

Alberta Brain
Injury Initiative

Survival Guide

Alberta 

**Additional copies of this guide
are available from:**

Your local Alberta Brain Injury Network Office
(See Resources Section)

OR

Alberta Supports
Please refer to the
Provincial Disability Supports Initiative
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Acknowledgments

This is an educational resource that is not meant to take the place of the advice and recommendations given by health professionals who are experts in the care of people with a brain injury. The chapter entitled “Paying the Bills” is not a substitute for financial or legal advice.

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Introduction

- > Family
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Alberta Brain Injury Initiative Survival Guide

The Provincial Disability Supports Initiatives Branch is pleased to bring you the Alberta Brain Injury Initiative Survival Guide.

The survival guide is intended to provide key information and support to the survivors of acquired brain injury and their families. This guide will try to point you in the right direction in order for you to learn where to find the support and resources that are available in Alberta. It is not meant to answer everyone's questions or provide information that can be given by health professionals or advisors.

The goal of this guide is to provide basic, overall information that is applicable throughout the province. As a result, individual services and/or agencies that offer these services to survivors of a brain injury are not listed in this guide.

Available at your local Alberta Brain Injury Network office, the service coordinators in your area have a list of the resources available in your region.

In addition, the Alberta Brain Injury information line has current and accurate information on several support groups located in the province of Alberta. The information line's listing of the various resources is frequently updated. Contact your local Alberta Brain Injury Network office for guidance concerning the resources at your disposal (see Resources, Chapter 13).

Additional copies of this guide are accessible through the Alberta Brain Injury Initiative and from service coordinators of the Alberta Brain Injury Network Office (see Resources, Chapter 13).

We would like to offer our thanks to everyone involved in the creation of this guide, especially the numerous people from within the brain injury community who devoted their time, knowledge and input. This project was funded and administered by Human Services' Provincial Disability Supports Initiatives Branch.

Family

Dear family, friends, advocates, and caregivers,

Although most of this guide is written with the survivor as the target audience, it is certainly intended for you too. We know that this is a difficult time for you and you most likely have a lot of questions. We hope that this guide can be a starting point.

Even though the sections in this guide called “Family Matters” will probably be of special interest to you, you will be required to read the whole chapter in order for you to get all of the information you need.

Survivor

Dear survivor,

The purpose of this guide is to give information and support you, the survivor of a brain injury. It is also meant to help your family, friends, advocates, and caregivers to understand more about your brain injury and for you to understand what they are

experiencing. Not all of the information in this guide will concern you, considering that each brain injury is different. The Provincial Disability Supports Initiatives Branch hopes that this guide will assist you on your journey after your brain injury.

This guide is not intended to be a step-by-step guide to living with a brain injury. It is not meant to replace any information provided by the health professionals working with you and your family. This guide offers overall information on difficulties you may be faced with after a brain injury and try to give you practical advice. You may discover that there will be readjustments at every stage.

This guide will try to guide you in the right direction to obtain the support and resources in Alberta that you need.

Recovery from a brain injury is a long process. Considerable improvements may be seen in the first year and progress may carry on for several years.

You and your family's adjustment is also a long process. We hope that you will discover some indication of your personal experience in this guide.

In turn, you will realize that you are not alone and your responses to this sudden and major change in your life are shared by others.

The suggestions you find in this guide are from survivors living with a brain injury, who claim that these strategies worked for them. The suggestions are from survivors who had to relearn easy tasks, learn to live with the challenges, and may have lost former friends and family because of their brain injury. These survivors have learned how to live with their brain injury and they are still learning. We hope that you can learn from their suggestions and experiences.

The effects of a brain injury are varied and different for each person. Although this guide will mention several challenges that you may encounter and recommend various ways to overcome these challenges, everyone's experience will not be the same. You will need to see for yourself what works out best for you.

While this guide is mostly aimed towards survivors of a brain injury, it is full of information that will be

very beneficial for your family, friends, advocates, and caregivers. It will help them understand what you are experiencing. It will be helpful for you to read the sections called “Family Matters”. This is a troubling time for them too and it will help you to understand how they feel.

How to Use This Guide

Throughout the entire guide, there are opportunities for you to write about your own feelings, concerns and experiences. Since there was not enough room to spare for your written answers, we recommend that you start a journal to write down your difficulties and achievements. This will emphasize your accomplishments and serve as an important memory tool.

The end of every chapter in the guide has “Notes” pages for you to write. These can be used as a reminder and a way to record your personal experiences.

Notes

Notes

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Background on Brain Injury

- > Acquired Brain Injury
- > Parts of the Brain and How Injury Affects Them
- > Stroke
- > Severity of Brain Injury

Background on Brain Injury

In this chapter, you will:

- Read about Alberta's definition of Acquired Brain Injury and how that affects which supports you will be able to access.
- Learn about the different parts of the brain, and how damage to that part of the brain is likely to affect you.

Acquired Brain Injury

This book is for all survivors of a brain injury and their families. An acquired brain injury means your brain was hurt sometime after you were born, not before. Also, the damage must be the result of an injury or an illness, but not an illness that gets worse with time, like Alzheimer's disease or multiple sclerosis.

In Alberta, if you injured your brain when you were younger than 18 years old, you may be able to get supports through Persons with Developmental

Disabilities. Call 310-0000 to ask for the number of the Persons with Developmental Disabilities office nearest you. If your brain injury occurred when you were 18 years old or older, you are not eligible for supports from Persons with Developmental Disabilities, but we hope that this manual will help you find the supports you need.

Examples of acquired brain injury include:

- Traumatic brain injury, like a blow to the head, concussion or motor vehicle accident.
- Brain tumours.
- Brain infections, like meningitis and encephalitis.
- Lack of oxygen, like what happens when someone almost drowns.
- Strokes.
- Violent shaking or whiplash injuries.

How Brain Damage Happens

Damage to the brain results from the changes to the brain caused by an injury or illness. Each injury or illness acts in different ways. Some common ways in which the brain can be damaged include:

- Bruising.
- Bleeding (also called a hematoma).
- Brain swelling.
- Fever.
- Lack of blood or oxygen to the brain (called hypoxia and anoxia).
- Shearing or tearing of brain cells when the brain is rapidly moved back and forth or twisted around (called diffuse axonal injury).
- Pressure inside the skull (called increased intracranial pressure).
- Objects taking up space in the brain (like tumours).

An acquired brain injury can lead to either local or diffuse damage. **Local damage** happens when only one or a few parts of the brain are hurt. If you are injured in this way, you would usually only notice a few changes. **Diffuse damage** happens when many parts of the brain are injured. If you have this type of damage, you would usually find many changes.

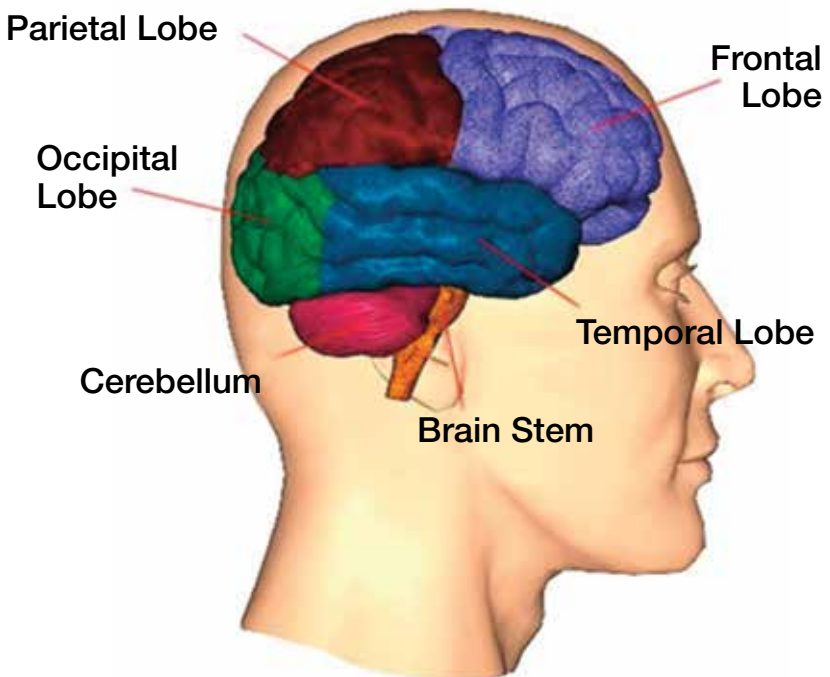
An example where either local or diffuse damage could occur is in a car crash. If a person's head hit the dash board and the brain hits the front of the skull it can be bruised or scraped. This damage is local because it happens only to the front of the brain.

A person can also have diffuse damage in a car crash. The brain is made up of millions of tiny cells. These cells connect the different parts of the brain to each other, but they are not very strong. In a crash where the brain moves rapidly back and forth, these brain cells are stretched and torn. This leads to tiny points of damage throughout the brain. This is an example of diffuse axonal injury.

Parts of the Brain and How Injury Affects Them

Although we do not completely understand how the brain works, we know that different parts of the brain help you do different things. The following section includes descriptions of parts of the brain that are often talked about. These descriptions include where the part is, what it usually does, and what behaviours a person might see after it is damaged. Memory problems can occur with any type of brain injury.

Brain Map



Frontal Lobe

The part of the brain just behind your forehead is called the frontal lobe. It is further divided into front and back areas. The front is called the prefrontal area. This part of the brain helps a person do the following:

- Plan and organize.
- Solve problems.

- Pay attention or shift attention.
- Control impulses.
- Get started on something.
- Be aware of one's strengths and weaknesses.
- Be aware of what others are thinking and feeling.

If you have an injury to this part of your brain, you might seem like a different person. You might appear more forward than before. Your activity level might drop. You may even sit back and do nothing, unless told to. Many survivors may have more trouble paying attention or focusing than before the injury or the illness. Others complain that they cannot get organized. Tasks like planning parties and even deciding what to wear can become a chore after this type of injury. In many cases, the survivor of a prefrontal lobe injury may not be aware of the changes they have gone through, or they may not realize how others are affected by these changes.

The back area of the frontal lobe includes the precentral and the premotor areas. They help to plan the movements of the body. Damage to this part of the brain leads to problems starting and coordinating movements of arms, legs, and other body parts.

Things like opening or closing your hands can take a lot of thought and effort after this kind of damage.

Temporal Lobes

Your temporal lobes are located along the sides of your head above your ears. This part of the brain helps you:

- Understand things you hear.
- Remember things you see and hear.
- Feel emotion.

Your right temporal lobe helps you understand and remember visual things like pictures and faces, and identify sounds. Your left temporal lobe helps you to understand and remember words, talk, and do math. Both lobes help you feel emotion. If you have damage to this part of the brain, you may be unable to speak, understand others, read, recognize faces, or do math. You may have memory problems. You might also have trouble controlling your emotions, especially anger.

Parietal Lobe

Behind your frontal lobe and between your temporal lobes is the parietal lobe. It is at the top of your head. This lobe is where information from sight, hearing, and touch are brought together. This area helps you:

- Recognize how something feels (hard or soft, rough or smooth).
- Know where your body parts are (my hand is on my lap).
- Know where you are.
- Coordinate seeing and moving (for example, hand-eye coordination).
- Draw.
- Read, write, and do math problems.

If you have damage to this lobe, you might get lost easily, or you might have trouble reaching for things around you. You might not recognize your spouse's face, you may be unable to read a map or draw a simple shape. You may also have problems with speaking, writing, reading and doing math.

Occipital Lobe

Behind the parietal lobe, at the back of your brain, is the occipital lobe. This part of your brain helps you to understand things that your eyes see.

Problems with blindness and recognizing everyday things, like a toaster or a lamp, result from damage to this lobe. If you have damage to this lobe, you may have trouble naming colors, shapes, and other things you see. You may also have blind spots; however, all of these problems are rare.

Cerebellum

Your cerebellum is at the very back and bottom of your brain. This part of your brain helps to make the movements of your body smooth and coordinated.

Damage here can lead to poor balance, jerky movements and shrinking muscles. This can make many everyday activities like walking, talking and eating difficult.

Brain Stem

The brain stem is where the brain connects to the spinal cord. This part of your brain controls “involuntary functions” of your body, like your breathing and heart rate. It also controls how awake or sleepy you are. All of the nerve fibres that connect the different parts of your body to your brain travel through your brain stem. If you have a brain stem injury, you usually have trouble moving some part of your body. You may have an unusual walk or have to use a wheelchair. Your speech may be a little slurred or you may not be able to talk at all.

Stroke

A stroke is an injury to a part of the brain. It happens when blood vessels, called arteries, become blocked or burst and the blood supply to the brain is cut off. Without the supply of blood, the brain does not get the oxygen and nutrients it needs. Permanent damage happens when the blood supply is cut off for too long.

Every stroke is different and recovery depends on which part of the brain and how much of the brain has been damaged. Some people suffer a mild stroke which means there can be very little injury to the brain. People experiencing mild strokes often fully recover or have fewer problems. Others may have a severe stroke in which a lot of damage is done. In these cases, it may take a very long time for survivors to regain even partial use of their arms, legs, speech, memory or whatever else may have been affected.

Strokes can affect the way a person moves, feels, behaves, talks and thinks. Some parts of the brain may work well while other parts do not. How a person is affected by a stroke depends upon:

- Where in the brain the stroke occurred.
- How serious the stroke was.
- The person's age, health and personality before the stroke.

Common effects of a stroke may include:

- Paralysis or weakness of one side of the body.
 - Weakness usually occurs on the side of the body opposite of the side of the brain where the injury occurred.
- Vision problems
 - Some survivors may lose part of their vision in one or both eyes, a condition known as visual field deficit.
- Aphasia
 - Aphasia is difficulty in using or understanding language.
- Perceptual challenges
 - A person's perception of everyday objects may be changed in that they may not recognize familiar objects or know how to use them.
- Being tired
 - It often takes more energy to do things after a stroke. As a result, many survivors get tired more quickly and more often.

- Depression
 - Depression can be a direct result of the brain injury but people may also become depressed because they feel they cannot accomplish things the same way they did before the stroke.
- Emotional expression
 - A term used to describe emotional responses that are exaggerated or inappropriate. Outbursts of anger, moaning, laughing or crying uncontrollably for little or no reason are common results of this condition.
- Memory challenges
 - Survivors may also have memory problems or have difficulty learning and remembering new information.
- Changes in personality
 - Damage to the brain can cause survivors to have less control over their positive or negative emotions, which can change the way they behave or interact with others.

For survivors, rehabilitation is an important part of recovery. Brain health requires stimulation on a regular basis. The more brain exercises a survivor

can do (memory games, puzzles) the better the outcome of recovery. Rehabilitation can help survivors cope with the effects of a stroke. More information on rehabilitation can be found in Chapter 3, called “Ongoing Physical Problems”.

Following a brain injury, if individuals reduce their activity and participation in their world because of their brain injury, there is potential to slow down recovery, emphasizing the need for ongoing rehabilitation and socialization.

Severity of Brain Injury

When someone is injured, everyone wants to know, “how bad is it?” and “will you be normal again?”

It is difficult to answer these questions. The reason for that is because there is no way to perfectly predict how much a person will recover. Health professionals sometimes use the severity of the injury as an indicator of **prognosis**. Prognosis is a medical term meaning how well you will recover. With traumatic brain injuries, the terms “mild”, “moderate” and “severe” are used to determine prognosis.

For traumatic brain injuries, the judgment of severity is based on the Glasgow Coma Scale stages of emerging from a coma. The score is based on your ability to talk, to follow direction and to make eye contact.

Another measure of severity is your ability to retain or recall information. After an injury, people often cannot remember what has just happened. They may not remember they are in a hospital or what day it is. This inability to remember is called **post-traumatic amnesia**. The severity is based upon how long your post-traumatic amnesia lasts after the injury.

Severity of injury is not always a good predictor of recovery and can vary greatly between individuals. The general rule is the more severe the injury, the more difficult it will be to make a full recovery and return to life as it was before experiencing the injury.

Someone with a mild brain injury might not even be admitted to the hospital. Most frequently, a mild injury is the result of a hit on the head caused by a fall or sudden violent motion, such as a car crash. At the time of the injury, you may have one or more of the following symptoms:

- Brief loss of consciousness.
- Loss of the memories from immediately before, during, or after the injury.
- Dizziness or clouded thinking at the time of the injury.

Symptoms of a mild brain injury often go away completely or lessen in time. Recovery is considered complete if symptoms do not stop you from doing your daily activities.

If you think you have had a mild brain injury, it is important to see a health professional who is experienced in treating a brain injury. Health care professionals without this experience may brush the injury off because it is mild. Also, medical tests often do not show damage to the brain if time passes between the injury and the medical test.

This means you might have a brain injury even if your medical test says your brain looks normal. A professional who knows about brain injury can give you information and encouragement to help you as you recover.

The most common symptoms of a brain injury include:

- Poor problem solving skills.
- Language problems.
- Personality changes and bursts of emotion.
- Physical problems (poor balance, problems with vision, headache, fatigue and physical disabilities, such as difficulties with walking, sitting and much more).
- Problems in daily living (poor memory and attention, difficulties planning and setting goals, slowed thinking and understanding, decreased sexual drive, increased aggression and impulse buying).
- Social problems (difficulty making or keeping friends, poor judgment in groups, standing too close to others, saying the wrong thing, and not understanding when people are tired, angry or bored).

Measures of Severity

Knowing that an injury is mild, moderate or severe tells us how bad things may be, but this is not a perfect measure. Each injury is different and each individual is affected differently. There are stories of people so severely injured that they were near death but who recovered and went on to university. There are also stories of people with much less severe injuries whose lives have fallen apart. Measures of severity are, at best, a guide. It is how you are doing now and the improvements that you are making that are the best indication of where you are going.

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After the Hospital

- > Discharge and Reduced Therapy
- > The Impact of Limited Resources
- > Steps to Independence
- > Finding Information on Brain Injury

After the Hospital

In this chapter, you will:

- Learn the reasons for discharge and/or decrease in medical or therapy services.
- Learn how to find resources and information on brain injury.

Discharge and Reduced Therapy

Questions about Discharge

When you are discharged, you may wonder why you have to leave the hospital. This is a common concern and reflects people's fears about having to face how their lives have been changed by the injury. This may also be difficult for your family who may be worried about having to take care of you. These fears are often at their greatest when the injury has been severe, causing clear changes in your ability to think, get around, take care of yourself, and manage your

feelings and behaviours. In these situations, the move out of the hospital is another major life change. Like many others, you may have questioned discharge because you still had many needs and you felt the move out of hospital or rehabilitation was too quick.

One answer is that you may have gained what you could from your hospital or rehabilitation stay, and needed to move on to make further improvements. Discharge from the hospital usually happens once you are medically stable. Discharge from a rehabilitation ward occurs when your treatment goals have been reached or when the rehabilitation centre does not have the capabilities or resources to help you continue with your treatment goals.

You may have been discharged without being sent to a rehabilitation ward at all. That may be because you are not yet ready for the intense level of treatment offered. Those who are not ready may be sent to a long-term care centre or back home. To you, this may feel like your needs are being ignored. Remember, some individuals experience a slower recovery. When ready, you can begin treatment at the rehabilitation ward.

Returning home has benefits over staying in hospital. You may discover strengths and weaknesses at home, school or work that would not be seen in the hospital or rehabilitation ward. These strengths and weaknesses can be brought to the attention of health professionals. Finally, going home is a chance for independence that is hard to achieve in a hospital or rehabilitation ward.

Dealing with Discharge

You can ease the stress of discharge by taking the following basic steps:

1. Ask the hospital staff if there is a discharge planner who can assist you with your discharge.
2. Get an **advocate**. An advocate is someone who will help you with some of the skills you have lost. They may help you organize your papers, take care of your finances, or help you get the supports you need. Choose someone who is good at the skills they will be helping you with. Choose someone who works well with you. If you have many needs, you may want to choose several advocates so that it is not too much work for one person.

3. Get organized. This is something an advocate can help you with. You may have lost your organizational skills or your motivational skills.

You may find that you are not well enough or too tired to deal with organizing your papers. You should start a binder or folder containing reports, handouts, notes from meetings, and lists of names and phone numbers. Include anything that forms a record of your care and could be used to help you or your family members to better understand the injury and its effects. This information will also be useful if you need to give detailed information to your lawyer or rehabilitation centre.

4. When a problem arises, get in touch with someone who has provided you with care in the past. This could be your family doctor or a specialist, your lawyer or a rehabilitation worker. It is often not until you return home or go back to school or work that you notice problems. This is the time to contact professionals who can help you meet new challenges.

Questions about Therapy

You may also feel your therapy is being limited. This concern usually arises when outpatient or community therapy, often provided by an occupational therapist, physiotherapist, social worker, speech-language pathologist or recreation therapist, is reduced.

Many therapists believe that life is the best therapy. Healthy people need to take care of themselves, get regular exercise, and find interesting things to do. Instead of visiting a therapist, the experience of living motivates survivors of a brain injury. That is, life provides exercise, stimulation and training. Life should provide similar benefits for you.

Even if you may always need someone to assist you in living, that person does not need to be a therapist. A family member, friend, home health aide or community worker could assist you. You are your own best advocate because only you know your life goals, but you may need a group of people to help direct you. It is important to have people around who can encourage you to do the things you need to do.

Independence is another reason to move forward. Therapists believe that limiting the length of therapy can help you maintain your independence. If you rely on a therapist to keep fit and active, you are not being given the chance to take care of yourself. Feeling responsible for your own life can be a powerful feeling. People who have been given greater control over dressing themselves, feeding themselves, and doing everyday chores have shown amazing improvements in mood, conduct, and feelings of self-worth.

The Impact of Limited Resources

The final part of discharge and/or reduced therapy is that there is limited service available. There may not be enough beds, or people to provide services. In rural or northern Alberta or in small communities, the limits of available services may be the reason for discharge and/or reduced therapy.

In cases of discharge or reduced therapy due to limited resources, you will need an advocate to help you get better services. They may be able to help you adapt available resources to meet your needs.

Go to your health board, band, political representative, local Alberta Brain Injury Network office (see Resources, Chapter 13), or local brain injury association (see Resources, Chapter 13) and ask how to get better services.

Steps to Independence

For some people with severe cognitive deficits, achieving complete independence may be an unrealistic goal. Determining when it is safe to let go after a brain injury can be a heart-wrenching decision for families. All too frequently, families expect that discharge from a hospital or completion of a rehabilitation program indicates that the person is “well enough” or “cured”; however, most people will experience some ongoing problems with cognition. There is a delicate balance between protecting a person from potential harm and promoting independent actions that provide learning opportunities.

Involve Family in Rehabilitation

It is helpful for family members to witness first-hand how an injury impacts the person's ability to perform certain tasks. It also prepares the family to assume their role as the support system once the rehabilitation is completed.

Some people with frontal lobe damage lack awareness about their own impairments and may take unnecessary risks affecting their safety. It is helpful to gradually establish some safe activities for the person to manage independently like a program at a local gym where trained staff can supervise, monitor and assist. Recreational activities are good for re-establishing community involvement. Whatever services your family member chooses to participate in, ensure the person in charge is aware of the person's impairments and the extent of help they will need to participate safely and successfully.

Finding Information on Brain Injury

Another frequent concern for survivors and their family members is finding information on brain injury. This is not to say that nurses, doctors, social workers and therapy staff have not done enough teaching. They have likely given you information about your diagnosis (the name given to your type of brain injury) and prognosis (how you are likely to do after you leave the hospital). They also may have provided information on continuing therapy in the home, keeping safe and well, dealing with future difficulties and making arrangements for services in the community. For several reasons, you may still want to know more. For instance:

- There always seems to be more to learn. As you and your family face new challenges, the need for more information may grow.

- Information provided in meetings with hospital staff or community workers may not “sink in”. You may have been too tired or emotional to fully understand or remember it, or you may have memory or comprehension difficulties that prevent you from retaining information.
- You may want the “big picture”, meaning you want more in-depth information on brain injury, its usual course, common and uncommon problems, changes you might expect in your family, how to return to school or work, how to begin volunteering, how to work within the health care system or other organizations and soon. This type of information is usually provided a little at a time, when there is a specific problem or issue to deal with.

Finding More Information

The solution to feeling uninformed is to gather as much information as possible. There are books, manuals, pamphlets and videos your whole family can use. You can begin your search in the following places:

- Contact your local Alberta Brain Injury Network office (see Resources, Chapter 13).
- Contact the local brain injury association nearest to you (see Resources, Chapter 13).
- Search on the internet (see Resources, Chapter 13).
- Talk to local health professionals or workers and volunteers at community agencies.
- Talk to your local Family and Community Support Services office and find out what specific resources may be available in your region. Dial 310-0000 toll free and ask for contact information for the Family and Community Support Services in your area.
- Talk with other survivors and families of survivors who have gone through similar experiences. You may find their stories helpful and inspiring.

In your discussions with others, do not be afraid to ask to have things repeated or explained more than once. The information may have been provided in the hospital or by a community worker, and it may have been repeated several times already. However, none of that matters. What matters is that you understand the information. Always feel free to ask to have information repeated or written down. You could also ask people to say things in a way you understand. A good way to remember important information is to bring a tape recorder to record the meeting or bring an advocate who will take notes for you.

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Ongoing Physical Problems

- > Fatigue
- > Headaches
- > Dizziness
- > Mobility Problems and Physical Disabilities
- > Chronic Pain Syndrome
- > Managing Chronic Pain

Ongoing Physical Problems

In this chapter, you will:

- Find out some good techniques for coping with ongoing physical problems like fatigue, headaches, and dizziness.

Fatigue

The material in this section is condensed and adapted from the book “Managing Fatigue: a Six Week Course for Energy Conservation”.

Fatigue is a common problem among survivors of brain injury. You may not have the energy to do the things you used to do. This energy shortage or fatigue may be a temporary or a life-long problem. This section discusses basic concepts that will help you make the most of your energy.

What to Expect

It is likely, especially soon after your discharge from the hospital, that you will not be able to do all the things you did before the brain injury. You may experience fatigue in physical or mental ways. For example, you may:

- Feel as if your whole body is worn out, or just certain parts are tired.
- Find it difficult to concentrate or do other activities that involve thinking, focusing, remembering, or multitasking (all tiring activities for survivors of brain injury).
- Become “grumpy” or “short” with others.
- Say you are tired, lack energy, or lack the desire to do anything.
- Become frustrated and feel “down” because your overall activity level is reduced.
- Become troubled that you cannot do the things you used to do.

Stress from feeling frustrated or down can also increase fatigue. This creates a cycle of fatigue causing stress, which then increases fatigue.

Understanding that you are operating at a different speed will help everyone – yourself, family members and friends – adjust their expectations.

Managing Energy

To stop or prevent the cycle of fatigue from happening, you need to manage your energy. This involves developing an energy “budget”, saving as much energy as possible and spending energy on meaningful and important things first.

To budget energy, you may need help with setting priorities, evaluating standards and playing an active role in decision-making.

- Setting priorities means deciding what activities are most important and organizing the daily routine to accomplish these activities.
- Standards are expectations of the performance of an activity, such as how often something is done or how well it is done.

Changing standards can free up energy and allow you to do things you really want to do. As part of the re-evaluation, you may gradually stop doing certain things.

- Playing an active role in decision-making about how you will spend your energy will give you more control over your life. It might be helpful to make a list of activities and then decide what you will do, what you will not do, and what you might do if you have the energy.

Learning to Rest

Resting is one of the best ways to save energy. Since it is important to rest before becoming fatigued, alternate rest and activity periods. This is called pacing. By alternating between a tiring activity and a rest period, you will accomplish more.

There are many ways to rest: sitting, lying down, spending time in a quiet environment without distractions, listening to music, sleeping or engaging in a quiet hobby. You will need to experiment with what type of rest works best, and when, how long, and how often you need to rest.

Using a Daily Schedule

A daily schedule can be a big help in budgeting, saving and spending energy. To create a daily schedule, start by inserting rest times through the day; then, schedule activities around the rest times. Schedule the more difficult activities for times you are likely to have more energy, such as after a rest. You will spend less energy if your day is planned so that tasks requiring mental activity (concentration, thinking and problem solving) are broken into shorter periods of time. A daily schedule does not only provide a routine for the day, it functions as a memory aid and gives you a sense of control and accomplishment.

Headaches

Headaches are quite common after a brain injury. Their severity usually decreases over time, although some survivors are bothered by headaches for the rest of their lives. For severe headaches, it may be important to see a neurologist. Some survivors say they have found relief through alternative methods, such as acupuncture and massage, or by consulting an orthodontist or a chiropractor.

Some common terms for different types of headaches are:

- Muscle tension headaches tend to start from the back of the head and move around to the side or over the top to the forehead. They are often the result of stretched head and neck muscles, caused by the force of the head jerking rapidly forward and backward at the time of the injury.
- Migraine headaches tend to occur in the front of the head. Some survivors may complain that their forehead or temples throb, they may be sensitive to light, feel nauseated or actually vomit. Migraines may be caused by damage done to small blood vessels in the brain at the time of the injury.
- Some survivors report a very sharp, sudden pain in the head, but because the pain usually only lasts a short time, doctors may not treat this type of headache.
- Analgesic rebound headaches are actually caused by the use (usually overuse) of analgesics (painkillers) for headaches.

Treatment Tips

Treatment for headaches varies. The first step is to give the doctor a good description of the headache. This will help the doctor determine the best way to treat it. In difficult cases, it may be necessary to see a neurologist for help in controlling the headaches.

For muscle tension headaches, the following may prove helpful:

- Physiotherapy treatment, including exercises as instructed by the therapist.
- Experimenting with different pillows, including pillows specially designed to better support your neck. Poor neck position while sleeping can increase headaches.
- Ensuring the prescription for your glasses is correct. Straining while reading or watching television can increase muscle tension.
- Reading or watching television for short periods of time only, since the effort of concentrating may increase tension.
- Massaging uncomfortable muscles.
- Asking your doctor or therapist to show you how to do exercises that will help you relax your neck and shoulders.
- Using hot or cold packs on your neck or head.

Migraine headaches can be very difficult to treat. Medications are frequently used, but it can take time to find the right medication. It is very important to take medications exactly as prescribed. If you have trouble with your memory, you may need an advocate to remember for you. You can also use an aid, such as a watch alarm set to go off at medication time, or a blister pack and medication dispenser.

The following suggestions may be helpful for migraine type headaches:

- Take prescribed migraine medication and lie down in a dark, quiet room as soon as a headache starts. Bright lights and noises can make the migraines worse.
- Wear dark sunglasses (very dark ones are best).
- Keep track of what you have eaten prior to a headache since some foods can trigger a migraine. Also, it may be helpful to note what you were doing and what the weather was like prior to the start of a migraine. This may help you notice a pattern and help you avoid things that may trigger a migraine.

Several general tips can help ease muscle tension and migraine headaches:

- Get enough rest. Fatigue can often cause headaches.
- Practice deep breathing and relaxation exercises for 20-30 minutes per day. Many headaches are associated with stress and these exercises are excellent for relieving stress. Ask a psychologist, nurse, physiotherapist, or occupational therapist to teach you these exercises.
- Avoid noisy environments and too much stimulation.
- Do not concentrate too long on one thing.
- Stop smoking.

If headaches are severe and difficult to treat, you can keep a headache journal. In the journal, rate the severity of headaches on a scale discussed with your doctor, such as 1 to 10, with “1” being a mild headache and “10” being the worst. Also, write in the journal what events happened before the headaches. If a pattern can be seen, steps can be taken to prevent headaches.

Some over-the-counter medication can have serious side effects, such as liver damage, so be sure you do not take more than the recommended daily dose. If you are exceeding the daily dose or feel the daily dose is not enough, talk to your doctor about other solutions.

Dizziness

Dizziness is another common symptom that tends to get better with time. It can be described as a feeling of imbalance, lightheadedness, drunkenness, blurriness, or a “turning” sensation. It can last for seconds or hours and may be severe enough to make it difficult to climb, bend, or move around. It can also result in nausea and/or vomiting. Dizziness may result from an injury to the inner ear, eyes, neck, brain injury or it may be due to emotional distress caused by the injury, or by side effects of the medication you are on.

- Moving quickly can make dizziness worse. You can adapt by moving slowly, especially when changing from a lying to a standing position.

- If necessary, see an eye, ear, nose, and throat specialist, or physiotherapist for treatment. The specialist can help determine the exact cause of dizziness. The physiotherapist can provide exercises to help cope with dizziness.
- Be aware of what brings the dizziness on and try to avoid those things. For example, if you have difficulty taking elevators and escalators, use stairways instead.

Mobility Problems and Physical Disabilities

You may experience some mobility problems as a result of your brain injury or there may be other physical disabilities that limit your mobility. However, not every person who has experienced a brain injury will experience physical or mobility problems. The supports that are required by a survivor will depend on their degree of disability.

Rehabilitation for disability and mobility problems may include a number of people working together on a rehabilitation team. These could include:

- Your primary doctor, providing care and supervision for medical problems.
- A neurologist, specializing in the brain and nervous system.
- A physiotherapist, specializing in exercises and techniques to improve muscle control, balance and walking.
- An occupational therapist, helping survivors learn new practical skills.
- A speech-language pathologist, helping survivors learn other ways to communicate and deal with swallowing problems.

Chronic Pain Syndrome

With chronic pain, people may feel the pain is increasing even though there is no medical evidence for this. In these cases, other factors are at play including:

- Emotional functioning.
- Personality traits.

- Past learning experiences.
- The way others respond to the person's behaviour.

Sleep and appetite disturbances can intensify the disability that results from chronic pain. As time goes by, the person may become depressed, preoccupied with normal changes in bodily functioning, and may worry about experiencing new illnesses.

The person can develop a tendency to view all activities in terms of how much pain will be experienced. This can lead to a cycle of helplessness and despair, often accompanied by anger toward professionals who never seem to be able to cure their pain. In turn, professionals can lose patience with the person with persistent pain who may appear to have little medical justification for these complaints.

Managing Chronic Pain

Pain management strategies are usually based on one ultimate and constant objective – the reduction of pain, not its total elimination. If the person experiencing the pain and all the professionals who treat them do not make this the goal, frustration will

grow and result in failure to coordinate treatment efforts in a successful manner. Reasonable outcomes of pain management would include:

- Decreased medication use.
- Fewer physician visits.
- Fewer hospital visits.
- Improved flexibility and endurance.
- Increased strength.
- Improved functioning at home.
- Improved social interaction.
- Return to employment.

Research has shown that having realistic, helpful thoughts is an important part of pain management. Cognitive behavioural psychologists can help those with chronic pain to change their negative thoughts about their pain, its effects, and other sources of stress.

There are support groups and medical facilities set up to help people with chronic pain. Contact your local doctor or local Alberta Brain Injury Network office for contact details in your area.

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General Health

4

- > Nutrition
- > Medications
- > Alcohol and Street Drugs

General Health

In this chapter, you will:

- Learn how nutrition and general health can aid your recovery.
- Discover some tips on safe medication usage.
- Read how alcohol and street drugs can unfavorably affect your recovery.

Nutrition

Your brain injury may change the way you relate to food. For some survivors, memory problems may affect food intake. Damage to the brain can cause an inability to feel full or hungry, causing you to eat too much or too little without realizing it. You may have a changed or absent sense of taste or smell. This often happens in the earlier stages of recovery and may disappear as time goes on. This could also be a side effect of the medication you are on.

The simplest way to manage many nutritional concerns is to create a meal plan and record what you are eating. This way, if you have problems remembering when you ate, or cannot tell when you feel full, you can refer to the record you are keeping.

Canada's Food Guide

Canada's Food Guide to Healthy Eating provides basic information on good nutrition, encouraging you to enjoy a variety of foods. Canada's Food Guide to Healthy Eating identifies the four food groups and recommends the number of servings per day required for healthy Canadians. Factors, such as age, weight, gender, activity, and medical concerns will influence how many servings are required from each of the four groups. The serving sizes can be adjusted to meet individual needs.

Emphasize cereals, breads, other grain products, vegetables and fruit. Ensure that individual needs for energy, protein and other nutrients are met.

A nutritional assessment and follow-up by a dietitian may be required. Your doctor can probably recommend a dietitian for you to contact.

When choosing foods, take into account any problems you have with swallowing or food allergies. A speech-language pathologist can assess and treat swallowing problems. A dietitian can help with food allergies. Speech-language pathologists may be accessed through your Regional Health Authority or your local Alberta Brain Injury Network office (see Resources, Chapter 13).

Choose low fat dairy products, lean meats, and food prepared with little or no fat.

If you are overweight, you may need to control portion sizes as well as fat content. If you are underweight, or have increased energy requirements, you may need to eat higher fat foods to achieve and maintain a healthy weight.

You can also achieve and maintain a healthy body weight by participating in regular physical activity. Keep in mind that you may be restricted in what you can do because of poor balance, poor vision, fatigue or other complications resulting from your brain injury. Keep looking for something that you are physically able to do, that you enjoy, and that contributes to

your therapy. Physical, recreational or occupational therapists may provide advice on the kinds of activities most suitable for you.

Limiting salt may help control high blood pressure and fluid retention if you have these concerns.

Caffeine, which is found in coffee, tea, some soft drinks, and chocolate, is a stimulant. Your ability to tolerate caffeine may be very limited and it may be best to avoid all caffeine, especially in the initial stages of recovery. Even if the stimulating effect of caffeine is not a problem, Health Canada suggests having no more than four cups of brewed coffee (or the caffeine equivalent in other foods and beverages) per day.

Eating well is an important part of recovering from an illness and maintaining a good health. Follow Canada's Food Guide to Healthy Eating. If you are concerned about your nutritional needs, ask your doctor for a referral to an outpatient dietitian.

Medications

Since taking more than one medication at a time can lead to drug interactions, it is important for the doctor writing the prescription and the pharmacist to know which drugs are being taken. If you have problems with memory, you can carry a list of your medications to show the doctor and the pharmacist, or you can have a friend or family member accompany you with the list. Go to the same pharmacy for all your prescriptions and share the list with the pharmacist even when buying non-prescription or over-the-counter drugs, since interactions can happen with these as well.

Follow Instructions

It is essential to follow instructions when taking medication. Drugs are most beneficial when taken in the right dose, at the right time, in the right way. Not following instructions may prevent the drug from doing its job and may cause serious side effects.

Pharmacists will usually give you an instruction sheet each time you fill a prescription. If they do not automatically give you one, ask for it. It will provide important information, such as common side effects and what you can do about them, drugs that should not be taken at the same time, and special instructions to ensure the drug is most effective, like taking it between meals or with food. Take time to discuss any questions with your pharmacist.

Memory Aids

If you have problems with your memory, there are several aids available that can help you take your medications correctly. Purchase a **dosette**, a plastic container with separate pill compartments for different times of the day and different days of the week.

Ask your pharmacy if they can put the medications in individual bubble packages with labels, showing the time and day pills in each package should be taken.

If you have a serious memory impairment, you may need an advocate to remind you when it is time to take your medications.

Commonly Used Medications

Since the changes that can happen after having a brain injury vary widely, many different medications may be prescribed, based on necessity. This list of medications may include:

- **Anti-convulsants:** if you have seizures (convulsions) following the injury, you will probably be given a prescription for an anti-convulsant. The purpose of these drugs is to prevent seizures. The need for anti-convulsants will be re-evaluated by your physician on an ongoing basis. The drug may only be needed for a few months, but you should discuss the expected duration with your physician. Do not increase or decrease the dose without consulting your physician first.
- **Anti-depressants:** some survivors and their caregivers experience depression. Depending on the level of depression, the physician may prescribe anti-depressants to help relieve feelings of sadness and hopelessness.

Although originally used only to treat depression, this class of drugs is now proving useful in other situations. You may be given anti-depressants to

help you have restorative sleep – the kind of sleep that makes you feel well-rested. They may be prescribed to help deal with certain types of pain or they may be given to help decrease impulsiveness and emotionality, without causing the same side effects as other drugs.

- **Anti-spasmodics:** following a brain injury, muscles in certain parts of the body may be tighter than usual. This may cause pain and altered use of the affected joints. Anti-spasmodic drugs help loosen muscles, which reduces pain and makes it easier to move joints properly.
- **Analgesics (painkillers):** you may experience some amount of pain following a brain injury. Headaches and pain from tight muscles are two of the more common reasons for taking analgesics. Non-prescription painkillers, such as acetaminophen, are often useful for occasional pain relief. In more severe or chronic cases, a prescription medication may be required.

- **Psychotropics:** if you have problems with impulse control, meaning you do things without thinking about the consequences of your actions, you may be given psychotropic drugs. Acting without care for consequences can lead to embarrassing and even dangerous situations. Psychotropics may be helpful in controlling some impulsive behaviours.

Alcohol and Street Drugs

Survivors of brain injury should abstain from alcohol consumption. This is extremely important in the initial stages of recovery. Alcohol affects the brain's ability to function.

When the brain is already damaged, the effects of alcohol are more pronounced. Alcohol affects the brain in the following ways:

- Limits recovery.
- Increases problems with balance, walking, and talking.
- Increases the chance of saying or doing things impulsively.

- Interferes with the ability to think and learn new things.
- Increases the chance of becoming depressed.
- Increases the chance of having a seizure.
- Increases the chance of having another brain injury.

Consuming alcohol after a brain injury will likely increase complications. You may choose to ask your family or friends to help you by taking a break from drinking or not drinking in your company.

If you were consuming alcohol to excess before the brain injury, additional help may be needed to change this pattern.

Find a health professional familiar with both alcohol abuse and brain injury to help you.

Most street drugs, such as marijuana and cocaine, hold the same dangers for survivors as alcohol. If you did not use street drugs before your injury, it is important not to begin using them. If you did use street drugs before the brain injury, you may need the assistance of experienced drug counselors to stop. Continued drug use will put you at an extremely high risk of further brain injury.

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Rebuilding Skills

- > Getting Help
- > The Science of Rebuilding Skills
- > Rebuilding Skills
- > Conflicting Goals

Rebuilding Skills

In this chapter, you will:

- Discover how you and your family view the changes that have occurred.
- Learn ways to avoid conflicts.
- Find out what tools you need to rebuild your skills and learn how to work on them.

Getting Help

Everyone needs help at one time or another. After a brain injury, you and your family will probably need help. It can be hard to accept that you have lost some skills and independence after a brain injury. On the other hand, it is also hard for your family to accept that they may now have to take care of you, even though you used to be able to take care of yourself.

Because this is such a difficult situation and there are many issues to talk about, this chapter is divided

into sections for you, the survivor, and sections for your family. However, we hope that both you and your family will read both sections. This may help you begin to understand each other.

The question of helping is not always clear-cut. How much help should your family provide? How much help are you willing to accept? You and your family should consider these things:

Family Matters

Prior to injury, did the survivor tend to be independent or dependent, trusting or cautious, easygoing or difficult? How much has this changed since the injury?

Has their ability to think been affected? For example, do they have memory problems, has their thinking slowed down, or do they show poor judgment?

After their stay in hospital, does the survivor expect others to cater to them? This can affect their willingness to do things for themselves.

Survivor Matters

How do you feel about the changes in your life? Are you angry or depressed? Do you understand the changes?

Does your family expect you to follow their goals for your recovery instead of your own? Are they willing to give you the help you think you need? Does your family understand that the amount of help needed might change from day-to-day, depending on how well you are doing on that day?

It is not surprising that there are no simple answers to questions of how much help should or will be provided to you. The fact is, there is no “right” answer. The amount of help that should be provided depends on you and your family’s circumstances.

The Science of Rebuilding Skills

Since this is a difficult and emotional time for both you and your family, it might be helpful to lay down some ground rules to encourage compromise and avoid conflict. The first suggestion is to approach helping like a scientist. Scientists always test their ideas and you can do the same while you are trying to rebuild skills. Testing is important because although you may feel like you are capable of doing the same things you could do before the accident, this might not be true. Testing is a safe way of evaluating and improving your skills.

An added benefit of acting like a scientist is that the helper and the survivor can distance themselves from their emotions. Putting things to the test can lead to mutual cooperation between the helper and the survivor.

Rules to Remember

When putting things to the test, remember the following three rules:

Survivor Matters

1. The test must be safe. A good rule is to start small. This will set you up for success. If you want to cook a full meal, consider starting with a breakfast of toast and cereal or a lunch of grilled cheese sandwiches and soup. The results will give you and your family immediate feedback on any problem areas. If the test is a success, try something a little more difficult. If not, set more achievable goals or keep practicing to improve your skills.

Family Matters

2. Do not assist the survivor if you feel uncomfortable. If the survivor wants to do something you feel is too dangerous, simply say “no”. Saying “no” gives the survivor two important pieces of information.

First, it lets them know what makes you uncomfortable, which helps them understand what to expect of you and others. Second, it helps them make safer decisions. Like many of us, the survivor may sometimes push too far. Your refusal can lead to negotiations and a safer test. Remember, it is always okay to speak about your feelings and doubts.

Survivor Matters

Listen to your family if they are uncomfortable when you try something new. It may be true that you will succeed in this task, but it is important to keep a good relationship with your family by trying to understand their fears. You can discuss a solution that you will both be happy with, such as, “If I can make a grilled cheese sandwich three times without any mistakes, then I will be given a chance to make pasta by myself.”

Family Matters

3. Natural consequences can be the best teachers.

As a helper, it is important for you to allow natural consequences to follow actions, whether they are rewards or punishments. If the survivor waters the flowers, they enjoy credit for the beautiful blooms. If they burn the toast, they either eat it burnt or throw it out and have to do it again.

The important point is that you do not bring on the rewards or punishments. When you let natural consequences happen, the survivor is less likely to blame you when things don't work out. It can also lead to fewer disagreements and an increased sense of self-control for the survivor.

Rebuilding Skills

Communication

Communication is an important part of everyday living. Communicating is not just speaking. It is also getting ideas across to others through signs, symbols, gestures, body language and written language.

Brain injuries often affect a person's ability to communicate. Some brain injuries can cause problems with speech, which is called **aphasia**. There are two types of aphasia: **expressive aphasia** and **receptive aphasia**.

Expressive Aphasia

People with expressive aphasia may have difficulty finding the right words and forming sentences to communicate with others. They may also have trouble with writing words and sentences. Some people with expressive aphasia say that they know what they want to say, but they can't think of the words to say it. However, some people may not be able to think of what they want to say. Others may know what to say, but they are not able to control the muscles used in speech and voice production.

Receptive Aphasia

People with receptive aphasia may have difficulty with understanding what others are saying to you. Some of these people may be able to speak well,

but they may not understand when someone speaks to them. Sometimes, receptive aphasia affects a person's ability to read words. They may be able to repeat what someone says to them, but this should not be confused with understanding.

Brain injuries can affect the ability of the brain to send messages from the brain to the muscles of the mouth and throat that are involved in producing speech. This can cause problems with pronouncing words and/or using the voice to speak.

What You Can Do

Communication problems are very frustrating for both the person with aphasia and those without it. The following are ideas that can help communication with someone who has aphasia:

If you have aphasia...

- Slow down, take your time.
- Be patient with those trying to understand you.
- Keep a journal handy with common words and phrases, which you can refer to when needed.
- Ask someone who understands you to help you communicate.

- If you cannot think of a word, try describing it. For example, “It’s red, you put it on french fries” (ketchup).
- Practice talking and forming words.
- Use eye contact and body language to help you communicate.
- Do not give up.

If you are communicating with someone who has aphasia...

- Try to eliminate background noises and other distractions.
- Make sure you have the person’s attention.
- Speak slowly and clearly.
- Check for understanding.
- Encourage the person to keep trying.
- Do not interrupt or fill in missing words.
- Use a pen and paper to write down key words and to clarify the messages.
- Do not talk down to the person or use baby talk. Treat the person as the adult they are.

Where to Get Help

Professionals called speech-language pathologists are able to help people with aphasia. They can determine whether the problem is caused by the brain-muscle system or if it is a receptive or expressive problem. They can give you exercises and routines to help you with your speech. They can also help you develop your own way of communicating with pictures, printed sheets and other symbols.

Some communities may have support groups for people with aphasia. These groups, usually led by speech-language pathologists, are designed to give people an opportunity to practice communicating in a supportive environment.

You can call your Health Authority for information about how to get in touch with a speech-language pathologist or ask your doctor for a referral.

Memory

Family Matters

Family members, friends and support workers can play a key role in helping survivors cope more effectively with memory problems. Based on individual situations and strengths, many of the following strategies, which are best suited to your personal situation, can be used. Each time you introduce a new strategy, remember that the survivor may need specific instructions on how to use it. Take the time to review the strategy together on a number of occasions if needed.

The following memory aid tips may be helpful:

- Keep important items in a special place (for example, keys can be left on a small table next to the door).
- Label cupboards and drawers so the contents are known.
- Post instructions on how to use equipment, such as personal video recorder (PVRs), microwaves, and televisions nearby.
- Put checklists, schedules, calendars, bulletin boards, and other memory aids in a convenient, highly-visible place.

- Keep a notepad and a pen or pencil close to the telephone.
- Post important telephone numbers by the telephone.
- Telephone numbers can be programmed to telephones that have the capability.
- Use alarm clocks, calendars and alarms in your cell phone, watches, automatic shut-off devices, tape recorders, electronic timers for lights, computers, and electronic signaling devices (for example, keys that beep when you clap your hands).
- Check appliances before leaving home and make sure everything is turned off before you leave.

Make Lists of:

- Housekeeping duties.
- Groceries or various items to buy.
- Questions you want to ask your doctor or service coordinator.
- Bills to pay, etc.

Use Calendars and Cell phones to:

- Remember to pay bills.
- Remember appointments.
- Remember addresses.
- Keep track of work and social dates, etc.

Remembering Names:

- Say the name out loud or ask for the name again.
- Ask a question using the name.
- Use the name in a conversation at least once.
- Say goodbye by using the name again.

Many survivors can learn to be more independent through repetition, practice and use of memory compensation strategies. In addition to those already mentioned, there are a number of other techniques that can be used to help the survivor in rebuilding their memory skills. We encourage you to investigate more methods by speaking with your regional service coordinator to find out about additional resources.

Insight

Survivor Matters

Insight is a sense of one's own abilities. For example, knowing you can jump down three stairs, but not ten, is insight. The brain injury may affect your insight.

Insight may be slightly less than it was, considerably less, or as is the case for a small number of survivors, nearly gone. This is called lack of insight.

If you suffer from lack of insight, you may need help seeing the consequences of your actions. Regular and continuous results of tests done with a helper can provide this. For example, you could put up a chart in the kitchen and add check marks each time you successfully make toast. This provides you with clear, objective feedback and can help make up for your own lack of insight.

Initiation

Initiation is also necessary for people to rebuild their skills. Initiation is the drive that pushes us to do the things we want to do or feel we should do. Some survivors of a brain injury lose their drive. They are less interested in doing things for themselves than before their injury. This is called lack of initiation.

Family Matters

As a helper, you may often find yourself doing a lot more than you would like for the survivor. You may also find that the survivor does things around you, but not without you. Ask yourself what needs to happen to get the survivor to do things for themselves.

Here are some suggestions:

- Find something that motivates the survivor. Praise can be a very powerful reward. People are more likely to do something if they know that others appreciate their efforts. You should also offer bigger rewards for completing tasks that are more difficult or tasks that the survivor particularly dislikes.
- Use reminders around the survivor, such as lists or signs that say what to do next or verbal cues from helpers. It is helpful to ask the survivor what kind of reminders would be most useful to them.

Survivor Matters

- Do not be afraid to reward yourself for doing tasks that you dislike or find difficult. For example, you can ask a family member or a good friend if they will go with you to a movie after you finally accomplish the big task that you were having trouble with.
- Use reminders that you find most helpful. If you prefer an electronic daily planner over a list stuck to the fridge, then that is what you should use. Experiment with different types of reminders until you find the one that works best for you. Other people may have good suggestions, but only you know what works best for you.

Motivation

Survivor Matters

Lack of initiation should not be confused with lack of motivation. People who lack motivation do not want to do what is asked of them.

People who lack initiation want to do something, but will not do it without encouragement.

Learned Helplessness is a kind of lack of motivation. It happens when a person cannot or is not allowed to escape a hurtful or a difficult situation. From this experience, they begin to believe that they have no control over their world and lose motivation to help themselves. Some health workers believe that learned helplessness can occur during the stay in the hospital. Survivors who have learned helplessness may appear listless, depressed, and/or uninterested in things around them. If this is the case, you may want to:

- Try to do things for yourself, even if it is difficult or something you are not good at. This will help you regain a sense of self-control and help you remember that you can make a difference in your own life.
- Think about goals or desires that you would enjoy working towards and that would help you feel as if you were regaining control over your own life.
- Try to overcome any negative reactions over your lack of motivation. If you focus on staying positive, it may help you become interested in trying new things.

Conflicting Goals

Family Matters

The survivor has to want to rebuild their skills, but this desire is not always present. You may want the survivor to do things to ease the challenges of providing care (which can be very high) or health workers may recommend building certain skills. In both cases, the survivor may not want to do this. The result is that you become involved in a plan to build skills the survivor does not want.

The differences between you and the survivor may express themselves in two common ways: passive resistance and active resistance. Passive resistance is when they agree to work on a skill but do not practice it. Active resistance is when they argue or fight when you try to assist with the skill. Passive resistance is much more difficult to identify, but a key symptom is a feeling of dissatisfaction on the part of the helper. The reasons for your dissatisfaction will remain unclear until your differences are uncovered.

One way to reduce the differences between you and the survivor is to involve them in planning the rebuilding their skills. Experience has taught health workers that a key element to success is accepting the survivor's goals for treatment.

Accepting goals from the survivor may be even more important once they return home, but it may take extra effort. Survivors may be unable or unwilling to argue with health workers or caregivers. They may conceal their true feelings to keep the peace or because they do not want to offend anyone. They may resist the whole process of planning to work on their skills because they want to do it on their own. It may also be because they are upset by suggestions from others, such as how to behave appropriately. Such resistance may be reduced with certain techniques (outlined in the following “Survivor Matters” section).

Survivor Matters

- You may have different goals for yourself than your family or helper has for you. These differences in goals can cause conflict. In this situation, it may be a good idea to have a third person (someone who is not a part of this conflict) help you and your family or helper talk about your goals, either separately or together. The third person can bring both of you together to develop a new plan for building your skills.
- You and the helper can write down the goals that are most important to you. Then, after a discussion, a few goals can be chosen from each list with an agreement to try to work on them. This takes into consideration the needs of the family. Some of your goals must meet the needs of others.

Family Matters

- How does your family want to continue providing support if the goals of the survivor differ from your own? This is usually more of an issue when caring for the survivor takes a lot of effort and/or the survivor is resistant, lacking insight, or simply being difficult.
- When differences produce increased tension and dissatisfaction in your family, consult a counselor either as a couple or a family. Even if the survivor is unable to benefit from counseling, your family may find it helpful. Counseling can help you explore your commitment to the survivor and your concerns about providing care.
- A local brain injury society may be able to help direct you to a support group (see Resources, Chapter 13).

The discussion of the challenges of providing care brings up an important issue. Should family members be the ones helping the survivor rebuild their skills? Supervision, especially after a severe brain injury,

can be required 24 hours a day. This can create relationships that are lacking the usual give-and-take, or where contrasting roles, such as lover and caretaker, creates emotional conflicts for both the helper and the survivor.

In many cases, family members are the only ones available to help the survivor rebuild their skills. If community or financial resources are available, you may want to explore whether someone else can do this work. Someone from outside the family will not experience the same stress and strain. They may be able to provide the necessary direction and supervision without the emotional turmoil. Success at finding such a person can be difficult and the resource is often time-limited or places a heavy financial burden on the family.

Notes

Notes

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Family

- > Adjusting to the Changes
- > Changes in the Survivor
- > Anger Management
- > Increased Responsibilities
- > Changes in Roles
- > Changes in Relationships
- > Separation, Divorce, and Placing the Survivor Outside the Home

Family

In this chapter, you will:

- Find out about some anger management techniques.
- Read about how a brain injury in the family can cause changes in responsibilities, roles, and relationships.
- Learn about the possible effects of all these changes and ways to cope with them.

Adjusting to the Changes

Whether they are good or bad, life experiences change our families. Marriage, divorce, birth and death are some experiences that we may know well. Each of them brings new responsibilities, roles, relationships and feelings. The key to living with these changes is learning to adjust.

How well you and your family adjust depends on the experience and the impact on your family.

Living with a brain injury takes a lot of adjustment. That is not to say that you and your family will have problems adjusting. You may not. If you do, you should know that it is quite normal. You should also know that there are certain things that you can do to help yourself.

Often, the first step is to try understanding the changes that have happened. Greater understanding usually leads to a sense of control. Feeling in control can reduce stress and help you to make better choices, especially when dealing with the changes that come with a brain injury.

Changes in the Survivor

Changes to the family usually begin with you, the survivor. That is because it is what you can and cannot do that determines how your family must respond. However, not all changes are alike. Some can make a big difference to your family, while others do not.

Below is a list of common changes. You and each member of your family should go through the list and check off those that apply. This will help paint a picture of the changes that you see in yourself and the changes that your family sees in you. Hopefully, this exercise will help each member of your family understand how everyone views the situation.

- Aggressive
- Angry and critical
- Difficulty concentrating
- Balance problems
- Dependency
- Double vision or wandering eye
- Easily distracted
- Easily lost
- Emotional (anxious or depressed)
- Fatigue
- Forgetting appointments
- Headaches
- Immature
- Impulsive
- Inappropriate social behaviour
- Inflexibility
- Lack of initiation (does not try things)
- Lack of insight (unaware of problems)
- Loss of taste and smell
- Misunderstanding what is said
- Moods are up and down
- Poor judgment (bad decisions)
- Poor problem-solving
- Problems with memory
- Problems with reading or writing
- Saying the wrong thing
- Seizure disorder
- Self-centeredness
- Sensitive to noise
- Sexual interest has changed (more/less)
- Sleep problems
- Slowed response time
- Standing too close to others
- Swearing or verbally abusive
- Talking too much
- Tires easily
- Trouble with making decisions
- Uncoordinated movements
- Worrying too much

Anger Management

Anger is a completely normal emotion. However, when it gets out of control and turns destructive, it can lead to problems at work, in your personal relationships, and in the overall quality of your life. This section is meant to help you understand and control your anger. You may want to talk to a counsellor, mental health worker, or your service coordinator for more information on anger management.

Anger can vary from slight irritation to intense rage. Anger can be caused by both external and internal events. You may be angry at a specific person (co-worker or supervisor) or event (a traffic jam or a cancelled flight). Your anger may also be caused by worrying or brooding over your personal problems. The memories of traumatic or enraging events can also trigger anger.

The goal of anger management is to reduce both your emotional feelings and the physiological arousal that are caused by anger. You cannot always avoid or get rid of the things or the people that enrage you, nor can you change them, but you can learn to control your reactions.

It is best to find out what it is that triggers your anger, developing strategies to keep those triggers from tipping you over the edge.

We cannot physically lash out at every person or object that irritates or annoys us. Laws, social norms, and common sense places limits on how far our anger can take us.

People use three main approaches to deal with their anger: expressing, suppressing, and calming. Expressing your anger in an assertive, not aggressive, manner is the healthiest way to express your anger. To do this, you have to learn how to make clear what your needs are and how to get them met, without hurting others. Being assertive does not mean being pushy or demanding, it means being respectful of yourself and others.

Anger can also be suppressed or redirected. This happens when you hold in your anger, stop thinking about it, and focus on something positive. The aim is to suppress your anger and convert it into more constructive behaviour. The danger in this type of response is that, if your anger is not allowed to come out, your anger can turn against you. Anger kept inside you could impact your general health.

You can control your anger by calming down on the inside. This does not mean just controlling your outward behaviour, but also controlling your internal responses, taking steps to become calm, and letting the feelings subside.

Relaxation

Some simple relaxation tools, such as deep breathing and relaxing imagery, can help calm down your anger. There are books and courses that can teach you relaxation techniques and once you learn these techniques, you can call upon them in any situation. If you live with others who may also be hot-tempered, it might be a good idea for everyone to learn these techniques.

Here are some simple steps you can try:

- Breathe deeply from your diaphragm. Breathing from your chest will not relax you. Picture your breath coming up from your “gut.”

- Slowly repeat a calm word or phrase, such as “relax” or “take it easy”. Repeat it to yourself while breathing deeply.
- Use imagery. Visualize a relaxing experience from either your memory or imagination.
- Non-strenuous and slow yoga-like exercises can relax your muscles and make you feel much calmer.
- Practice these techniques daily. Learn to use them automatically when you’re in a tense situation.

Cognitive Restructuring

Simply put, this means changing the way you think. Angry people tend to curse, swear or speak in colourful language that reflects their inner thoughts. When you’re angry, your thinking can become exaggerated and overly dramatic. Try replacing these thoughts with more rational ones. For instance, instead of telling yourself “oh, it is awful, it is terrible, everything is ruined,” tell yourself “it is frustrating

and it is understandable that I am upset about it, but it is not the end of the world and getting angry is not going to fix it.” Be careful of words like “never” or “always” when talking about yourself or someone else.

Negative or angry statements can isolate and humiliate people who might have otherwise been willing to work with you on a solution.

Remind yourself that getting angry is not going to fix anything. It will not make you feel better. On the contrary, it may actually make you feel worse. Remind yourself that the world is not out to get you, you are just experiencing some of the rough spots of daily life. Angry people need to become aware of their demanding nature and translate their expectations into desires. In other words, saying “I would like” is healthier than saying “I demand” or “I must have”. When you are unable to get what you want, you will experience the normal reactions of frustration, disappointment and hurt. However, you will not feel any anger.

Problem Solving

Sometimes, our anger and frustration are caused by very real and unavoidable problems in our lives. To address everyday problems, make a plan and check your progress along the way. Resolve to give it your best, but also do not punish yourself if an answer doesn't come right away. You should approach your problems with your best intentions and efforts and make a serious attempt to face them head-on. That way, you will be less likely to lose patience and fall into all-or-nothing thinking, even if the problem does not get solved right away.

Better Communication

Angry people tend to act on and jump to conclusions even if some of those conclusions can be very inaccurate. If you are in a heated discussion, the first thing to do is slow down and think through your responses. Do not say the first thing that comes into your head, but slow down and think carefully about what you want to say. At the same time, listen carefully to what the other person is saying and take your time before answering.

Using Humor

“Silly humor” can help defuse your rage in a number of ways. For one thing, it can help you get a more balanced perspective. When you get angry and call someone a name or refer to them in some imaginative phrase, stop and picture what that word would literally look like. For example, if you think of someone as a “dirtbag”, picture in your head a large bag full of dirt standing in front of you.

There are two cautions in using humor. First, do not try to laugh off your problems. Rather, use humor to help yourself face them more constructively. Second, do not give in to harsh, sarcastic humor. That is just expressing another form of unhealthy anger.

What these techniques have in common is a denial to take yourself too seriously. Anger is a serious emotion, but it is often accompanied by ideas that, if examined, can make you laugh.

Changing Your Environment

Sometimes it is our immediate surroundings that give us cause for irritation and fury. Problems and responsibilities can weigh on you, making you feel angry at the “trap” you seem to have fallen into and all the people or things that made that trap. Give yourself a break. Make sure you have some personal time scheduled for times of the day that you know are particularly stressful.

Do You Need Counselling?

If you feel that your anger is really getting out of control, having an impact on your relationships or on important parts of your life, you might want to consider counselling to learn how to handle it better. A psychologist or other licensed mental health professional can work with you in developing a range of techniques for changing your thinking and behaviour.

Increased Responsibilities

After a brain injury, the survivor may not be able to do all the things they used to do. Other family members may have to increase their responsibility for chores or duties to keep the home running smoothly. How much more your family has to do can be a measure of how big the change has been.

Shifting Responsibility

Family Matters

Sometimes, the survivor is not able to do things that they did before. The family's work increases because the survivor's responsibilities shift to other family members. Here are some examples of shifting responsibilities:

- The survivor was used to handling money. Now, they make a lot of errors when doing math. As a result, another person may have to balance the cheque book.

- The survivor was used to helping with meals. Now, they forget simple things like how much water to add in the rice. When they have problems like this, they do not cook. The result is that you end up cooking all the time.
- The survivor was used to watching the children when you went bowling. Now, the survivor is losing their temper with the children all the time. As a result, you give up your bowling so that you can stay home and watch the children.
- The survivor was used to taking the kids to everything. Now, the kids think the survivor says embarrassing things and they either go alone or ask you to take them.

Added Responsibility

Some responsibilities may be totally new to your family. These are usually chores or duties the survivor did for themselves before the injury or illness. A few things that you might already have found yourself doing for the survivor may include:

- Taking care of them, such as getting them dressed, bathed, or on the toilet.

- Supervising the survivor.
- Dealing with medical needs, such as giving them medications or reminding them about appointments.
- Correcting the survivor or helping them to rebuild their skills.
- Dealing with out of control emotions and behaviour.

A helpful exercise might be to write a list of new responsibilities as you think of them.

Changes in Roles

Survivor Matters

Changing responsibilities leads to changing roles. Roles are appointed groups of chores that we do. For example, the role of homemaker includes cooking, cleaning, watching the kids and so on. However, there is more to a role. Being in a role means making decisions and taking authority. The homemaker not only does the cooking, but also decides what to cook and when to cook the meal. They also direct others to do things, like set the table.

Family Matters

Each member of the family should try making a list of the new roles that they and others have taken on. Do not forget to include how these new roles make you feel. For instance, roles bring work but they also bring status. Having status makes us feel better about ourselves. The family member who does more often gets more credit. This can lead to feeling valued and important.

Survivor Matters

It may be the opposite for you. You may do less and feel like you are valued less. You might react to this in a number of different ways:

- Grief, since you feel as if you are not needed.
- Anger at not being valued, especially if you have poor insight.
- Apathy because of your inability to change things around you.
- Relief because you can let go of your responsibilities.

Family Matters

How the family feels about the survivor's loss of roles is also important. A lot of families feel guilty. This often happens when the survivor is unhappy with the changes. Meanwhile, other families struggle with the dilemma of how to include the survivor. If they make the decisions alone, they risk triggering the survivor's anger. If they let the survivor decide, they might not be able to accept and live with the decision. Both of these options can lead to feelings of frustration, anger and resentment.

The one change in roles that spouses say is uniquely difficult is the shift from spouse to caregiver. A caregiver is a person that feeds, dresses, and cares for another person. It is a common role for parents of young children. Being a caregiver for a spouse is unusual and can be very unrewarding. Spouses need a give-and-take relationship in their marriage, which many do not get when they are a caregiver.

Changes in Relationships

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

- Shifting roles.
- Changes in the survivor's personality.
- Reduced amount of time spent with other family members.

Shifting roles can change the relationship between the survivor and family members. A child who watches over his father might not give him the same respect. A wife who cannot tease her husband and turn to him for advice may not feel she has a partner.

Changes in personality often alter how much you like the survivor. Likeable changes can strengthen the relationship, such as when a gruff father becomes warmer and kinder. However, the changes can frequently lead to a less likeable person. At its worst, the survivor changes so much that they seem like another person. A wife described her experience as being widowed and married at the same time to someone she would never have had as a friend.

A son said he could handle it if his dad had died and he could handle having a strange man in the house. However, the fact that the strange man was in his dad's body was more than he could take.

The relationships between all of the family members can change when the survivor demands a lot of time. Time spent on the survivor means that others in the family need to do more for themselves. This can be either good or bad. In families that have a child with a brain injury, about half of the siblings become more mature. They start caring more for others, become more independent, and develop a strong sense of wanting to help others. The other half become jealous and resentful. They say that they miss the time they had with their parents. Couples with either a spouse or child survivor may also go either way. Some will pull together and become stronger, while others will fall apart entirely.

Common Responses

Your reaction to the changes in your family is very important. How have you felt? What do you experience? What has been your and your family's reaction to the changes? Make a list of your thoughts, feelings, and reactions.

Effects of Changing Responsibilities, Roles and Relationships

Survivor Matters

Most people see very quickly that things have changed greatly since the injury or illness. The family has much more to do now than they did before. You might have to spend a lot more effort on even the simplest tasks. What you might not notice right away is how your feelings have changed. If you feel that the change has been particularly difficult and unrewarding, you might:

- Resent the unfairness of it.
- Grow frustrated with the process of rebuilding your skills.
- Be furious or enraged at others who do not understand.

- Fear letting your family down.
- Wish the brain injury had never happened or that you had died.
- Feel that you have been returned to a role you thought you left behind. As an adult, you may fear being treated like a child for the rest of your life.

It is important to realize that these feelings are normal. They are part of adjusting to the new family situation.

It is easy to feel unappreciated. Many of the things you do can go unnoticed. A lot of the difficulties you face are unseen by others. The brain injury has been called the invisible injury. It is its invisibility that frequently leads other people to underestimate what you have to do to manage.

Denial

Nobody wants to believe that they are in denial, but denial is common. It is a normal part of the healing process. When you do not take care of issues that must be dealt with, denial becomes a problem. This could mean that you or your family is ignoring a problem until it becomes dangerous. It can lead to trying something that is unsafe.

Denial can be the result of a misconception. You may think, “If I have a brain injury, I am useless to my family. In other words, I cannot have a brain injury.” Occasionally, all you need to do is change the misconception in order to put the denial behind you. “A brain injury means that I may have more trouble with some tasks than I did before the injury, but that does not mean that I am not an essential part of my family.”

Depression

Another common problem after a brain injury is depression. This may include feeling “down in the dumps” or thoughts of suicide. These feelings are normal and there is nothing to be ashamed of. It can take amazing strength to deal with a brain injury. At times, your ability to cope is simply overwhelmed. However, it is important to know if and when you need help. The following are signs that you may need to seek help from a professional counsellor or doctor:

- You find yourself crying uncontrollably for no reason.
- You are starting to feel hopeless, as if there is nothing you can do to make things better.
- You find that you have lost interest in things that you used to enjoy.
- You are tired and listless.
- You are having difficulty falling asleep or waking up early and are unable to get back to sleep.
- You had a significant change in appetite.
- You are having thoughts of hurting yourself or suicide.

If you are experiencing any of these, especially thoughts of hurting yourself or suicide, you should go see a counsellor or doctor right away.

Depression is extremely common at different stages of the recovery process and suicide can often be a risk.

Families and caregivers are often well-placed to be able to look out for the first potential signs of suicide. There is a gradual lead up to suicide, with a typical process of planning, organizing the means and acting.

Some possible warning signs can be:

- Becoming withdrawn and very depressed.
- Expressing a desire to die and talking about suicide.
- Suddenly becoming very cheerful or tidying up affairs, such as paying bills or saying goodbye to friends.

These can all indicate that a person may have made a decision to commit suicide.

An essential way to combat this is to let the person know that others do care about them. This may involve spending time with the person even if there is no talking or arranging for others to spend time with them. Listening can play a huge part in preventing suicide. It is tempting to tell the person why they should not kill themselves and give them advice, when simply listening to how they feel can help much more.

A person with depression can respond well to medication so make sure the person is in touch with their physician about their depression.

When there is a high risk of suicide, there are different strategies that can help such as counselling, referral to a psychiatrist, medication, hospitalization and case management. For more information, call the Mental Health Information Line at 1-877-303-2642.

Coping Ideas

Look over what you have learned about the changes in your family. Examine what you have written in your journal and ask yourself these questions:

- Have there been plenty of changes?
- Have these changes led to good, bad, or mixed feelings?
- In what parts of my family's life have I seen changes?
- What changes have led to really strong feelings?

Below are some coping strategies that may help if the changes in your family have become a concern to you or any of your family members.

WHAT YOU FOUND

Survivor Matters

Too many new responsibilities or difficulty keeping up with tasks that were simple before the brain injury.

Suggestions for Coping

The key element to coping is to reduce demands on your time.

You might try to do the following:

- Simplify your life. Things are not going to pick up where they left off. If you can, do not do anything you do not need to do for a while.
- Find out if you can pay for help. Home care, private companies, and live-in caregivers or housekeepers are some possibilities. You should check if the cost of this service will be paid by your insurance.
- Hand some duties over to a family member, advocate or close friend. Try to spread out the duties between several people to prevent everyone from feeling overburdened.

WHAT YOU FOUND

Family Matters

New roles are overwhelming. A lot of stress in roles comes from being responsible. The goal is to let go of your role for a while to take the weight off of your shoulders.

Suggestions for Coping

You might try to do the following:

- Hand some duties back to the survivor. Family members find themselves doing a lot for the survivor because they fear for the survivor's safety or dignity. Allowing the survivor to try things is the way to give these duties back to them. Suggestions for how to do this can be found in Chapter 5, called "Rebuilding Skills."
- Make time for fun or relaxation. It does not have to be much. It could be fifteen minutes of listening to music, getting coffee with a friend or an evening of playing ball. The goal is to drop the load you are carrying for a little bit and have fun.
- Take it one day at a time. When you feel overwhelmed, take it one hour at a time.

WHAT YOU FOUND

New roles are upsetting for the survivor or other family members.

Suggestions for Coping

You should acknowledge the survivor's feelings even if you cannot take care of the problem right away. When the family is ready to deal with the difficulty of new roles, you might try to do the following:

- The survivor and family should develop a plan together when making decisions about the recovery goals. Both the family and survivor should make a list of their concerns and problems. You may want to limit the list to each family member's top three concerns, to make sure that nobody feels overwhelmed or attacked. The key element is to avoid letting your worries build up until you lose your temper at the other person. You may want to have a professional involved when you do the planning. This will help you avoid a situation where one family member feels teamed up on.
- Write down all the family members' new roles. Confirm that everyone in the family has a role that

makes them feel like an important member of the family. These roles should be defined and clearly understood by each family member. Keep in mind that these roles can and should change as the recovery process goes on. Again, a professional might be able to help you.

WHAT YOU FOUND

The survivor is like a new, completely different person.

Suggestions for Coping

This can be a difficult experience. It is often best dealt with by talking to others who understand.

You might try to do the following:

- Go to a brain injury caregiver support group. Sharing your experience with other people who know first-hand what you are going through can be helpful.
- Talk to a counsellor who knows about brain injury. Talking to someone knowledgeable about these changes can help you understand your feelings and help you make life decisions.

WHAT YOU FOUND

Common Finding

You or another family member appears to be depressed.

Suggestions for Coping

- If you or another family member shows serious signs of depression, you should see a professional. You can start with your family doctor. Your service coordinator might be able to guide you to a private counsellor or support group.

WHAT YOU FOUND

Family Matters

Denial is causing difficulties in your home.

Suggestions for Coping

If it is your family who is in denial, they may be pushing you beyond your limits.

- Speak about the changes that you have noticed.
- This can be very effective, although sometimes the help of a professional is required.

If it is the survivor who is in denial, it may lead to them trying something dangerous.

- Help the survivor see what they can and cannot do. Use experiments to help them understand this concept.

WHAT YOU FOUND

You are unsatisfied as a caregiver.

Suggestions for Coping

This is likely the most uncomfortable issue to handle. The reason for this is because the situation may result in separation or divorce. You might try to do the following:

- Make a change in your way of thinking.
If you decide to stay, it is helpful to find a way of thinking that helps you feel better.

For example, some see caregiving as an honourable way to spend one's life.

- Find someone to talk to about your feelings. This could be a counsellor, friend, or support group.
- Look at other living arrangements.
- At times, the best choice for the family is to have the survivor live with someone else. For more information on your choices, read Chapter 9, called "Housing."

WHAT YOU FOUND

Some family members may seem to not be getting enough attention because nearly all of the attention has been directed at the survivor.

Suggestions for Coping

The goal is to see if you can make time for yourself and your family. You might try to do the following:

- Organize regular activities for those family members. It should be a special time for you and them. Certain families have found that relatives and family friends can also sometimes provide this quality time.
- Explore respite services in your health district. Respite is discussed in Chapter 9, called “Housing.”
- Plan a family getaway. This may involve leaving the survivor with someone else.
- Let the survivor get away for a while. If the survivor has a close friend or family member that they can visit for a week or two, it can help ease everyone’s tension.

One way to cope with all the changes in your family is to search for a support group. Your service coordinator may be able to help you find one in your area.

Separation, Divorce, and Placing the Survivor Outside the Home

Leaving the survivor is a sensitive issue. Families have a lot of different feelings in these situations:

- Guilt because they feel they should continue helping the survivor or they have wished the survivor was not their responsibility.
- Anger because they feel health care professionals deceived them into taking the survivor home or did not give them enough support after the survivor returned home.
- Concern about how the choice to leave might affect the survivor and the rest of the family.

There is no universal answer to the question of whether the survivor should live at home or somewhere else. This is a sensitive issue and must be an individual choice for every family. It is a good idea to discuss this issue extensively with the survivor's doctor, other health care professionals, a professional counsellor and with the survivor themselves before making any decisions.

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Lifestyle

- > The New Lifestyle
- > Energy Levels
- > Social Skills
- > Building a New Social Life
- > Staying Active
- > Maintaining Your Family's Social Life
- > Driving

Lifestyle

In this chapter, you will:

- Learn about the importance of rebuilding your social life.
- Discover how to adjust your social skills to accommodate changes.
- Read about when and how to have a driver evaluation done.

The New Lifestyle

Survivor Matters

Each family responds to the changes brought by the brain injury in their own way, at their own pace. It can take a long time. It is also complicated because you cannot predict what abilities you will eventually regain. Instead, you will be making adjustments throughout the different stages of recovery. One of the most helpful things you can do is let yourself

grieve for the losses. As your grief is expressed, it will become easier to move forward and build a new life for yourself.

Energy Levels

At first, you will not have the energy to maintain a busy lifestyle. While you may or may not regain the level of activity you did before the brain injury, most people's overall energy level will gradually increase. 'Gradually' is the key word. It may seem that not much is changing, but in the long term you will see a steady increase in your energy level. Exhaustion will also be a factor for your family, since their stress and responsibilities are greatly increased. Your whole family should consider making their lifestyle easier. If your energy level does not gradually increase, speak to your doctor.

Social Skills

Social skills are essential to maintaining friendships; yet, they may be affected by the brain injury.

You may have trouble with making eye contact, might dominate conversations, or say the same thing every time you see someone. You might stand or sit too close to other people, making you seem extremely rude. You may have difficulty showing emotions, causing your general expression to remain the same whether you are hearing happy or sad news.

Other common behaviours that affect social skills include:

- Impulsiveness.
- Distractibility.
- Inability to read subtle or non-verbal behaviour.
- Decreased consideration to other people's needs or social situations.

You may have acceptable social skills but lack the memory or capacity for abstract thinking that is required to participate in social activities.

If you have children, they may be most upset by your lack of social skills. Specifically, pre-teens and early teens are easily embarrassed by their parents at any time. They frequently find a parent who has difficulty with their social skills really embarrassing.

It may help children to tell their friends about your brain injury, although this may be a difficult thing to do.

It is important for your family to give you non-judgmental feedback about appropriate and inappropriate social behaviours. It may help you to practice various social situations with your family, a professional counsellor or coach to help you relearn appropriate behaviour. If you have trouble remembering or implementing learning from one situation to another, you may have to repeat these lessons. With repetition and coaching, a lot of survivors regain their social skills.

Building a New Social Life

When you first return home, plenty of energy will be spent adjusting to the new situation. At this point in time, it is important not to restrict your social life too much. This applies to everyone in the family. Since you may not have the physical energy or intellectual skills required to maintain your former social life,

you may need to be creative in your efforts to build a new one. You could do the following:

- Consult your family or a friend you can trust for direction in choosing safe social activities. If your judgment is impaired, it could lead you into dangerous situations. Your family's role is to encourage you to take risks, within reason, in order for you to gradually gain confidence in social situations.
- Meet people in a familiar setting, doing a quiet activity. As you gain energy, you will be less tired and not as easily distracted. Then, you can increase the complexity of social situations. Remember that crowds, noises and certain types of light can affect some survivors.
- Learn from past incidents. If a situation does not go well, ask yourself: What happened? How was it set up? Was there anything you could have changed to make it easier? Be positive. Wisdom comes from experience, whereas experience comes from making mistakes.

Establishing New Friendships

Spending time with friends is one of the most satisfying parts of life, but changes caused by a brain injury often results in former friends drifting away. They may not get why your behaviour changed or accept the changes.

If your former friends are drifting away, it is easy to be upset with them. Often, we choose our friends based on common interests. For that reason, it is not surprising that when the common interests disappear, the friends leave as well. You should make efforts to find new friends with new common interests. A good way to begin is by finding new activities you enjoy. Leisure activities and volunteer work provide social settings where common interests may be discovered. Shared interests are the foundation of new friendships.

Family Matters

Losing friends is especially traumatic for children and adolescents. Unfortunately, it is a common situation for young people with any type of disability.

There are no easy answers; however, there are some things you can do:

- Focus on the abilities your child has now and use that to encourage new friendships based on common interests.
- Emphasize abilities and do not be discouraged by the initial reaction of other children.
- Provide your child with opportunities to interact with their peers, as you would with any other child.
- Involve your child in activities they enjoy. If you need an additional pair of hands to enable them to participate, ask local church groups, guides and scouts, or mentor programs. For more suggestions, contact Children’s Services about the provincial programs for children with disabilities or talk to your child’s school.
- Look at your extended family. Your child’s deepest friendships may be with cousins, aunts, uncles or grandparents.

In your efforts to build new friendships for your child, focus on the quality rather than the quantity. For more information about supporting a child with a brain injury, consult Chapter 10, called “Work”.

Staying Active

Survivor Matters

Since many people do not return to work after a brain injury or do not work full time, it is important to find meaningful activities. The changes in your abilities can make this a challenge. Your family can be of a great help by providing you with coaching, feedback and instructions. In addition, there are outside resources available, such as your local Alberta Brain Injury Network office (see Resources, Chapter 13). Do not hesitate to seek assistance.

Recreation and Leisure

The brain injury may affect what you do for fun. For example, exhaustion may affect your ability to take part in a few leisure activities, while a loss of social skills may affect your ability to enjoy these activities with others. In order to adapt to the changes affecting your leisure activities, you should try the following:

- Being open to participating in activities in new ways. For instance, if you enjoyed curling before

- the brain injury but are no longer able to curl, think about getting involved as a spectator or volunteer.
- Modifying an activity you enjoy to qualify with your current abilities. For example, if you loved playing cards games but you now have memory and concentration problems, search for card games where luck is more important than memory.

Family Matters

Find a “leisure buddy” to accompany the survivor to various activities. In addition to aiding the survivor boost up their self-confidence, a leisure buddy can give you a few hours of rest.

If you need guidance, get in touch with your local Alberta Brain Injury Network office (see Resources, Chapter 13) and ask them to guide you to a recreational therapist. If you live in a larger community, contact the municipal recreation and/or leisure services department and ask about the services and facilities in your area.

Volunteering

Survivor Matters

Once you are physically capable to do more, it may be beneficial to participate in volunteer activities. Volunteering will give you a chance to do something for others. It can improve your self-esteem and help you get back into a structured daily routine. Some survivors have claimed that volunteering is essential for bridging the gap between recovery and work. Look at the volunteer opportunities in your neighborhood. Make sure to look for volunteer opportunities that correspond with your activity level and social skills.

Your local Brain Injury Association (see Resources, Chapter 13) may offer a volunteer program to help you get started.

If you hope to return to employment in the future, you will need to work on regaining as many skills as possible. As such, social skills and energy levels are essential to a successful return to employment.

Start by making a daily schedule that includes meaningful activities (such as leisure and volunteering) in addition to activities aimed at helping you practice and improve your skills. This will aid your recovery by giving structure to your day. You should begin with only just one or two hours of structured time each day and gradually increase it. This will help you work on your organizational and time management skills and help you discover your best “daily method of operation”. Ask yourself: do you work best if you take a five-minute break to stretch once every half an hour? Does an electronic daily planner work better for you than a notepad? Do you work better first thing in the morning or late in the evening?

For more information, consult to Chapter 10, called “Work”.

Maintaining Your Family's Social Life

Family Matters

It is crucial for family members to maintain social contact with others. If you, the spouse, are the caregiver:

- Do not quit your job unless it is absolutely necessary.
- Balance your need to speak about the stress of your situation with your need to speak about other things.
- Organize social activities for yourself and follow through.
- Arrange for respite care to give you a rest (discussed in Chapter 9, called “Housing”).

Studies have steadily shown that people with strong social networks manage stress a lot better. If friendships disappear, establish new ones by taking part in one or two social interests or hobbies or by joining a support group for families of survivors with a brain injury. Your local Brain Injury Association (see Resources, Chapter 13) should be able to guide you to one of these support groups.

Driving

Survivor Matters

Upon discharge from the hospital, many survivors of a brain injury should not be driving. Not only are your reflexes and decision-making slow, but your judgment is also impaired. You may have light sensitivity and visual problems that you did not have before the brain injury. However, these changes may be subtle. It is not rare for the changes to go unnoticed at first, by you, your family and doctor. In fact, it may take time for you to realize that you should not be driving or only drive in light traffic. You should evaluate your driving skills and decide whether you should wait before you start to drive again. It is especially important, considering that your brain is still in a very fragile condition and even a little accident may be dangerous for you. You may want to contact your local Alberta Brain Injury Network office (see Resources, Chapter 13) to learn if there is a driver retraining program available in your area.

The Alberta law requires that if you have a condition that will probably affect your ability to drive, you must inform your insurer.

At the time of discharge from the hospital, your doctor will usually advise you and your family about whether it is safe for you to drive. In either case, the Alberta Transportation Driver Fitness and Monitoring program must be informed.

To inform the Alberta Transportation Driver Fitness and Monitoring, you can either call them directly (310-0000) or get in touch with the nearest license and registry office (check the yellow pages online) and explain your situation. They will provide forms for you and your doctor to fill out. Then, they will review the information from your doctor and determine if you may drive. If the doctor tells you that it is safe to drive when you are leaving the hospital, it is legal for you to continue driving until the Alberta Transportation Driver Fitness and Monitoring reaches a decision.

Family Matters

Since you deal with the survivor daily, you may realize it is dangerous for them to drive even though your family physician believes it is safe. This can be stressful if you are in support of having the survivor's license removed against their and other family member's wishes. In this case, a driver evaluation may prove useful.

You may contact the Alberta Transportation Driver Fitness and Monitoring (310-0000) and make an anonymous request to have the survivor evaluated for their ability to drive.

For plenty of survivors, losing their driver's license is a serious blow to their independence, especially if they live outside of the city. You and the survivor may need support to work through the process. Communicate with your local Brain Injury Association (see Resources, Chapter 13), health professionals in your area, or talk to the families of other survivors.

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Paying the Bills

- > Paying the Bills
- > Getting Help with Paying the Bills
- > What if You are Not Satisfied
- > Helping the Survivor
Handle Money

Paying the Bills

In this chapter, you will:

- Discover who can help you to pay the bills and how to appeal for more resources.
- Find out about the various possibilities for handling the survivor's finances.

Survivor Matters

A brain injury may change your family's income and monthly expenses. The changes will depend on a lot of things. Did you have insurance? Will you be able to take care of yourself? Do you need special devices to get around, talk or assist you with your care? Are you eligible for a disability pension? Will you need to find a new residence? Do you require help returning to school or work?

Learning who pays which bills and handling your money in the early stages of recovery can be overwhelming. It is beneficial to have an advocate to do these things for you. However, it can be an additional burden for the family members. Companies and government agencies try to be friendly and open; however, for someone unfamiliar with insurance and the health care system, it can be stressful and confusing. Understanding your choices can make paying the bills less demanding.

In this chapter, you will review possible locations where you can find financial support. If you think that you are unable to handle your own money, we will discuss certain things that you can do. Please take note that this information is not meant to replace speaking with lawyers, financial planners or other professionals in these areas of expertise.

Getting Help with Paying the Bills

Insurance Coverage

You may be eligible for insurance coverage.

The following are the most common policies:

- The Workers' Compensation Board, which covers people injured at work.
- Canada Pension Plan Disability Benefits, which may offer a disability pension for those with a work history.
- Private disability insurance from the survivor's workplace.
- Private disability income plan carried by the survivor.
- Home or other policy where the person was injured. For example, school boards have insurance to cover injuries that happen during school events.

First, consult the insurance representative concerned with the benefits of your policy. In order for you to receive benefits, some sort of application is necessary. Health professionals must frequently fill out forms on your behalf.

A few benefits are very clearly defined in a policy. Meanwhile, other benefits are less clear-cut. More documentation will be required to prove the need for uncommon or expensive items that could possibly be covered by insurance.

It can be extremely helpful to consult with a lawyer experienced in the domain of brain injury and insurance regarding the interpretation of insurance policies. In particular, seek advice concerning private policies to guarantee that you receive all of the benefits that you are entitled to.

Motor Vehicle Accident Claims Fund

A lot of brain injuries are caused by motor vehicle accidents. Every driver in Alberta is supposed to have insurance in case they cause an accident. However, some drivers do not have insurance and they usually do not have the money to pay for the damages and injuries caused by the accident. Occasionally, the guilty driver drives away from the scene of the accident and the victim does not know

who to sue. In other cases, people may be involved in a single vehicle accident, such as a rollover, where there is no other vehicle involved.

The Motor Vehicle Accident Claims Act makes sure that these types of victims can obtain funds to cover the costs associated with their injuries. You can apply for the Motor Vehicle Accident Claims Fund to pay your actual expenses, up to a maximum of \$95,000. These funds can cover the costs of hospitals, medical treatment, ambulance services, certain appliances and rehabilitation. If Alberta Health Services or your insurance plans cover only a part of your medical costs, the no-fault benefits from the Motor Vehicle Accident Claims Fund may help to pay for the rest of these expenses.

You need to have been injured in a motor vehicle accident in Alberta to qualify.

For additional information, call the Motor Vehicle Accident Claims Fund at 780-427-8255 (toll free by dialing 310-0000 before the phone number).

Social Assistance

If you or your family does not have adequate income anymore, social assistance may be able to support you. If your brain injury is considered to be permanent, severe, and leaves you unable to do your work, you may be eligible for Assured Income for the Severely Handicapped. To learn if you are eligible for Assured Income for the Severely Handicapped, call 310-0000 and ask to be connected to their nearest office. You will be required to bring your complete personal, financial, and medical information with you when you meet up with an Assured Income for the Severely Handicapped intake worker. Assured Income for the Severely Handicapped will not complete the intake package for you. Alberta Supports will offer assistance with completing some of the paperwork. Additionally, your brain injury coordinator can help you with the application process. If you believe that your application was incorrectly denied, you can request an appeal of this decision.

If you are not eligible for Assured Income for the Severely Handicapped; however, you need an income or income supplement, you may apply for Alberta Works Income Support. This helps you to pay for your basic necessities, such as food, clothes and a residence. Call 310-0000 to discover where the nearest office is and bring your complete personal and financial information with you.

Individuals who live on a First Nations reserve must apply for social assistance with their band office.

If you do not qualify for social assistance, you may still be able to receive extended health benefits intended to cover certain medical costs for families with lower incomes. You can phone 310-0000 to learn how to apply for extended health benefits.

Asking someone else to pay for things is difficult. It may be beneficial to follow these guidelines:

- Learn what the insurance plan or program covers.
- Be assertive when asking for what you want.
Under the pressure of having to request help, a few people will refrain from asking for what they need.

They take the risk of not getting it. Meanwhile, others become furious when they are uncomfortable. Growing more furious can harm your relationship with your worker or representative. In other words, it is essential to remain calm and polite at all times.

- Look to professionals to help you with making your requests. A lot of the times, a representative cannot accept to pay for something without a letter from a professional.
- When you are making telephone calls or office visits, use an advocate whenever it is possible.

What if You Are Not Satisfied?

If you believe that you are not receiving the benefits that you are entitled to, you may file an appeal. When you make an appeal, remember that you may not be given what you ask for. This may possibly lead to disagreements. Some general points on how to deal with a disagreement are

discussed in Chapter 11, called “Children with Acquired Brain Injury”. It may be helpful to consider them in this situation.

Keep in mind that insurance companies will only offer the benefits stated in their policy. Unless those benefits are described in their policy, they are not obliged to pay for things that will make your life easier, even if it is a medical necessity.

The Workers’ Compensation Board has an Office of the Appeals Advisor that can assist the survivor and their families appeal decisions. This service is free of charge. The Office of the Appeals Advisor does not have the power to reverse a decision, but they will be able to help you with the appeal process. You can get in contact with the Office of the Appeals Advisor at 780-498-8640. If you are outside of Edmonton, call the toll free number 1-866-922-9221 and then enter 498-8640.

The Workers' Compensation Board has a review process when dealing with appeal decisions. There are four steps in the process:

STEP ONE:

Contact your Case Manager

If someone who is interested in a claim does not understand or agree with a decision on that claim, they should communicate with the judge or case manager who made the decision and ask for a full explanation.

If there is further disagreement with the decision of a claim, the decision should be discussed with the judge or case manager's supervisor.

If the worker still has concerns about the decision, a request for review can be submitted to the Workers' Compensation Board.

STEP TWO:

Request a Review by the Decision Review Body

Someone who is interested in a claim and has already undertaken the first step has two options:

- Complete a “Request for Review” form.
- Submit a written request for review of one or more Workers’ Compensation Board decisions on claim or employer account files to their case manager.

A “Request for Review” form or written request must be submitted to the Workers’ Compensation Board within one year from the date of a customer services decision.

STEP THREE:

Supervisory Review

When the Workers’ Compensation Board receives the forms, the request for review is first considered by the customer service supervisor. If the decision cannot be changed, the request for review is handed over to the Decision Review Body.

STEP FOUR:

Consideration by the Decision Review Body

Once the Decision Review Body receives the written request for review, a review specialist will be appointed to conduct the review. After reviewing the request and file, the review specialist will call or write to the applicant to discuss the decision and inform them of the most suitable way to handle the request and next steps.

Since every case is different, the Decision Review Body has developed various methods to deal with the reviews. These range from informal and timely methods for fast resolution of simple matters to formal and thorough methods for complicated matters. The review specialist will determine the best method. If the results of the review are not satisfactory, the next step is to communicate with the Appeals Commission.

Workers can receive support with the reviews and appeals related to their claims by calling 310-0000 to get in touch with the Office of the Appeals Advisor.

If you have any questions concerning the Canada Pension Plan Disability Benefits or other programs and services offered by the federal government, you can call the toll free number at 1 800 O-Canada (1-800-622-6232).

If you are not satisfied with their decision, private insurance companies may have an appeal process for you to follow. You will need to learn about that process.

You may not feel comfortable dealing with the appeal process by yourself. In this situation, you may look for someone else to help you present your case. Your local Alberta Brain Injury Network office (see Resources, Chapter 13) may be able to help you find an advocate.

Rehabilitation Practitioners have a great deal of knowledge in this field and can be great advocates when they are available.

Helping the Survivor Handle Money

Family Matters

Occasionally, a survivor is no longer capable of making financial decisions for themselves. This is better known as incompetence. If the family is convinced that this is the case, they may decide that someone else should make financial decisions for the survivor. There are several ways to do this.

Power of Attorney

A **Power of Attorney** grants a person, the attorney, control over the survivor's property and finances. The survivor must have signed the Power of Attorney when they were competent to do so. In other words, competence means that the survivor was able to understand the nature and effects of the Power of Attorney when they signed it. The survivor assigns an attorney to make their financial decisions and handle their property. In order for the authority of the attorney to carry on after the survivor becomes

incompetent, the Power of Attorney must contain a statement indicating that the authority of the attorney is to continue or endure after the mental disability or illness of the survivor. On top of that, the Power of Attorney could also indicate that it is to “spring” into effect only at the time of the mental disability or illness of the survivor. With either an Enduring or a Springing Power of Attorney, the attorney would have the power to make financial decisions and handle the survivor’s property after they become incompetent. In the event of the survivor’s death, the authority of the attorney comes to an end. After that, the attorney must account to the personal representative in charge of the deceased survivor’s estate.

Considering that the law and interpretation by the court frequently change, you will be required to speak with a lawyer or the Office of the Public Guardian and Trustee to ensure that you have the most current information about the Enduring Power of Attorney. You may find the publication “Enduring Power of Attorney Booklet” helpful. You can order it from the Office of the Public Guardian and Trustee by dialing 310-0000.

Trusteeship

An **informal trusteeship** is when a person assists the survivor in dealing with their financial affairs, without a Power of Attorney or formal trusteeship order. Informal trusteeship can take several forms, depending on the survivor's circumstances, and may be an easy and effective way of handling their financial and property matters. Informal trusteeship can be something simple such as having a joint bank account with the survivor or may include finishing some documentation with a specific benefits program. Even so, this can put the survivor at possible risk of theft or fraud and the informal trustee at risk of accusations of theft or fraud.

A **trusteeship order** is when the court assigns a trustee to deal with the survivor's finances and property. The trustee's obligations include:

- Setting up a budget to make sure that the survivor is living within their means.
- Taking care of all of the assets of the survivor, including preserving and insuring any land or estate and dealing with any debts owed by the survivor.
- Applying for the financial benefits that the survivor is entitled to and investing the survivor's money in a suitable way given their circumstances.

- Maintaining detailed accounting records of the trustee's handling of the survivor's financial matters.
- Submitting an accounting record of the trustee's administration of the survivor's financial affairs to the court when it is required or requested.

A trustee must comply with the trusteeship order and trusteeship plan that has been approved by the court. The trusteeship order will state all of the requirements needed for the order to be reviewed by the court or for the trustee to submit the trustee's accounts to the court for examination and approval. If there is suspicion of an offense done by the trustee, there is a formal process within the legislation to make complaints against a trustee.

Occasionally, someone outside of the family will be asked to become the Trustee because of the amount of work involved. In the appropriate circumstances, a trustee may be provided by the Office of the Public Guardian and Trustee. For additional information on public trusteeship, call your nearest Office of the Public Guardian and Trustee at 310-0000.

Additionally, there are a few other alternatives.

If the survivor owns a lot of money or property, a trust company is usually chosen. The trust company will charge the survivor's estate to pay for their services.

A trustee may request compensation for performing the trustee's duties, which must be approved by the court.

Applying for trusteeship involves finishing several regulated documents and obtaining a Capacity Assessment Report on the survivor, which confirms that they are in need of a trustee. You can employ a lawyer to help you with the application process, but you do not have to if you are comfortable with completing all of the necessary documents on your own. The lawyer will inform you of your choices and tell you about the costs involved. Information concerning the application process and copies of the application documents can be obtained on the Office of the Public Guardian and Trustee website. Additionally, there are various organizations that will assist you with the application process. You can communicate with the Office of the Public Guardian and Trustee, who will identify these organizations to you.

Guardianship

The Adult Guardianship and Trusteeship Act inform us that one or more individuals can be appointed as a guardian of the survivor. A **guardianship order** is when the court appoints a guardian to make personal decisions for the survivor. A guardian can make all of the personal decisions or only a few of them if the survivor can make certain decisions for themselves. On top of that, a guardian can act as an informal trustee or formal trustee, although this may not necessarily be the case.

A guardianship order is usually expected to last until the survivor's death. However, with a brain injury, the survivor may recover a lot of their skills and the necessity of a guardianship may need to be re-evaluated periodically.

A court decides who will become the guardian and their obligations. If you wish to apply to become a guardian, you will need to follow these general steps:

- Complete the regulated application documents required to apply for the guardianship of the survivor.

You can employ a lawyer to assist you in finishing the necessary documents or complete them by yourself. There are various organizations that will help you with the application process. You can contact the Office of the Public Guardian and Trustee, who will identify these organizations to you.

- Speak to the doctor taking care of the survivor or call a designated Capacity Assessor in order for you to obtain a Capacity Assessment Report on the survivor.
- Submit the completed application documents, along with the Capacity Assessment Report, to the Office of the Public Guardian and Trustee for review and processing. If the application is finished, the Office of the Public Guardian and Trustee will handle the application and eventually submit the application to the court for consideration.

Applying for guardianship will take some time, and there is quite a lot of paperwork involved. However, it is not a difficult process if there is not any disagreement concerning who should become the guardian. The forms have been designed in a manner that allows

anyone to complete them. However, a lot of people prefer to work with a lawyer. There are costs associated with filing for the guardianship and court order. If you hire a lawyer, you will be required to pay the lawyer's fees too. If the court permits it, you can get these fees back by charging the fees to the survivor's estate.

If the survivor is a parent with children under the age of 18, preparations may need to be done for the care of those children in the event of the other parent's death. It is possible for the other parent to state in a will that another person besides the survivor should serve as the guardian for the children under the age of 18. Such a statement would be subject to a legal challenge by the survivor or another person that is concerned.

Since the law and their interpretation by the court frequently change, you can consult a lawyer or get in touch with the Office of the Public Guardian and Trustee at 310-0000 for additional information about Guardianship.

Discretionary Trusts

Discretionary trusts may be of interest to families who desire to leave money in their will to a survivor who receives social support. In general, any additional income that you give to the survivor will reduce the amount of social support the survivor receives. You may want to provide a better quality of life to the survivor, but you find that you are prevented from doing that because of the limitations of social support. In this case, a discretionary trust may be set up in the wills of the people who desire to give additional funds to the survivor. With a discretionary trust, money is handed to a trustee, who dispenses the money to provide a better quality of life to the survivor. You should speak with a lawyer to make sure that the discretionary trust in the will is properly drafted.

Brain Injury Coordinators

Survivor Matters

A coordinator is a professional who helps people to locate the services they need. A coordinator could help you find lodging, receive financial assistance,

and get a referral to the right health professional. In general, they can help you to navigate the system when you are experiencing difficulty finding assistance and services. Your local Alberta Brain Injury Network office (see Resources, Chapter 13) may be able to help you find a coordinator.

Lawyers

Lawyers understand the laws, how the court works, and how to make a legal case. They can be really helpful when you need someone to represent you. Lawyers can be very powerful advocates. A lawyer could be of assistance to you in the following situations:

- Organizing a power of attorney.
- Seeking guardianship and/or trusteeship.
- Writing a will.
- Setting up a trust fund.
- Learning about the legal rights or insurance inside and outside of the province of Alberta.
- Learning about the insurance coverage and requirements.

- Making a lawsuit against someone. In certain situations, the brain injury has happened because of the fault of another person and sufficient insurance coverage is not available. When that is the case, it may be necessary to consider taking legal action for compensation. A lawyer should be consulted for advice in order for you to decide if it is worth your while to go to court.

Choosing a lawyer can be difficult. There are a few steps you can follow to make sure you acquire the right lawyer:

- Ask your local Brain Injury Association (see Resources, Chapter 13) to suggest a good lawyer who is familiar with brain injury.
- Contact the Lawyer Referral Service at 1-800-661-1095. They have lists of lawyers who work in certain domains. The lawyers themselves request to be placed on certain lists based on their specific area of expertise. Names on the list are given out on a rotational basis, resulting in each name being given out an equal amount of times. Considering that most lawyers have one or more areas of specialty, nearly all of them are on several lists.
- Choose a lawyer and organize a consultation. Most lawyers will speak with you for half an hour

free of charge. They will inform you of how they can be of help to you. Ask about the legal fees in the first call or consultation.

After you have chosen the lawyer you will work with, there are a few other things to remember:

- Learn how much experience the lawyer has had working with brain injury. If the lawyer does not have any experience at all, you may think about choosing a different lawyer.
- Make sure that you got everything in writing before you dedicate yourself to working with a specific lawyer. This should include all of the fees, services to be performed, amount of money to be paid to the lawyer, and what happens if you lose your court case.
- If you are required to calculate how much money you will need to live for the rest of your life, make sure that your lawyer employs an experienced financial forecaster.
- Tape-record each of your consultations with your lawyer. Additionally, you may consider bringing an advocate along with you to the consultations.
- Confirm the main points at the end of each consultation.

Financial Planners

A financial planner helps people to decide how best to handle their money. There are not any legal standards concerning the qualifications necessary to be called a financial planner. Banks, insurance companies and brokerage firms all hire individuals with different backgrounds to do the job of a financial planner. A few planners offer advice for a fee and sell products, while other planners will only sell products. Some steps you can take when deciding on a financial planner include:

- Getting in touch with Advocis, the Financial Advisors Association of Canada at 1-800-563-5822. They have a list of many qualified financial planners.
- Talking to a chartered accountant. They may be able to help or recommend someone who can help you.
- Confirming that the financial planner you use is familiar with brain injury and any benefits that may apply to your situation.

- Paying a visit to some financial planners. Ask them about their qualifications and their experience in the area in which you require assistance. Make sure to be clear about the kind of advice you need.
- Requesting to speak with a satisfied client.
- Before dedicating yourself to working with a specific financial planner, write everything down. This should include all of the fees and services that are to be performed.

Credit Counselling

If you are having trouble paying your bills or handling finances, you can get credit counselling for free through a Government of Alberta sponsored service. For additional information, call Alberta Supports at 1-877-644-9992 or 780-644-9992 (Edmonton).

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Housing

- > Possible Options
- > Local Resources
- > Age and Place of Residence
- > A Home Away From Home

Housing

In this chapter, you will:

- Learn about all the options where you could live and get supports.
- Discover how to find residential supports and resources.

Possible Options

Survivor Matters

Deciding where you could live is an important decision, both for you and your family. Your age, severity of your brain injury and availability of resources will impact your decision.

There are several options concerning where you choose to live. You may:

- Live alone.
- Live alone with informal support from your family.
- Live alone with formal support from an agency such as Home Care or a private agency.

- Live in a transitional setting.
- Live in an institutional setting.

Family Matters

The family of the survivor may:

- Provide all care.
- Provide care with informal support from extended family and friends.
- Provide care with formal support from Home Care or a private agency.
- Provide care with informal or formal arrangements for respite.

Respite

Respite gives you a break from your caregiving duties. Informal arrangements may involve having another family member (besides the primary family caregiver) provide care or having the survivor go to someone else's home for a certain amount of time. Formal respite may range from having someone

from Home Care or a private agency come in for a few hours each week to the survivor spending a few weeks at a group home, personal care home or special care home.

Local Resources

Your local Alberta Brain Injury Network office (see Resources, Chapter 13) can help you find available residential supports and resources in your area.

You can request a referral to an agency such as Home Care from the health professionals working with you and your family. Additionally, you can find Home Care listed in your local telephone book or by calling your Regional Health Authority. Home Care coordinators in your area will be aware of which services are available through your Regional Health Authority and private agencies.

In addition to lodging, private agencies may offer nursing care, personal care, homemaking help, supervision or companionship. Check to see if your insurance policies cover any of these services, especially if they are not provided by Home Care.

Age and Place of Residence

For a young adult who has been living alone, the decision is more complicated. Depending on their abilities, it may be unsafe for them to continue living alone. If the decision is to move back to the parental home, adjustments will need to be made. Older parents may be unable to provide the supervision required or the young adult may oppose the parental authority and supervision.

If the survivor is an adult with children, the needs and safety of everyone in the family must be taken into consideration. If the survivor is an elderly adult with a spouse, the physical and mental ability required of the spouse to provide the proper amount of care must be taken into consideration.

Each family is different. The decision you make must be the one that works best for you.

Keep Your Options Open

Survivor Matters

It is not uncommon to try several residential choices in the first couple of years. While you go through the stages of recovery, your family will learn the extent of their caregiving capabilities and limitations. Your first decision may not be the permanent solution. You may want to progress towards more independent living arrangements. Your family may require additional assistance as they drain their own physical and mental resources.

Feeling Overwhelmed

Family Matters

It is normal to feel overwhelmed by the needs of the survivor. However, this does not mean that the survivor should not live at home. Discuss your feelings with the health professionals who are working with you. They are familiar with the emotions that you are currently experiencing. Speaking with them will help you realize that the burden of caring for the survivor is not yours alone. In fact, it may lead you to discover more practical living arrangements.

A Home Away from Home

There may come a time when the family decides it is better for the survivor to live in a more structured setting. The first step in this process is to communicate with your local Home Care office or continuing care counsellor through Alberta Health Services. They will get you in touch with the department responsible for arranging these placements.

The most common places are group homes, personal care homes and special care homes. The home care worker or other contact will inform you of the options available in your area, in addition to any waiting lists.

Learn as much as you can about the places you are taking into consideration. To do this, you can:

- Visit the places you believe are suitable.
- Talk to the staff and ask them questions.
- Speak with a few of the people who live there and ask for their opinion.
- Pay a visit to various homes. It may help you to feel more comfortable with the decision.

- Discuss the possible options together. There are currently varying supportive housing options for survivors with acquired brain injury. There are many ways to determine the best options available, such as conducting research, speaking with others, and much more.

Coping with Guilt

Placing a family member in any residential setting outside of the home, especially an institutional setting, can be very stressful and it is not uncommon to experience guilt. This decision does not mean that you are abandoning the survivor. Considering the needs of your entire family, it may be the best course of action. You can continue to be active in the life of the survivor through regular visits and home passes. You may even notice that the time you share together is of higher quality.

Talk about your feelings with the home care coordinator or social worker in the survivor's new home. Speak with other people who have had to make the same decision or get in touch with a local Brain Injury Association support group (see Resources, Chapter 13).

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Work

- > Returning to Work
- > Signs of Readiness
- > Returning to the Previous Job
- > Searching for a New Job
- > Keeping the Job

Work

In this chapter, you will:

- Read about the steps that may gradually help you return to employment.
- Learn about searching for and keeping a job.

Returning to Work

Survivor Matters

Work is important to everyone. It brings in money to pay the bills. It gives us an identity. It allows us to do something meaningful. It is not surprising that a lot of survivors want to go back to work as soon as they can.

Returning to work after having a brain injury is not easy. Studies reveal that only half of the survivors who needed help going back to work were still employed at the end of the year. Out of all of those who were still employed, only half were in the same position that they started with at the beginning of the year.

A different study claimed that if a survivor did not return to employment within the next six months after the brain injury, they would likely never go back to work. However, this all depends on many factors such as the individual, brain injury, job and much more. Giving yourself time to recover and making use of every resource available will improve your chances of returning to work successfully.

If you were highly trained or experienced before the injury or illness, your chances of keeping a job are higher. However, this does not mean that you will return to your former position.

Many survivors may never return successfully to the workplace. Additionally, if your job provides medical benefits, they will usually not cover the cost of a pre-existing condition like a brain injury. It may be very difficult for you to adjust to these situations.

It is essential to know that even when a return to work is successful, there can be other difficulties. At times, the survivor and family believe that things will improve once the survivor has a job. That is not always the case.

Starting a new job is always stressful and even more so for the survivor of a brain injury. When you begin, you will be:

- More exhausted.
- Learning a new job or relearning a former one.
- Interacting with more people.
- Dealing with fears of failure.

You and your family need to be prepared for the possibility that work may cause things to be more difficult at home.

It is important not to put job success before your family. If your family life is suffering, it is most likely a sign that you need a more gradual transition into the world of work.

Family Matters

It is essential to understand that when relearning a job, some of the survivor's social skills with the family may decline. At this time, try to be patient with the survivor. Make sure to communicate to the survivor any changes in the way they are behaving with the family, since they may not be aware of it.

If their behaviour has undergone some changes, suggest to them that they slow down their transition back to work.

Survivor Matters

There are several questions that need to be considered when deciding whether to go back to work or not, such as:

- How do you know when you are ready to return to work?
- What is the best way to return to work?
- What kind of assistance will you need when you return to work?
- Who can help you?
- What happens if the return to work is unsuccessful?

Signs of Readiness

The signs that you are ready to go back to work are different for each individual. They relate to the work that you will be returning to and the type of boss and co-workers you have. In general, you are very likely to not be able to return to work until you see a few or all of these signs:

- You have enough energy to work for at least half a day.
- You can carry a conversation, know how to behave with others, and pick up important social cues (such as when someone is upset).
- You can plan and follow through on easy tasks.
- You use aids, such as a daily planner, when they are necessary.
- You are able to control your temper.
- You are able to recognize your own mistakes.
- You are able to start work on your own.

This may be more important in some jobs than in others. Additionally, you may be able to receive support to help you with this.

Returning to the Previous Job

When you try to return to employment, your previous job may be considered first. This is most likely to happen when:

- You had been in the previous job a long time and knew it considerably well.
- You had an insurance plan that states that you must try to return to your former job first.
- Your last employer is committed to you.
- You have problems with learning new things.

The last point is important because learning new information is hard for quite a few survivors. Returning to your previous job means that you do not have as much new information to learn; however, you may still have difficulties with relearning information.

Even when going back to a former job, there are a lot of things to consider. How many hours should you work each day at the start? Do the work hours need to be changed? Should you begin with only a few tasks? Which tasks should those be? Are there changes required to the workplace or to your work station?

When considering going back to the previous job, the following is usually recommended:

- Gradually return to work. Begin with only a couple of hours a day or week and slowly increase the work time over weeks, months, or years. No matter how much you want to go back to your former hours, force yourself to take it at a slow pace. You may not be aware of your limitations yet and it is better to set yourself up for success rather than failure.
- Gradually increase the amount of different job tasks you do. You should start with the easiest and most frequent tasks and build to the more complicated and uncommon tasks.
- Ask to change job demands to help you deal with your disabilities. Make sure to use empowering speech when you do this. You are not asking for special treatment, but for an accommodation that will give you the chance to produce the same work. A few examples of adjustments may be asking for a work station where the amount of noise is reduced, distractions are at a minimum,

and lighting is appropriate. If you do your best at work when only working a few hours a day, you may ask for an extended time frame for assignments. Make use of devices like daily planners, earplugs, canes, or strategies. For example, strategies that you can use would be scheduling rest time into your days or tape recording important meetings in order for you to not have to rely on your memory.

Family Matters

- You may need to introduce compensatory devices and skills to the survivor. Try to present them with as many alternatives as possible, although not all at once. Let the survivor choose those that work best for them.

Survivor Matters

Occasionally, going back to your previous job does not work out. This is most likely to happen when advanced work skills are required, the price to pay for making mistakes is high, or cannot be corrected. For instance, a successful return to work is less likely to happen for a surgeon than a store clerk.

Your employer may be willing to give you another job if your former job does not work out. If this happens, it is essential that the new job fits your strengths.

The use of an occupational therapist or vocational counsellor to help you set up your return to employment is usually recommended. They can prepare your workplace, help you anticipate difficulties, and help you negotiate the return to work. On top of that, they may be able to arrange for a support person or job coach to assist you with your initial return to work. Additionally, there are often tests and interviews to determine how ready you are to go back to work.

Searching for a New Job

There are several reasons why you might choose to search for a new job. Some of these reasons consist of the:

- Possibility of failure at your previous job.
- Loss of important work skills that do not allow you to go back to your previous job.
- Loss of the former job (such as when absence from work leads to replacement).

There are professionals who can help you evaluate what skills you will require to be successful at various jobs. Most survivors need some assistance in returning to work. A vocational counselor or occupational therapist is usually the best support. These professionals can be of most help if they are informed about both brain injuries and the job market.

The majority of employers will not provide you with an occupational therapist or vocational counsellor. However, there are a few organizations that provide these services to survivors free of charge. To learn more, contact your local Brain Injury Network office

(see Resources, Chapter 13). You may also get help from your rehabilitation centre or hospital. If you have the financial resources, you could hire a vocational counsellor or occupational therapist to help you with your return to work.

An occupational therapist or vocational counsellor will frequently take these steps:

- **A vocational assessment:** this usually involves evaluating your job skills and interests. It may also include short job placements.
- **A neuropsychological assessment:** the tests used in this evaluation measure your thinking ability. This includes abilities like memory and attention. There is a possibility that this test will sort you in the normal range. However, in the end, your daily functioning after the brain injury is a better way to measure how much you have been affected by your brain injury.
- **Job skills training:** a few locations offer training in job skills needed for any workplace. This includes skills like being punctual, being respectful, dressing appropriately and learning specific tasks related to your job.

- **School or retraining:** before starting a new job, it is sometimes obligatory to get additional education. This education usually teaches you how to perform a job that you have never done in the past. Survivors of acquired brain injury, who have done very well in their recovery, still face huge difficulties when returning to school. Several factors following an acquired brain injury make this difficult:
 - First, any loss of short term memory will make it difficult to remember information and learn.
 - Second, attending school often has a fair amount of exhaustion associated with it. People with a brain injury frequently have limited energy. They may feel good in the morning, but their energy fades as the day progresses. Many students with acquired brain injury may have a lack of insight concerning their capabilities and feel that teachers are against them when they are given performance feedback that is negative.
 - Lastly, impaired organizational skills can be a factor. A student may know what they want to accomplish, but they have trouble starting or ending the assignment on time.

- **A job tryout:** a lot of survivors have trouble taking what they have learned somewhere and using it elsewhere. For these survivors, it does not make sense to learn about a job in the classroom. They need to learn on the job. A job tryout shows whether you work quickly and well enough to get a paid job, in addition to whether you would enjoy the work. Finally, the tryout can reveal how much assistance you may require to get or keep a job.
- **A job search:** a job search includes writing a resume, searching for jobs, speaking with employers, applying for jobs, and attending interviews. There are certain programs that can help with this. Get in touch with your local Alberta Brain Injury Network office to find a program near you (see Resources, Chapter 13).

Some individuals will only need assistance with their job search. Others will require help with all of the steps. You may need something in the middle. The amount and type of help required is usually based on an evaluation, your wishes, and results of job tryouts or education.

Job Coach

Many survivors could benefit from having a **job coach**. A job coach spends time to help you learn the job. Additionally, they help you to see how well you are doing on the job and how much you are getting along with others. Social skills are the biggest reason behind your success or failure in jobs. You may avoid the lunchroom since it is very loud and crowded to the point that it drains you, making it difficult for you to concentrate in the afternoon. Other employees may think that you always eat lunch in your office because you dislike them. A job coach can help you see these problems and may be able to propose alternative solutions, such as inviting a couple of your co-workers to eat in your office with you and explaining to the other co-workers your problem with crowds.

The job coach may work close to you for some time. This will only happen if your employer is willing. This may be required when there are deadlines or work quotas. This support may last until you can do your job efficiently enough by yourself.

If the job tryout succeeds, you might have a job. At times, it is necessary to try working in various places. By trying out several types of jobs as a part of the evaluation, you will be better able to discover what kind of work suits you best. Job tryouts can also help you practice crucial work skills, such as arriving at work on time and listening to your supervisor.

Keeping the Job

Finding work may be easier for survivors than keeping a job. The most common causes for loss of work are:

- Poor conduct (temper issues, social difficulties).
- Poor attendance (coming in late too frequently or absence from work).
- High levels of distress experienced by the survivor.

Having someone like a job coach can sometimes prevent these problems from causing you to lose your job. The job coach can increase your awareness of potential difficulties and help you bring about change.

In addition, a job coach can educate your coworkers and employer about brain injury. Long-term follow-up is equally important.

When the survivor starts work, co-workers and employers will frequently put up with poor conduct rather than speak about the issue. Then one day, they get fed up and fire the employee. Follow-up has to be long enough to cover this risk. Even if you do not have a job coach, try to remain in contact with others. Ask your employer and co-workers questions, such as, “How have I been performing this week? Is there anything I could improve on?”

There are no guarantees of keeping a job, but professionals inform us that there are certain things that are more likely to lead us to success. The most important thing is social skills. Social skills include talking with other people, being aware of how they are feeling and treating them with respect.

Some other qualities that will help you to obtain and keep a job include:

- Having well defined work interests and abilities, in addition to considering them when choosing a job.
- Being assertive instead of aggressive.
- Being able to move about well and having a good work ethic.
- Being able to work on your own for a long period of time.
- Using strategies to help you with certain difficulties, such as issues with your memory.
- Enjoying your job.
- Having a good support network.
- Having great communication skills.

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Children with Acquired Brain Injury

- > What to Expect from Your Child
- > Grief, Guilt and Depression
- > Returning to School
- > Your Role as a Parent
- > Working with the School
- > Handling Disagreements with the School
- > The Importance of Early Intervention for Young Children

Children with Acquired Brain Injury

In this chapter, you will:

- Learn what to expect after your child's brain injury.
- Learn how to deal with the difficulties of reintroducing your brain injured child to the school system.
- Read about how to minimize misunderstandings or disagreements with teachers, principals, and aids by discussing plans and options in advance.

What to Expect from Your Child

Family Matters

The following changes may affect your child's behaviour. This is not an exhaustive list. Your child may experience many of these changes or none at all:

- Fatigue.
- Irritability, angry outbursts and impulsiveness.
- Passive behaviour.
- Depression.

- Forgetfulness.
- Poor organizational skills.
- Difficulty following directions.
- Immature behaviour.
- Inappropriate sexual behaviour.

Fatigue

Fatigue is the most common problem children experience after sustaining a brain injury. Your child may also suffer from vision problems, light sensitivity or headaches that they did not have before the injury. To prevent fatigue, you may need to give your child rest periods in a quiet place. Remember, it is important that your child participate in school and other activities only when they have the mental and physical energy to do so.

Irritability and angry outbursts are also common among children learning how to deal with the stimulation of school, day care and/or playgrounds. Look at what precedes the behaviour. Do you notice a pattern? Is there something you can change, such as introducing a rest period, that will help prevent or reduce the frequency of the behaviour?

Immature or inappropriate behaviours include interrupting frequently, making tactless remarks, displaying messy eating habits, or repeating words over and over. Inappropriate behaviours may also include making inappropriate sexual comments, or gestures or actions that are out of context. Your local brain injury association may have books in their library that will provide helpful information on coping with these and other behavioural problems. For additional information, contact your local Alberta Brain Injury Network Service Coordinator (see Resources, Chapter 13).

Grief, Guilt and Depression

Many parents of young brain injury survivors experience grief, guilt and/or depression over what has been lost. These are normal emotional responses. You need to grieve your losses and so may your child. You may feel guilt over the circumstance of the injury even if it could not reasonably have been prevented. Guilt is often expressed as anger and blame directed at others.

Depression is another common response. If you or your child is finding it difficult to move through these emotions, communicate with your local school board, Regional Health Authority, local Child and Family Services, or local Alberta Brain Injury Network office and ask them about counselling (see Resources, Chapter 13).

Returning to School

In the case of a child with a brain injury, both the family and the child may be eager for a return to school. There are resources available to assist with this transition:

- In the education system, most school boards provide special needs services, so your child does not necessarily have to attend a specific school. The manner in which schools provide services; however, may vary.
- Your local Brain Injury Association can be of assistance when your child returns to school. They can provide education on brain injury to your school, consult with teachers, and provide a link

to the hospital and other medical services.

Contact your local Alberta Brain Injury Network Service Coordinator for more information about a brain injury association near you (see Resources, Chapter 13).

- Health professionals who may provide assistance with your child's return to school are psychologists, speech language pathologists, and occupational therapists.

The Family Support for Children with Disabilities program, operated by local Child and Family Service Authorities, will be able to provide you with information about the types of supports that are available. Dial 310-0000 toll free and ask to be connected to the nearest Child and Family Service Authorities office.

Brain injury associations, health professionals, and the education system should work as a team with the family and child.

Because school is a highly stimulating environment, it will be difficult at first for your child to deal with all the noise and activity. This is why many children return to school gradually.

Your child may start by attending a few hours, two or three days a week, without educational demands. As they gain energy, attendance is gradually increased and a curriculum started. Eventually, your child may be able to attend full days, five days a week.

In rural areas, transportation limitations may mean your child is at school for longer periods than appropriate. If fatigue in school is a problem, ask if your child can have a rest period.

Your Role as a Parent

Consistency between home and school gives your child the best chance for recovery. As a parent, you are the constant in your child's life, the mainstay in changing school and health care environments.

Your perspective and input are therefore vital. Talk to your child's teachers about what your child was like prior to the injury and what he/she is like now. Share what you have learned in promoting acceptable behaviour and helping your child achieve their highest potential.

Working with the School

Almost all children with brain injuries will return to school. Your school; however, may have had few, if any, children with brain injuries in the past. The more you can assist the school, the better it will be for your child.

Each school board has someone responsible for services to students with special needs. This person will have access to information and a variety of resources to help your child return to school with as much support as possible. Contact your local school board and ask to meet with the special needs coordinator.

About Teachers

Within the school, the classroom teacher and resource room teacher will be the most involved with your child. Although many teachers do not have training specifically for working with students with brain injury, many of the adaptive strategies and teaching techniques used for brain injury survivors are familiar

to teachers. Interest, flexibility and commitment to learning about brain injury are often hallmarks of an effective teacher.

Keep in mind that the classroom teacher is not an expert in special needs situations; the resource room teacher has more knowledge in this area. The classroom and resource room teachers should work together to create a suitable program for your child.

Getting Started

When helping your child return to school, the following tips on getting started may be helpful:

- Get in touch with the principal of your local school as soon as possible after the injury. This will give the school time to prepare.
- Arrange a meeting with the principal. It is the principal that will arrange any assessments that your child will need. They will explain your school board's process for reintroducing your child to school.

- Bring background information to the meeting. For example, if you have reports that identify your child’s areas of ability and difficulty, bring copies to the meeting. More importantly, bring names and contact numbers of health professionals who can help the school develop an appropriate program. The more information you can give the school, the better program they can design.
- You may also bring a “support” person: a friend, family member, or health professional. The purpose of the meeting is to give the school enough information to develop a teaching plan for your child.
- Prepare for the meeting by writing down your short and long term goals. What do you want for your child? What are your child’s strengths, etc.? Remember to write down and ask any questions you have.
- You may want to meet with the classroom teacher and resource room teacher.

After the first formal meeting, the school (with your permission) will collect information about your child. This information will allow the school to provide additional services such as: a teacher aide, tutoring, special equipment and summer programming.

Remember, while it is important for your child to have all the services they need, it is equally important not to think of more services as better service. Think about what your child needs and look for services that best meet those needs.

The Teaching Plan

A second meeting is needed to discuss the plan for teaching your child. If you do not hear from the school, call and initiate the meeting yourself. It is important that you have an opportunity to discuss the teaching plan with everyone working with your child. Ask for a copy of the plan prior to the meeting. Read it ahead of time. Write down your questions and concerns.

The teaching plan is not meant to be set in stone. Instead, it should have regular review times built into it. It may be helpful to set actual meeting dates for these reviews; however, do not hesitate to call your child's teacher at any time.

Reviews will evaluate how well the plan is working in relation to your child's emotional adjustment, functional skills and available peer support.

Over time, long range goals may change as your child's abilities become clearer. Formal plans can be made to help prepare your child for expected developments, such as a change in teachers, grades or even schools. Ongoing discussions between you, the school, and related health professionals will ensure appropriate changes are made.

Consulting a Specialist

Since brain injuries often affect the parts of the brain that control speech and language, you may want to ask the school to arrange an appointment with a speech-language pathologist if your child is experiencing problems in this area.

It may also be helpful for you and your child to have a consultation with neuropsychologist. Neuropsychologists have advanced training in the relationship between brain function and behaviour. Standard psychological tests tend to provide information on past learning; whereas, children with brain injuries have problems learning now. The tests used by neuropsychologists provide information on your child's ability to learn, communicate, plan,

organize and relate to others. Such an assessment can provide critical information for building effective and efficient educational plans.

Talk to a health professional, or your local Alberta Brain Injury Network office about whether your child could benefit from a consultation with a specialist (see Resources, Chapter 13).

Handling Disagreements with the School

Children benefit most when the parents and the school operate as partners. Because it is in people's nature to see things from different points of view, there may be disagreements.

What to Do When You Disagree

First and most importantly, in the event of a disagreement between parents and the school, it is necessary to remain constructive. As a parent, your goal is not to win the argument, but to ensure your

child has the best education possible. Here are some general guidelines for handling a disagreement:

- Convey your disagreement to the school calmly. Many disagreements are easily and quickly resolved. For example, you may have information the school does not. Simply giving them that information may resolve the issue.
- In most cases, solving problems informally works better than formal appeals. Start by talking to the person closest to the situation, usually the classroom teacher. Outline what you are unhappy about and why. Explain how you would like the situation changed.
- If you are unable to resolve the problem, talk to the principal. If you are still unable to resolve the issue, get in touch with the local school board and talk to the person responsible for student services or the Director of Education for the Board.
- Finally, if your problems are still not being addressed to your satisfaction, you may want to talk to the Minister of Learning, or the Alberta Human Rights and Citizenship Commission. Call 310-0000 to be connected toll-free to these offices.

- Remember, disagreements can be an opportunity for more in-depth problem solving and that can lead to improvements for your child.

What to Do When You Are Emotional

When people relate to each other angrily, the result is often counterproductive. Although it may seem obvious that anger can be unhelpful in dealing with people, where your child is concerned it is not always easy to remain calm. Some guidelines for dealing with situations that make you emotional are:

- Preparing ahead of time by writing down points that you would like to discuss in the meeting. This will prevent you from forgetting any important points, as well as help you to present your concerns in an effective manner.
- Always responding with well thought out arguments. Not only will these help you communicate your point more effectively, but they will take time to develop, and that time can help temper your anger.
- Attending the meeting with an advocate who can voice your concerns should you become too emotional.

- Asking for a recess, if you are finding yourself getting angry in a meeting. If necessary, ask to resume the meeting another day.
- Simply stating the point you disagree with and why. You will be a stronger advocate for your child if you present yourself in a credible, professional matter. A disagreement does not mean you have to be angry.
- Asking for an agreed upon action plan, and not leaving without it. Record the plan in writing, review it with the educator, and leave a copy with them.

The Importance of Early Intervention for Young Children

Many people assume that an injury in a very young child is less serious than in an older child or adult because of the remarkable recuperative abilities of young children. This may apply to physical problems, but unfortunately, for intellectual tasks, such as thinking, problem solving, and planning, an early injury may be more serious. This means that early intervention by a professional is very important.

Children lack the years of learning and experience acquired by older people. An older child or adult can often compensate for learning difficulties by building on past knowledge; whereas, a young child has not had the opportunity to lay that foundation.

The nature of a brain injury can also make learning more difficult as time goes by. For example, young children do not have the same capacity to think abstractly as adults may have, so any deficiency in this area may go unnoticed until the age when abstract thinking becomes expected. Due to the brain injury, the child suddenly lags behind his peers. To help prevent this type of situation, it is important to have early intervention for young survivors.

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Sexuality

- > Introduction to Sexuality
- > Common Changes
- > Coping With Changes

Sexuality

In this chapter, you will:

- Discover how the brain injury can change one's expression of sexuality.
- Learn how to deal with altered expressions of sexuality.

An Introduction to Sexuality

Our sexuality is conveyed by our social interactions and the roles we fulfill. When confronting issues related to sexuality, the normal maturational cycles should be considered while reporting uncommon patterns or behaviours. The brain injury may change your expression of sexuality. A mother, father, child, lover, friend, employee and caregiver are all people that may be affected by an altered expression of sexuality caused by a brain injury.

Since a lot of people view sexuality as a private matter, they are hesitant to talk about the topic. The purpose of this chapter is to let you know that sexuality is an important matter and it is okay to ask questions.

Concerns about your expression of sexuality may vary depending on your age and role at the time of the brain injury. If you are married or hoping for a romantic relationship, this may interest you.

Several potential changes or concerns about sexuality can happen as a result of a brain injury. If you have any questions regarding topics that were not covered here, do not hesitate to ask the health professionals working with you and your family or your local Brain Injury Association (see Resources, Chapter 13).

Common Changes

The most common changes after a brain injury consist of a reduced interest in sexual relationships, impotence or unrestrained behaviour in inappropriate situations. In each of these cases, it is beneficial to remember that this behaviour is because of the brain injury.

Cognitive difficulties are frequently the source of inappropriate behaviour, such as unrestrained speech or actions, poor social judgment and misunderstanding social cues. You may say certain things out loud that other people think but do not say. For example, others may simply think that a stranger is beautiful while you may bluntly let this stranger know that you consider them attractive. You may interpret friendliness as a sexual approach and be surprised by the rejection you experience when it is clarified that it was not a sexual approach.

A few of the changes may leave you vulnerable to exploitation. For instance, impaired judgment may prevent you from identifying a potentially dangerous situation or you may lack the intuition that alerts you when someone who appears to be friendly is actually trying to take advantage of you.

Social skills are a crucial part of sexuality and having difficulty with them will impact your relationship with others. If you have memory impairment, display little change in facial expression, or take longer to express thoughts into words, you may find it hard to form

friendships. Restricted social relationships will lower the chances for a romantic relationship. Without a doubt, this can be the cause of a great deal of anxiety.

Depression is a common occurrence for both the survivors and their families. Feeling down or depressed can have an influence on someone's sexual desire. In this case, you may want to ask for help from a professional counsellor. Your local Alberta Brain Injury Network office (see Resources, Chapter 13) may be able to help you find a counsellor.

Family Matters

Parents of children with a brain injury may notice that their sexual relationship with their spouse changed. Stress, exhaustion, and intense emotions, such as anger, guilt and depression can have an impact on sexual interest. This can cause tension in the marriage.

A spouse who becomes a caregiver may find it difficult to maintain a sexual relationship, since the roles of caregiver and lover do not combine easily. Quite a few caregiving spouses revealed various

reasons for their declining interest in sex. They may not have much energy. The survivor's appearance, behaviour, intellectual abilities, and personality may change and they may no longer be the type of person the spouse would have chosen as a sexual partner.

A few survivors have a dramatic increase or decrease in their interest in sex. If they have memory difficulties and cannot remember when they last had intercourse with their partner, keeping a diary or written log may help manage a give-and-take sexual relationship with their lover. If this persists to be a problem and causes tension in the relationship, you may want to look for professional help.

Coping with Changes

Survivor Matters

To prevent inappropriate sexual behaviour and encourage suitable behaviour, discuss and practice suitable behaviour for specific situations. Memory difficulties may make it necessary for you to review and practice these lessons often. Considering that you may have difficulty identifying when you are

conducting yourself in an inappropriate way, you may want to establish a discreet signal or phrase with your family and friends that they can use to advise you if you are acting inappropriately.

Family Matters

When the survivor conducts themselves in a sexually inappropriate way, handle the situation in the same manner as any other inappropriate behaviour.

Describe the behaviour to the survivor, give an explanation of why it is considered inappropriate, and offer an appropriate alternative action.

Additionally, you and the survivor could agree in advance on a signal or phrase to warn the survivor if they are displaying inappropriate behaviour. If inappropriate behaviour persists, inform the survivor that the behaviour is inappropriate and that you are going somewhere else and will not interact with them until the behaviour ceases. The objective is that the survivor will eventually learn how to control their own behaviour to a greater level.

Talking About Sexuality

Survivor Matters

Even though you may feel uncomfortable discussing issues related to sexuality with others, it is beneficial for you to talk about what is happening and how you are feeling. Speak with a health professional who is familiar with brain injury and its effects or talk to other survivors and their families. As a spouse, you may feel guilty or angry concerning the changes in your relationship. These feelings are completely normal. Talking about them with a knowledgeable person can help prevent additional stress and depression.

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Resources

- > Service Coordinators'
Contact Information

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Service Coordinators' Contact Information

Northwest Region

Accredited Supportive Living Services

Towne Centre Mall

#29 9845-99 Avenue

Grande Prairie, AB T8V 0Y1

Telephone: 780-539-0433

Toll Free: 1-877-539-0433

Fax: 780-538-2946

Email: info@aslslimited.org

Website: <http://www.aslslimited.org/>

-Or-

4902-59 Street

Grimshaw, AB T0H 1W0

Telephone: 780-332-4183

Fax: 780-332-1553

Blue Heron Support Services

Box 298 - 5209-50th Street

High Prairie, AB T0G 1E0

Telephone: 780-523-0036 or 780-523-0071

Fax: 780-523-4116

Email: admin@bhssa.ca

Website: <http://www.bhssa.ca>

Northeast Region

St. Paul Abilities Network

4637 45 Avenue

St. Paul, AB T0A 3A3

Telephone: 780-645-3441

Toll Free: 1-866-645-3900 or 1-866-645-3900

Fax: 780-645-1885

Email: Mail@spanet.ab.ca

Website: <http://www.stpaulabilitiesnetwork.ca/>

Blue Heron Support Services

4925 51 Avenue (P.O. Box 4238)

Barrhead, AB T7N 1A2

Telephone: 780-674-4944

Fax: 780-674-6294

Email: admin@bhssa.ca

Website: www.bhssa.ca

Central Region

Canadian Mental Health Association

5017 50 Avenue

Red Deer, AB T4N 4B2

Telephone: 403-342-2266

Fax: 403-342-5684

Email: office@reddeer.cmha.ab.ca

Website: <http://www.reddeer.cmha.ab.ca/>

Catholic Social Services

5104 48 Avenue

Red Deer, AB T4N 3T8

Telephone: 403-347-8844

Fax: 403-342-1890

Email: Webmaster@cssalberta.ca

Website: <http://www.catholicsocialservices.ab.ca/>

Edmonton Region

Brain Care Centre – Edmonton Office

229, 10106 111 Avenue

Edmonton, AB T5G 0B4

Telephone: 780-477-7575

Toll Free: 1-800-425-5552

Fax: 780-474-4415

Email: admin@braincarecentre.com

Website: www.braincarecentre.com

Brain Care Centre – Edson Office

(Box 30105) 524 50 Street

Edson, AB T7E 1Y2

Telephone: 780-712-7560

Toll Free: 1-800-425-5552

Fax: 780-712-7567

Email: tannis@braincarecentre.com

Calgary Region

Southern Alberta Brain Injury Society

102, 2116 27 Avenue NE

Calgary, AB T2E 7A6

Telephone: 403-521-5212

Toll Free: 1-866-527-2247

Fax: 403-283-5867

Email: sabis@sabis.ab.ca

Website: <http://www.sabis.ab.ca/>

South Region

REDI Enterprises / Brain Injury Relearning Services

856 Allowance Avenue

Medicine Hat, AB T1A 7S6

Telephone: 403-528-2661

Fax: 403-528-2647

Email: birs@redi.ca

Website: www.redi.ca

REDI Enterprises Society / Brain Injury Relearning Services

Suite 250 719 4th Avenue South

Lethbridge, AB T1J 0P1

Telephone: 403-320-7402

Fax: 403-327-7425

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Points to Remember

About the people in your life

Health care teams are dedicated to helping the individual and their family following a brain injury.

Patients, family and friends are important members of the team because of their expertise and existing relationship with the individual living with the brain injury.

About recovery

Recovery from a brain injury is a process that takes time and the time needed to recover differs from individual to individual.

Most adults with brain injury progress thru common recovery stages. The length and outcome for each stage cannot be predicted.

During recovery, a person may shift back and forth between stages; inconsistency is common.

Recovery from a brain injury slows with the passage of time.

Feelings of sadness, frustration and loss are common after a brain injury. If these feelings become overwhelming or interfere with recovery, the individual could be suffering from depression.

Being depressed is not a sign of weakness, nor is it anyone's fault. Depression is an illness that can be a result of biochemical or structural changes in the brain following an injury.

Adapting to a brain injury

The way a person adapts to a brain injury depends on the extent of the injury, the pre injury personality along with the attitude of family and friends.

Adjusting to the changes created by a brain injury can take many years. Family and friends can assist with the process by

- Encouraging the individual to talk about fears and concerns.
- Helping the individual to set realistic goals.

- Remaining hopeful for continued recovery.
- Seeking professional help within the community to develop new resources and understanding of what is happening to you and your family.

Support for caregivers

As a caregiver, ask for help when you need it and find options for assistance such as home health care or planned respite.

Take time to exercise for exercise increases stamina, lessens anxiety and depression and increases self-confidence. These benefits make exercise a worthwhile use of your valuable and limited time.

Join a support group- support groups are an outlet for sharing problems and calming emotions. People with similar issues have a better understanding of what you are experiencing.

Providing care to an individual with an Acquired Brain Injury (ABI) can be a bit like running a marathon. Be prepared for the times you feel like quitting, yelling, leaving or breaking down – remember to pace yourself for the long haul; trying too hard in the early stages may mean you lose all your energy further down the track at a time when your need to provide care may be more crucial.

Other points to remember

Finding the proper balance of control by the family and gradual relinquishing of control are the stepping stones toward greater independence.

While existing long term memories remain intact, an acquired brain injury can significantly impact short term memory.

Glossary of Terms

GLOSSARY OF TERMS

Accommodation – occurs when a person adjusts their goals and expectations to match their level of capability, eg: moving to a position that requires less responsibility or hours.

Acquired Brain Injury – a term used to reference all injuries to the brain that occur after birth.

Advocate – someone who can act on your behalf when an individual's capacity to do this for themselves has been compromised.

Analgesics – pain killers that may be prescribed by your doctor to help alleviate or lessen the pain that may be present following a brain injury.

Analgesic Rebound Headaches – headaches that are caused by the use or virtual overuse of analgesics for headaches.

Anomia – being aware of a word you want to use but being unable to come up with it. Everyone has anomia to some degree. Those with a brain injury experience it more frequently.

Anomic or nominal aphasia – occurs when an individual may be able to understand what other people are saying and may be able to read, but has trouble naming people or objects or coming up with nouns making it difficult to understand what someone is trying to communicate.

Anoxia – the deficiency of oxygen in tissues.

Anticonvulsant – a drug that is used to prevent the onset of seizures.

Antidepressant – a drug used to relieve the feelings of sadness or hopelessness that may be present after a brain injury.

Antispasmodic – a drug that helps to loosen muscles which reduces pain in the affected area making it easier to move joints properly.

Aphasia – the difficulty in using or understanding language.

Apraxia – a problem with muscle control and planning movements limiting an individual's ability to make gestures such as waving good bye or blowing a kiss.

Assimilation – the modification of the work environment and the expectation of other people, eg: Introduction of specialized equipment and educating office staff about the nature of support required.

Brain stem – the part of the brain that connects the brain to the spinal cord, this part of the brain is responsible for involuntary body functions such as breathing and heartrate.

Broca's aphasia – a type of aphasia where an individual may only be able to get out bursts of a few words, vocabulary is limited and can result in the individual being difficult to understand, it is very possible that the individual will have no trouble understanding what others are saying to them.

Case manager – a professional who helps people find needed supports and services.

Cerebellum – the part of the brain located at the very back and bottom of your brain, this area is responsible for making body movements smooth and coordinated.

Diffuse axonal injury – the shearing or tearing of brain cells when the brain is rapidly moved back and forth or twisted around.

Direct discrimination – occurs when a person is treated less favorably than others because of some real or perceived characteristic.

Dosette – a plastic container with separate pill compartments for different times of the day and different days of the week.

Dysarthria – a speech problem due to weakness, slowness or poor coordination of the muscles used for speaking, when this problem is present, speech is often slurred and difficult to understand.

Dysphagia – difficulty swallowing caused by weakness or lack of sensation in the mouth.

Expressive aphasia – a type of aphasia where people have difficulty finding the right words to form sentences and communicate with others.

Frontal lobe – the part of your brain located just behind your forehead and is responsible for problem solving, organization and planning, impulse control and awareness.

Glasgow Coma Scale – for traumatic brain injuries resulting in a coma this scale is used to determine the stages of emerging from a coma, the score is based on one’s ability to make eye contact, talk and follow basic instruction.

Global aphasia – total or near loss of the ability to use language. An individual with global aphasia may not be able to read or write. This type of aphasia often occurs immediately following a stroke, and if the damage to the brain is not severe, improvement can occur.

Guardianship order – occurs when the court appoints a trustee to manage personal decisions for the family.

Hypoxia – the deprivation of oxygen that can lead to tissue death.

Indirect discrimination – occurs when a condition prevents a person with a disability from doing something due to physical barriers, policies, procedures or practices, selection or admission criteria rules or requirements.

Informal trusteeship – an agreement where upon an individual with limited capacity gives permission for funds to be released to a relative, friend or advocate who will then use that money to ensure that all financial obligations are taken care of.

Migraine headache – headaches that usually occur in the front of the head and may be caused by damage done to small blood vessels in the brain at the time of an injury.

Muscle tension headache – a headache that starts at the back of the head and moves around to the side or over the top of the forehead. They are often the result of stretched head and neck muscles caused by the force of the head jerking rapidly forward and backward at the time of the injury.

Neurologist – a doctor specializing in the brain and nervous system.

Occipital lobe – located at the back of the brain behind the parietal lobe and is responsible for processing vision.

Occupational therapist – a therapist that assists individuals learn or revisit practical skills necessary for daily living.

Parietal lobe – the part of the brain located behind the frontal lobe and between your temporal lobe, this lobe is where information from sight, hearing and touch come together.

Physiotherapist – a therapist that specializes in exercises and techniques to improve muscle control, balance and walking.

Prognosis – a medical term meaning how well one is expected to recover. With traumatic brain injury the terms mild, moderate and severe are used to judge prognosis.

Post traumatic amnesia – the inability, post injury, to remember or learn new information such as the day of the week.

Psychotropics – drugs that may be prescribed to help control impulsive behaviours that may be present following a brain injury.

Receptive aphasia – a type of aphasia that can cause problems with understanding what others are trying to say to you.

Remediation – the relearning of skills with practice until a desired level is achieved, eg: Practicing typing speed.

Speech language pathologist – a therapist who helps individuals to learn other ways to communicate and deal with swallowing problems.

Stroke – an injury to a part of a brain that happens when blood vessels, called arteries become blocked or burst and the blood supply to the brain is cut off.

Substitution – the maximizing of previous skill or learning a new skill to overcome a difficulty, eg: using self-instruction to improve concentration skills.

Temporal lobe – the part of the brain located along the sides of your head and above your ears. This area is responsible for helping to understand things you hear, remember things you see, and to feel emotion.

Traumatic brain injury – (TBI) an acquired brain injury caused by a blow to the head or by the head being forced to move backward or forward, usually with some loss of consciousness.

Trusteeship order – occurs when the court appoints a trustee to manage an individual's finances and property.

Wernicke's aphasia – a type of aphasia that causes one to speak without hesitation often using the wrong words or being difficult to understand; an individual with this type of aphasia may have difficulty understanding what is being said to them or with reading or writing.

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