and use the resources available to improve the chances of returning to work successfully.

Manitoba Family Services and Consumer Affairs' MarketAbilities program offers adults with disabilities a wide range of employment-focused services in the following areas:

- preparing for work
- finding a job
- keeping a job

Available Services

Vocational counselling: vocational counsellors work with people to explore their employment goals. To develop these goals, counsellors talk with participants about their interests, abilities and skills.

Vocational training: This may include specific job development and/or post-secondary or other adult education courses.

Support services: Offers support to overcome disability-related barriers to employment.

Direct employment services: Helps with job searching, resume preparation, establishment of contacts with job placement agencies, job referral, and on-the-job training.

To apply for MarketAbilities program, contact:

Society of Manitobans with Disabilities
825 Sherbrook Street
Winnipeg, Manitoba

204-975-3010
Toll-free: 1-866-282-8041

RELATIONSHIPS

There are three things that change in relationships after a brain injury:

- role reversal
- survivor's personality change
- less time for family members

Shifting roles change relationships between the survivor and family members. Spouses and children suddenly become caregivers. Being a caregiver is overwhelming and adapting to changes, personality changes included, is challenging.

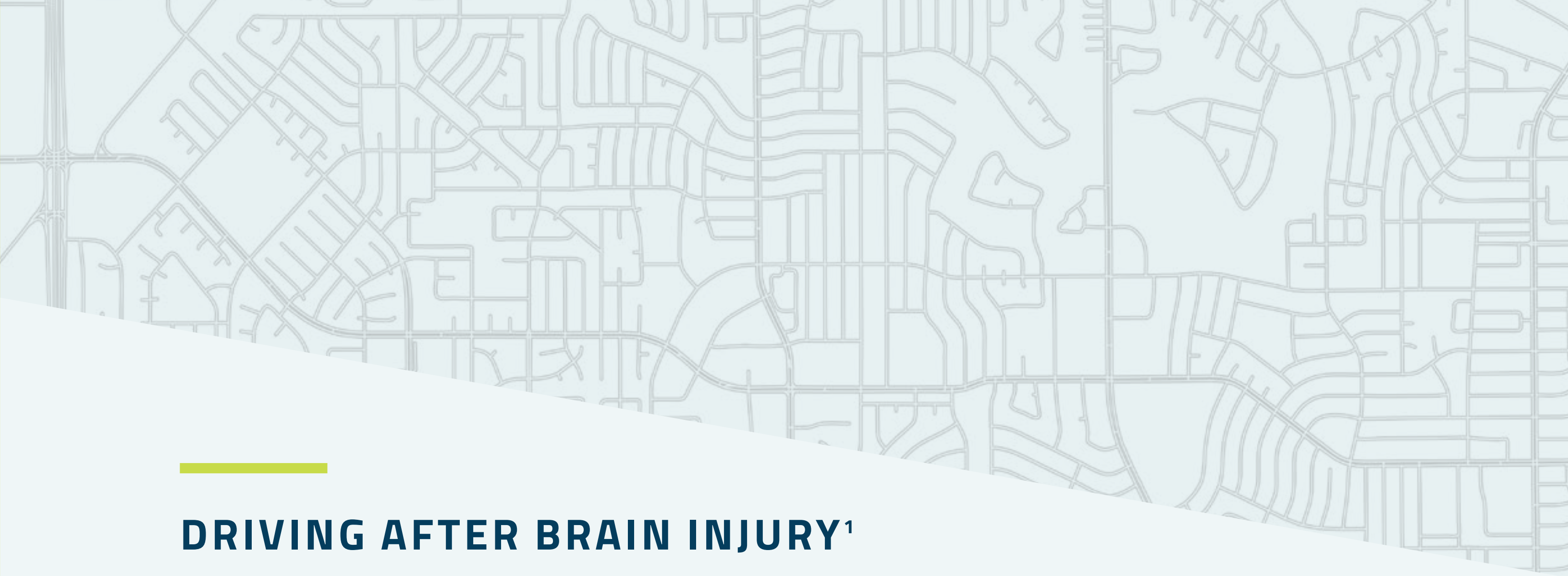
Seeking out social support can help lessen stress and loneliness. A support group can help you to make connections with other people who have similar concerns and needs. Contact the Manitoba Brain Injury Association for support group services.

SEXUALITY

A brain injury can alter the expression of sexuality. Sex involves the expression of our male and female identities. It's affected by our attitudes and behaviour within the relationship. After a brain injury, you may find differences in the ability to *appropriately express* learned sexual behaviours. You may find differences in behaviours such as kissing, hugging, and touching.

A majority of people regard sexuality as a private matter so it may be difficult to talk about this topic. People who have a suffered a brain injury may benefit from professional support and guidance to deal with sexual issues.

"Seeking out social support can help lessen stress and loneliness."



DRIVING AFTER BRAIN INJURY[1]

Driving is the activity that requires the greatest use of all our multitasking abilities.

It requires our complete and total focus and concentration at the same time as requiring a sharp awareness of everything that is happening around us. It requires rapid decisions and quick physical reactions.

After a brain injury, many survivors should not be driving because their reflexes and decision-making are slow. There may also be issues related to light sensitivity and vision problems that can affect driving ability. These changes are not uncommon, but may be subtle and go unnoticed. More important, the brain is still in a very delicate condition and even a small accident may be dangerous for the survivor.

In Manitoba, if you have a medical condition that may affect your ability to drive, your doctor must report it to the Medical and Assessment Division of Manitoba Public Insurance (MPI). This is required by law as well as the medical professional code of ethics.

This report may result in the following:

- a request for further medical reports
- a request that the individual undergo driver's testing.
- a referral of the individual to the Driver Assessment and Management Program (DAMP) located at the Health Sciences Centre or to MPI's DriveABLE program
- restrictions placed on an individual's driver's license
- reclassification of the individual's license to a lower classification
- suspension of the individual's license **UNTIL FURTHER INFORMATION IS RECEIVED**

The suspension of a driver's license **is not** automatic following an acquired brain injury. The course of action depends upon each unique medical situation.

The process of re-earning a driver's license is as unique to each individual as the effects of his or her specific brain injury.

Driving is one of the things we take for granted until we lose the right to drive. After a brain injury, driving usually requires more concentration than before. When considering a return to driving discuss the issue with your physician and request a referral to the DriveABLE program (DAMP) for an assessment.

[1] Jim SInclair, brain injury survivor.

ADVOCACY

The act of advocacy involves representing the needs of those who are unable to do so for themselves. After a brain injury, it is common for the loved ones of the survivor to negotiate on his or her behalf with the professionals involved such as health care workers, social services, insurance companies, and many others.

A guideline for effective advocacy is as follows:

- **Prepare:** Define the issue, gather information, identify supporters.
- **Plan:** Review the issue, identify preferred solutions, choose the route, delegate tasks.
- **Act:** Carryout tasks.
- **Evaluate:** Determine if action has resulted in progress.

FINANCIAL CONCERNS

It is normal to be concerned about the financial stability of your family and the implications this sudden change of events might have.

Insurance Coverage

The following are the most common sources of insurance coverage:

- Workers Compensation Board (WCB) for injuries occurring at work
- Manitoba Public Insurance (MPI) for motor vehicle accidents
- Compensation for Victims of Crime Program through Manitoba Justice
- Canada Pension Plan Disability Benefit, which provides a pension for those with a work history
- private disability insurance carried by the survivor's workplace
- private disability insurance plan carried by the survivor

Often health professionals must fill out insurance forms on the survivor's behalf. It can be helpful to consult a professional (lawyer or social worker) who has experience in the area of brain injury.

Social Assistance

Speak with a social worker at the hospital to see if employment income assistance might be available. If you were employed, you may be eligible for employment insurance, long-term disability, or the Canadian Pension Plan Disability Benefit program.

Handling money

Sometimes a brain injury survivor may not have the ability to make good decisions for themselves. If this is the case, the family can pursue the following:

Power of Attorney

- Power of attorney gives a person other than the survivor complete control over the survivor's property and finances. The survivor grants this power to someone they know to be responsible and who will look after his or her well-being such as parents or spouses.

Trustee

- A trusteeship order is when the court appoints a trustee to manage the survivor's finances and property. The disadvantage of this appointment is that it puts limits on the survivor's rights.

Case Manager

- A case manager is a professional who helps the survivor with financial or legal matters. Sometimes a community social worker or rehabilitation practitioner will act as a case manager.

Lawyers

- Lawyers are helpful in the following situations: arranging power of attorney, writing a will, setting up a trust fund, learning about insurance coverage and obligations.
- Call the Manitoba Brain Injury Association or Legal Aid Manitoba (see resources section) for names of recommended lawyers.

USE OF ALCOHOL AND DRUGS

Brain injury survivors should stay away from alcohol and illegal drugs. Those substances can further interfere with the brain's ability to function. When the brain is already injured, the effects of alcohol and illegal drugs become worse and limit recovery.

Talk to the members of your rehabilitation team about the use of alcohol and drugs. There are treatments programs to help those with a brain injury deal with substance use problems.

Survivor's Story:

A Man of Confusion

I was 33 years old in 1990, when on an annual road trip to Regina with a buddy, my life changed forever.

For several years we had been travelling to the annual Labour Day Classic, a football game where the Winnipeg Blue Bombers and Regina Roughriders clash in a fierce rivalry. This was a fun time that we enjoyed each year.

I have no memory of the single car collision that threw me into the bushes alongside of the highway. Had it not been for my buddy's persistence asking the emergency responders, "Where is my buddy?" over and over again, they would not have found me. I would not have survived.

I grew up in a middle class family in Winnipeg. My father was a postman and my mother a stay-at-home homemaker. I grew up with two brothers, one was ten years older and the other was one and a half years younger. School was not easy for me, but my younger brother and I were passionate about sports. We played baseball, football, and hockey. My favourite was baseball. As our family never owned a car, Dad would take us on the bus to our sports events. When we weren't playing organized sports groups of friends would gather for pick-up games on our street.

During high school I worked at KFC. I enjoyed the social aspect of working and would frequently go to socials on the weekends with friends. At the time, I was a social drinker, sometimes drinking too much like most young people. I never tried drugs. I do not drink now.

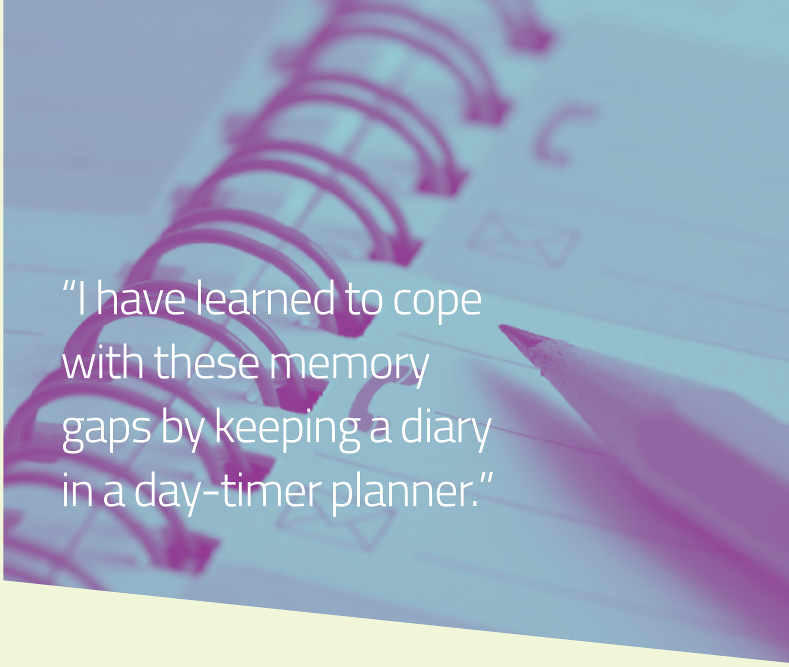
In 1979 I began work at Eaton's on the receiving dock. I later moved to a position driving a low motor to transport goods from trucks to the receiving department. This is the position I held at the time of my accident.

I met my wife through a mutual friend. We were married in 1986, bought a home, and settled into married life. I was the primary financial support as my wife worked little outside the home. Life was pretty good; we had no children, but socialized with extended family and friends. I continued playing sports and attending sporting events.

The year before my accident my father was hit by a car when crossing the street and he required a leg amputation. I do not recall if he returned home before he passed away. Immediately following my collision, I was taken to the hospital in Regina. They tell me I had been in a coma because I had suffered a head trauma, but that I had no other injuries. During the early days after the accident, a shunt was surgically implanted to relive some of the pressure on my brain. I have a deep indent on the right side of my head that can be felt but is not visible to others. My buddy who was driving at the time of the accident had a separated shoulder but no other injuries.

My first memory after the accident was opening my eyes and seeing a row of airplane windows, probably during my transport back to Winnipeg. I do not remember being in a hospital in Regina, how long I was there or how long the physical rehabilitation process took. I was transferred from Regina to the Health Sciences Centre in Winnipeg. When I awoke from the coma my memory and vision were affected. I remember sleeping on a mattress on the floor because I would roll out of bed.

Although I do not remember feeling frustrated, I do remember having episodes of explosive anger where I'd "blow up" at family and friends. I would repeatedly ask when Dad was coming to visit, and was continually forced to relive the loss of my father when family reminded me that he had passed away.



> “I have learned to cope with these memory gaps by keeping a diary in a day-timer planner.”

My rehabilitation included occupational, physical, and speech therapy. I would go home on weekend passes with my wife during this rehab process and was eventually discharged home. I continued outpatient therapy. During this time, I was not really aware of how well I was doing. I would lose my temper; I would throw things, and one time broke the bedroom door. During these times my mother would come and take me out when things were (or were not) going well.

The most profound and long-lasting effect of my brain injury has been the loss of memory. Remote events I can remember, but recent events are often forgotten. Timelines and the sequence of events following the accident are hard to remember.

Over the years, I have learned to cope with these memory gaps by keeping a diary in a day-timer planner. I write out appointments, names and numbers. At times I feel frustrated when I cannot remember details, but after reviewing my day-timer I know what I have been doing. People tell me that I am never late for appointments. Occasionally though, I am in trouble if I lose my glasses or my day-timer. I have learned to use humour to deal with these memory losses.

I do not remember much about my marriage before the accident. Over time, my marriage dissolved and my wife and I divorced. This is a part of my life that I have difficulty leaving behind. I still feel angry and hurt and can easily become upset when I talk about it.

Today, I have many people who work with me and protect me in the areas that I have difficulty. For instance, the Public Trustee Office works with me to manage my finances. I have a community mental health worker that I meet with regularly and who has arranged to have someone come into my home a couple of times a week to assist, ensuring that I keep my place clean, do my laundry, and gives me support to be independent as I live in my own home.

I can no longer participate in active sports due to my slowed reaction times and reflexes. I continue my love of sports as a spectator with season tickets to the Winnipeg Blue Bombers football and the Winnipeg Goldeyes baseball teams. Mini-packs of tickets to the Winnipeg Jets satisfy my hockey needs. I bowl weekly with a group from the Manitoba Brain Injury Association.

As I am no longer able to work, but I contribute to my feelings of self-worth and community by volunteering. I volunteer with a number of charitable organizations including: Oyate Tipi, which provides meals, food hampers clothing, and household goods to the less fortunate; Special Olympics, where I coach a bowling team of special needs children; and helping out at MBIA with various tasks. I sometimes help my older brother with yard work and chores as he grows older.

It has been 23 years since my life was changed by a brain injury caused by a single vehicle collision. A lot has changed in my life. I am grateful for the care that I have received in hospital and in the community.

Some of my friends have stopped calling and several have passed away, as have both my parents. My social life consists of volunteering, spectating at sporting events, and spending time with my brothers. I remain physically healthy, although I don’t eat as well as I could because my cooking skills are limited.

I am satisfied with my life. I have one dream that I would like to achieve—to attend a home game of my favourite football team, the Green Bay Packers.

It is not always easy living with a brain injury, but if I keep positive and keep busy I realize I have a lot going for me. I am thankfully for the people in my life. My life is definitely different and I have had many losses that I still struggle with and parts of me that I still mourn. I have a new best friend since my brain injury—my day-timer. I never do anything without him and he accompanies me everywhere.

- Gary McFarlane

Resources

Organizations

CANADIAN COUNCIL ON REHABILITATION AND WORK
406-428 Portage Avenue
Winnipeg, MB R3C 0E2
Fax: 204-775-4119
Employment Coordinator: 204-783-7946
Outreach specialist: 204-775-1949

CANADIAN DISABILITIES RIGHTS COUNCIL
926-294 Portage Avenue
Winnipeg, MB R3G 0P8
Phone: 204-947-0303
TDD: 204-943-4757
Fax: 204-942-4625
Email: ccd@ccdonline.ca

CANADIAN MENTAL HEALTH ASSOCIATION - WINNIPEG REGION
930 Portage Avenue
Winnipeg, MB R3G 0P8
Phone: 204-982-6100
Fax: 204-982-6128
Email: office@cmhawpg.mb.ca
Website: www.cmhawpg.mb.ca

EASY STREET MISERICORDIA HEALTH CENTRE
Parkade Building Unit 6
25 Sherbrook Street
Winnipeg, MB R3C 1A2
Phone: 204-788-8158
Fax: 204-774-7646
Email: easystreet@misericordia.mb.ca

INDEPENDENT LIVING RESOURCE CENTRE (ILRC)
311A-393 Portage Avenue
Winnipeg, MB R3B 3H6
Phone: 204-947-0194

KLINIC COMMUNITY HEALTH CENTRE
870 Portage Avenue
Winnipeg, MB R3G 0P1
Phone: 204-784-4090
Crisis Line: 204-786-8686 or 1-888-322-3019
Email: klinic@klinic.mb.ca
Website: www.klinic.mb.ca

LAW PHONE-IN AND LAWYER REFERRAL PROGRAM
Phone: 204-943-2305
Toll-free: 1-800-262-8800

LEGAL AID MANITOBA
Application Centre
294 Portage Avenue
Winnipeg, MB
Phone: 204-985-8500
Toll-free: 1-800-261-2960
TTY: 204-943-1131
Website: www.legalaid.mb.ca

MANITOBA CAREGIVER COALIATION
Phone: 204-953-3720
Email: mb.caregivercoalition@yahoo.ca
Website: www.ccc-ccan.ca

MOVEMENT CENTRE OF MANITOBA INC
1646 Henderson Hwy
Winnipeg, MB R2G 1N7
Phone: 204-489-2679
Fax: 204-255-2947
Email: info@movementcentre.ca

MANITOBA FARM AND RURAL SUPPORT SERVICES
Toll free: 1-866-367-3276
Email: help@ruralsupport.ca
Website: www.ruralsupport.ca

MANITOBA COMPENSATION FOR VICTIMS OF CRIME PROGRAM
Phone: 204-945-9344
Toll-free: 1-800-262-9344
Website: gov.mb.ca/justice/victims/compensation.html

MANITOBA HOUSING AUTHORITY
Suite 100-185 Smith Street
Winnipeg, MB R3C 1M5
Phone: 204-945-3884

MANITOBA HUMAN RIGHTS COMMISSION
Toll Free: 1-888-884-8681
TTY: 1-888-897-2811
Email: hrc@gov.mb.ca
Website: www.manitobahumanrights.ca

MANITOBA LABOUR BOARD
Phone: 204-985-8832
Toll free: 1-800-665-2410

MANITOBA PUBLIC INSURANCE
Box 6300
Room B100, 234 Donald Street
Winnipeg, MB R3C 4A4
Toll Free: 1-800-665-2410
Phone: 204-985-8832

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SOCIETY OF MANITOBANS WITH DISABILITIES
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WINNIPEG REGIONAL HEALTH AUTHORITY HOME CARE CENTRAL INTAKE
Phone: 204-788-8330

WORKERS COMPENSATION BOARD
333 Broadway
Winnipeg, MB R3C 4W3
Toll- free: 1-800-362-3340
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Glossary of Terms

Advocacy
The act of pleading or arguing for something on behalf of a person.

Affect
The observable emotional condition of an individual at any given time.

Agnosia
A difficulty with recognizing familiar objects perceived through one or more of the senses, such as difficulty recognizing an object visually or by touching it. This is not due to aphasia.

Agraphia
Inability to express self through writing.

Alexia
Inability to read.

Amnesia
Lack of memory about events occurring during a particular period of time.

Aneurysm
A balloon-like deformity in the wall of a blood vessel. The wall weakens as the deformity grows larger, and may eventually burst, causing a hemorrhage (bleeding).

Anoxia
Lack of oxygen to tissue, particularly to the brain, which may result from trauma or toxic substances. Results in brain damage or damage of central nervous system.

Aphasia
The inability to use and/or understand language. Expressive aphasia is an inability to express oneself, even though one knows what one wants to say. Receptive aphasia is the inability to understand or comprehend what someone else is saying.

Apraxia
Inability to sequence movements to perform purposeful acts or manipulate objects.

Brainstem
An area at the base of the brain before the spinal cord begins that contains several centres vital to consciousness and life. It is the origin of all nerves to the face—controlling sight, smell, hearing, taste, swallowing, and movements of the eye and face.

Cerebrospinal Fluid (CSF)
A clear, continuously produced and reabsorbed fluid that surrounds the brain and fills the ventricles within the brain and circulates down the spinal cord. Blockage of its circulation leads to hydrocephalus. A CSF leak can lead to brain infection (meningitis).

Cognition
Ability to perceive, understand, organize, recall, problem-solve, reason, and make judgments in response to daily activities.

Cognitive rehabilitation
Therapy programs to help a person having problems with perception, memory, thinking, and problem-solving. The person learns strategies and skills to help improve functioning. The interventions are based on an assessment and understanding of the person's brain-behaviour deficits.

Coma
A state of deep unconsciousness.

Confabulation
Providing misinformation or embellishing the facts because of gaps in memory.

Cranioplasty
A surgical repair of the skull.

Depression
A mood state marked by sadness, low self-esteem, fatigue, poor appetite, and loss of interest in activities.

Disability
The inability or a limitation in performing tasks, activities, and roles in the manner or within the range considered normal for a person of the same age, gender, culture, and education. It may refer to a physical, mental, or sensory condition.

Edema
Swelling as the result of abnormal build up of fluid in cavities or tissues in the body.

Electrocardiogram (EKG)
A test measuring the electrical activity of the heart. There are no significant side effects.

Electroencephalogram (EEG)
A test measuring the electrical activity of the brain. There are no significant effects.

Emotional Lability
Rapid mood changes that appear as exaggerated responses to events or thoughts and sometimes seem to occur without reason.

Fractures
Broken bones are called open fractures when they penetrate the skin and closed fractures when they do not.

Frontal lobe
The front part of the brain responsible for controlling motor skills (movement) and higher cognitive (thinking) functions.

Glasgow coma scale (GCS)
A system for assessing consciousness level immediately following injury.

Hemorrhage
The bleeding that occurs following trauma as a result of damage to blood vessels in the brain.

Home care
Home-based training and case management services. Home care may include nursing and home health aide services; physical, occupational, and speech therapies; and home counselling services.

Hydrocephalus
A buildup of pressure in the fluid-filled cavities within the brain.

Independent living
A community-based living arrangement designed to maximize an individual's ability to be self-supporting and self-directed.

Intensive Care Unit (ICU)
The hospital unit responsible for the highest level of medical care.

Limbic system
A system within the brain that connects lobes and mediates moods, emotions, motivation, attention, and memory.

Magnetic Resonance Imaging (MRI)
A machine that uses powerful magnets to take detailed a picture of the brain. No X-rays are used.

Meninges
The three membranes that cover the brain and spinal cord - dura mater (the outermost, toughest, and most fibrous membrane); arachnoid mater (the middle membrane); and pia mater (the innermost membrane that contains the blood vessels).

Muscle tone
The amount of resistance a muscle shows in response to passive stretching.

Neurological examination
An evaluation of the mind, brain, and nerves; usually performed by a physician.

Neurologist
A physician specializing in the nervous system and its disorders.

Neuropsychology
The branch of psychology dealing with the assessment and rehabilitation of brain behaviour.

Occipital lobes
Positioned in the back area of the brain, the occipital lobes are responsible for visual perceptions.

Occupational Therapy (OT)
Assessment and treatment aimed at improvement of activities of daily living. It may involve modifying living or working spaces, use of adaptive devices, or changes to the way you move or do things.

Paralysis
A neurologic muscular weakness to the point of not being able to move. Paralysis causes muscles to become smaller (atrophy).

Parietal lobe
One of the four lobes of the cerebral hemisphere in the brain, located behind the frontal lobes and in front of the occipital lobes.

Perceptual deficits
The difficulty in correctly perceiving visual, spatial, auditory, or tactile (your body's position in space) kinesthetic information.

Perseveration
A meaningless repetition of an act (or words) even after the stimulus that caused the act is removed.

Physiatrist
A physician specializing in physical medicine and rehabilitation.

Prognosis
A prediction of the likely course of a disease or injury and the chances of recovery.

Respite care
A program or plan designed to provide time-limited relief to the family or other primary caregiver from the ongoing responsibilities of caregiving.

Seizure
An uncontrolled discharge of nerve cells, which may spread to other cells nearby or throughout the entire brain. This will affect how a person appears or acts for a short time.

Shunt
A procedure to draw off excessive fluid in the brain. A surgically-placed tube running from the ventricles, which deposit fluid into either the abdominal activity, heart or large veins of the neck.

Spasticity
An abnormal increase in muscle tone that causes difficulty in movement or coordination.

Spontaneous recovery
Recovery that occurs after a brain injury as a result of the body's natural responses to trauma.

Survivor
An individual who has sustained a brain injury and remains alive.

Temporal lobe
One of the four lobes of the cerebral hemisphere in the brain, lying between the frontal and occipital lobes.

Tracheostomy
An operation in which a surgeon places a breathing tube through the neck, directly into the trachea.

Transitional living services
A nonmedical residential program that provides training for living in a setting of greater independence.

Whiplash
A neck injury due to forceful back-and-forth movement. It most often happens as the result of a motor vehicle accident. This causes a "rattle" effect of the brain within the skull, which can cause bruising of the brain.

RELATING TO A PERSON WITH A BRAIN INJURY

The family is an important part of the rehabilitation team. The following suggestions may help in relating to the person with brain injury.

Creating a Familiar Environment

- Speak of familiar names, places, interests, and experiences.
- Talk about familiar people and what is happening at home.
- Bring in photos of family, friends, and pets.
- Have a few friends or family visit regularly, but not more than two people at one time.
- Hang a calendar or clock in the room.

Stimulation

- Keep a balance between stimulation and quiet times.
  - Examples of stimulating activities are watching TV, listening to the radio, sitting in a chair.
  - Examples of quiet-time activities are resting, no TV, no visitors.
- Follow the schedule for visiting times and rest times.
  - Too many visitors are confusing
  - Too much TV is hard for the person
- Remember, the person with brain injury is thinking in slow motion.
- Follow the schedule consistently, but be aware that the survivor may fluctuate day to day in his/her tolerance for activity (stimulation). The person may withdraw, "explode", cry, or become combative in response to overstimulation.

CONSISTENT SCHEDULE

Source: Patient Education and Discharge Planning Manual for Rehabilitation, Kelly B. Wascher(ed.), Aspen Publishers, Inc., 1995

Communication

- Remember that communication is important to the survivor who is thinking in slow motion.
    - Ask simple questions.
    - Ask positive questions.
- Let the person make choices. For example: "Do you want a drink?" rather than "Don't you want a drink?"
- Give praise when appropriate greetings and conversations happen.
- Let the person search for the right word, but say the word before he or she gets frustrated or says the wrong word.
- Support and encourage efforts to talk. For example, when the person says, "I want to... " it may help to repeat "I want to ..." as the person searches for the next word.
- Ask the person to name objects or describe actions. Give clues such as: "What are you holding in your hand?" or "What are you doing with your toothbrush?"
- Remember, the person may have problems finding words. This does not mean he or she is not smart.
- Tell the person when he or she repeats a word or activity repetitively, but don't make an issue of it.
- Ask questions with yes/no answers. It is better to ask, "Was Dad here last night?" rather than, "Who visited last night?"
- Encourage gestures and talking with hands to help find the right word.
- Be prepared for swearing and use of wrong words.
- Discourage exaggeration of facts or made-up stories.
- Orient the person to day, date, time, and place.
- Say exactly what you mean. The survivor will take everything literally.
- When communicating with the person with a brain injury, **DON'T DO THE FOLLOWING:**
    - Tease or encourage the person to say inappropriate words.
    - Put the person on display or force him/her to speak in front of others. This may be upsetting or embarrassing.
    - Insist that the person use correct pronunciation, or "talk straight". There is nothing he or she wants more than to do just that.
    - Overestimate the person's ability to understand what is being said.
    - Pretend to understand.
    - Talk for the person unless necessary.
    - Use sarcasm. Everything said will be taken literally. For example, saying, "I'll be back in a minute," means just that—a person will be back in one minute.

Source: Patient Education and Discharge Planning Manual for Rehabilitation, Kelly B. Wascher(ed.), Aspen Publishers, Inc., 1995

ATTITUDES

DO	DON'T
Be honest about the injury.	Over-encourage, such as, "You'll be all right. You'll be back to work in no time."
Look ahead—not back—and help the person do the same.	Compare present abilities with abilities before the injury.
Praise appropriate behaviour immediately.	Scold—for example, for lost control of bowel/bladder.
Laugh with the person when appropriate.	Laugh when a situation is not funny. Often, the person may not know what is funny.
End each visit on a positive note.	Leave angry.
Redirect the person to another activity when he or she feels embarrassed.	Tease, punish, or make the person feel guilty or childish for mistakes.
Remember that no two people are alike.	Compare.
Remember the person may laugh or cry easily.	Tease when this happens.
Help the person relax by being calm and patient.	Use one-word commands like "Relax!" This may cause anger, resentment, and agitation.
Keep the person safe.	Rely on what the person says he/she can do.

Source: Patient Education and Discharge Planning Manual for Rehabilitation, Kelly B. Wascher(ed.), Aspen Publishers, Inc., 1995

FAMILY/CAREGIVER'S ASSESSMENT

Caregiver Self-Assessment Questionnaire

How are you?

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own wellbeing. Pease take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

1. Had trouble keeping my mind on what I was doing ☐ Yes ☐ No
2. Felt that I couldn't leave my relative alone ☐ Yes ☐ No
3. Had difficulty making decitions ☐ Yes ☐ No
4. Felt completely overwhelmed ☐ Yes ☐ No
5. Felt useful and needed ☐ Yes ☐ No
6. Felt lonely ☐ Yes ☐ No
7. Been upset that my relative has changd so much from his/her former selt ☐ Yes ☐ No
8. Felt a loss of privacy and/or personal time ☐ Yes ☐ No
9. Been edgy or irritable ☐ Yes ☐ No
10. Had sleep disturbed because of caring for my relative ☐ Yes ☐ No
11. Had a crying spell(s) ☐ Yes ☐ No
12. Felt strained between work and family responsibilities ☐ Yes ☐ No
13. Had back pain ☐ Yes ☐ No
14. Felt ill *(headaches, stomach problems or common cold)* ☐ Yes ☐ No
15. Been satisfied with the support my family has given me ☐ Yes ☐ No
16. Found my relative's living situation to be inconvenient or a barrier to care
17. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill",
    please rate your current health compared to what is was this time last year. ______

Comments *(Please feel free to comment or provide feedback)*

Source: Patient Education and Discharge Planning Manual for Rehabilitation, Kelly B. Wascher(ed.), Aspen Publishers, Inc., 1995

FAMILY/CAREGIVER'S ASSESSMENT CONTINUED

Self-evalutation

To Determine the Score:

1. Reverse score questions 5 and 15 (For example, a "No" respnse should be counted as "Yes" and a "Yes response shoud be counted as "No")
2. Total the number of "yes" responses.

To Interpret the Score:

Chances are that you are experiencing a high degree of distress:

- If you are answered "Yes" to either or both Questions 4 and 11; or
- If you total "Yes" score = 10 or more; or
- If your score on Questions 17 is 6 or higher; or
- If your score on Questions 18 is 6 or higher.

Next Steps:

- Consider seeign a dorctor for a check-up for yourself.
- Consider having some relief from caregiving. (Discuss with the doctor or a social worker the resources available in you community.)
- Consider joining a support group.

Additional tools for caregiving or aging, visit www.CaregiversLibrary,org

Source: Patient Education and Discharge Planning Manual for Rehabilitation, Kelly B. Wascher(ed.), Aspen Publishers, Inc., 1995

PERSONAL NOTES

Date/Time	Personal Notes

PERSONAL NOTES

Date/Time	Personal Notes

PERSONAL NOTES

Date/Time	Personal Notes

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