patient and family passport

After a Brain Injury
# What’s inside

## After a Brain Injury

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your Brain Injury Team</td>
<td>7</td>
</tr>
<tr>
<td>The Brain</td>
<td>9</td>
</tr>
<tr>
<td>Injury Worksheet</td>
<td>15</td>
</tr>
</tbody>
</table>

## What is an Acquired Brain Injury?

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>16</td>
</tr>
</tbody>
</table>

## Recovering after a Brain Injury

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glasgow Coma Scale (GCS)</td>
<td>21</td>
</tr>
<tr>
<td>The First Few Weeks</td>
<td>22</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>23</td>
</tr>
</tbody>
</table>

## The Rancho Los Amigo Scale: Levels of Cognitive Functioning

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No response</td>
<td>26</td>
</tr>
<tr>
<td>2</td>
<td>Generalized response</td>
<td>26</td>
</tr>
<tr>
<td>3</td>
<td>Localized response</td>
<td>27</td>
</tr>
<tr>
<td>4</td>
<td>Confused – agitated</td>
<td>28</td>
</tr>
<tr>
<td>5</td>
<td>Confused – inappropriate</td>
<td>29</td>
</tr>
<tr>
<td>7</td>
<td>Automatic – appropriate</td>
<td>31</td>
</tr>
<tr>
<td>8</td>
<td>Purposeful – appropriate</td>
<td>32</td>
</tr>
<tr>
<td>9</td>
<td>Purposeful – appropriate</td>
<td>33</td>
</tr>
<tr>
<td>10</td>
<td>Purposeful – appropriate</td>
<td>33</td>
</tr>
</tbody>
</table>

## Thinking and Memory Changes after a Brain Injury

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in attention and concentration</td>
<td>34</td>
</tr>
<tr>
<td>Changes in memory</td>
<td>36</td>
</tr>
<tr>
<td>Changes in judgment and problem-solving</td>
<td>37</td>
</tr>
<tr>
<td>Changes in planning</td>
<td>38</td>
</tr>
<tr>
<td>Changes in self-awareness</td>
<td>39</td>
</tr>
</tbody>
</table>

## Communication and Language Changes after a Brain Injury

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in Understanding (comprehension)</td>
<td>41</td>
</tr>
</tbody>
</table>
## Changes in Expression ................................................................. 41
## Changes in Speech and Voice ....................................................... 42

### Vision, Hearing, and Dizziness after a Brain Injury 44

- **Vision** .................................................................................. 44
- **Hearing** .............................................................................. 46
- **Dizziness** ............................................................................ 46

## Changes in Perception after a Brain Injury 47

- **Unilateral Neglect** ............................................................... 47
- **Changes in spatial relations** .................................................. 48
- **Trouble organizing movements (apraxia)** ............................. 49
- **Trouble recognizing familiar things (agnosia)** ..................... 49

## Physical Changes after a Brain Injury 51

- **Sensation** ........................................................................... 51
- **Muscle tone, strength, and coordination** ............................. 52
- **Posture** ............................................................................. 52
- **Balance** ............................................................................ 53
- **Endurance** ......................................................................... 53

## Swallowing Changes after a Brain Injury 54

## Bowel and Bladder Changes after a Brain Injury 56

## Weight Changes after a Brain Injury 59

## Skin Changes after a Brain Injury 60

## Using Alcohol and Drugs after a Brain Injury 61

## Seizures after a Brain Injury 62

## Fatigue after a Brain Injury 63

## Headaches after a Brain Injury 65

## Social and Emotional Changes after a Brain Injury 66

- **Behaviour and personality** .................................................. 66
- **Mood swings and managing anger** ..................................... 66
Depression........................................................................................................67
Lowered self-esteem.........................................................................................68
Social Situations..............................................................................................69
Effects due to stress.........................................................................................69

Recreation and Leisure Changes after Brain Injury 71
Life after a Brain Injury 73
Caring for the Caregiver after a Brain Injury 75
Intimacy and Sexuality after a Brain injury 76
Going Back to Work after a Brain Injury 78
Going Back to School after a Brain Injury 79
Driving after a Brain Injury 80
Leaving the Hospital after a Brain Injury (Discharge Planning) 81

Discharge Checklist .........................................................................................81
Getting Ready for a Successful Discharge .....................................................82

Resources and References 83
After a Brain Injury

A brain injury affects every part of a person’s life—their relationship with family, friends, and others they are close to.

No one knows what the final outcome will be. The long-term effects can affect thinking, be psychological, social, emotional, and/or physical. No two people are affected exactly the same way by a brain injury.

How someone looks on the outside doesn’t always tell you what the long-term effects are. This can cause problems because the person may look fine—people may wonder how he can have so many problems.

Family and friends may struggle to cope with the changes in behaviour the brain injury may cause. Family and friends may feel shocked, numb, guilt, afraid, angry, anxious, or depressed.

Roles and responsibilities may change within the family. This can cause stress, feeling burdened, and even depressed by the sometimes big changes in activities, responsibilities, schedules, leisure, and support needed to adjust to someone with a brain injury.

Many people with a brain injury can go home after rehabilitation. Family members may find that they have to do many of the things that the person used to be able to do. He or she may never be able to do some of these tasks ever again. These can include:

- knowing how to behave socially
- being able to think, problem-solve, and so on like before (cognitive)
- going back to the job they had before the injury (vocational)

Along with the support of family and friends, other supports may be needed. This can include community resources, professional support, social service agencies, or through your place of worship. The person with the injury, his family, and his friends all need support while learning how to cope with the change in their lives.
To the person with the injury, going from being independent, active, busy with sports or hobbies, working, or having an active social life, to losing any of these because of the injury can be hard to accept. He may feel useless and depressed. Family and friends become the greatest source of support, yet they themselves are trying to cope with the changes.

It’s best to make big adjustments in small steps—take things a step at a time. It takes time for the brain to heal. Speak with a member of the healthcare team if you have questions or concerns.

**How to use this passport**

Each section in this package will give you information about brain injury. It will tell you know who the best team member may be to talk to about a certain topic. There is also space for you to write down thoughts or questions.

We will also tell you where you can find good information about brain injuries. Ask anyone on your healthcare team if you need help finding resources.
Your Brain Injury Team

The healthcare team is an important source of information and support to both the person with the brain injury and to family and friends. The team can do things like recommend a treatment plan or help the person learn new skills to meet his or her new needs.

The team meets regularly to review how well the person is healing; his progress, and to make plans for future treatment, etc. They will also schedule family meetings (conferences) to update the family and answer questions, as well start planning for discharge.

Below are some of the people on the healthcare team:

**Attending Doctor:** Responsible for the medical care and treatment. This doctor may be a specialist in trauma, neurosurgery, or a hospitalist (like a family doctor who takes care of patients in the hospital). These doctors may have residents, fellows, and medical clerks working with them.

**Nurse Practitioners (NP):** Nurses with extra training who can assess, treat, order tests, and prescribe medicine. The NP works closely with the doctors, nurses, and therapists.

**Physiatrist:** A doctor who specializes in physical medicine and rehabilitation.

**Registered Nurses (RN):** Nurses with training and experience in brain care injury, rehabilitation, and discharge planning. They care for the everyday needs of the person.

**Psychologist:** Evaluates and treats issues with mood, coping, adjusting to the injury, and being in hospital.

**Neuropsychologist:** Evaluates changes or concerns with thinking skills and behaviour. Teach the patient, family, and treatment team ways to manage these concerns.

**Physiotherapists:** Evaluates and treats changes in physical abilities (like walking and balance training).

**Occupational Therapists:** Help the person learn or re-learn independent living skills (like dressing, cooking, or managing finances).

**Speech-Language Pathologist/Speech Therapists:** Evaluates and treats communication and swallowing issues. Looks at how the person understands what they speak, read, and hear.

**Recreation Therapists:** Helps the person explore and take part in leisure activities. Also helps the person learn new activities or new ways to do activities he or she did before.
**Brain Injury Co-ordinator or Case Manager:** Helps coordinate the care of people with brain injuries. Support families and other healthcare providers by offering information, resources, and services that are available.

**Social Worker:** Evaluates and treats coping and adjustment after a brain injury. Help with discharge planning, finances, and community resources.

**Dietitian:** Makes sure nutritional needs are met and teaches about healthy eating.

**Transition or Home Care Co-ordinator:** Nurses and therapists with information about home care services, equipment, or other options for supported living.

**Person with the brain injury and family members:** Make the final decisions about the person’s care and rehabilitation, including goals and plans. The family also gives emotional support and help the person learn and practice new skills and techniques. Extended family and friends can also be a great source of support.
The Brain

The brain is the body’s control centre. It’s made up of billions of nerve cells, called neurons. The neurons are arranged in patterns that work together to control how we think, feel, act, see, taste, touch, and move. They also control our breathing, heart rate, and blood pressure.

Each neuron gives off chemicals that trigger an action in other neurons. These chemicals are called neurotransmitters (like epinephrine, norepinephrine, or dopamine). They act like messages that are sent down through the axon, or tail, to other cells. Where it meets is called the synapse. How fast the message is sent depends on the path to the cell (the axon) and how they “talk” to each other through the chemicals released at the synapse (Figure 1).

![Figure 1: A nerve cell]
Information goes through many nerves that connect to certain parts of the brain: One main route from the brain to the rest of your body is the spinal cord.

Messages sent to your brain tells it about things like hot and cold, pressure, pain, and where your arms and legs are positioned.

Other nerves carry information from the eyes, ears, tongue, and muscles on the face to the brain. These are called cranial nerves.

The brain then sends messages to the muscles through a different set of nerves so you can do things like move, walk, talk, and swallow.

The brain is covered by three layers (membranes). These are called the dura, arachnoid, and pia mater (Figure 2).

Figure 2: Three membranes covering the brain
The brain and spinal cord sits in a clear fluid that bathes the brain and circulates into the ventricles of the brain. This is called the cerebrospinal fluid or CSF (Figure 3).

Four major arteries supply the brain with oxygen and other nutrients:
- two vertebral arteries that follow the spinal column up into the brain
- two carotid arteries that come up on either side of the throat

These four major arteries branch and join to form a network that carries oxygen, nutrients, and blood to the brain (Figure 4).
Areas of the Brain

The brain is divided into two halves (called cerebral hemispheres). While the two halves look nearly the same, they do different things.

For most people, the left half of the brain controls verbal functions like language, thought, and memory-involving words.

The right half controls non-verbal function like recognizing the differences in visual patterns and designs, reading maps, and enjoying music. The right half is also involved in expressing and understanding emotions.

Although each half of the brain does different things, the two parts actually work closely together to control the activity of the body. The left side of the brain controls movement and sensation in the right side of the body and the right side of the brain controls movement and sensation in the left side. This means that damage to the right side of the brain may cause movement problems or weakness left side of the body.

<table>
<thead>
<tr>
<th>Left side of the brain</th>
<th>Right side of the brain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Controls the <strong>right</strong> side of the body.</td>
<td>Controls the <strong>left</strong> side of the body.</td>
</tr>
<tr>
<td>Listening, reading, speaking, and writing.</td>
<td>Judging the position of things in space and knowing body position in space.</td>
</tr>
<tr>
<td>Memory for spoken and written messages.</td>
<td>Understanding and remembering things we do and see.</td>
</tr>
<tr>
<td>Analyzes information in detail.</td>
<td>Putting bits of information together to make up an entire picture.</td>
</tr>
<tr>
<td>Receives sensation signals from the <strong>right</strong> side of the body and space.</td>
<td>Receives sensation signals from the <strong>left</strong> side of the body and space.</td>
</tr>
</tbody>
</table>
The two halves of the brain are divided into four areas called lobes, the cerebellum, and the brain stem (Figure 5). Each area of the brain has a different function.

**Occipital lobe**
- Damage to the left occipital lobe may cause problems seeing things on the right side of space.
- Damage to the right occipital lobe may cause problems seeing things on the left side of space.

**Parietal lobes**
- Damage to the left parietal lobe may lead to problems in reading and math. It can also cause a loss of sensation on the right side of the body. This means that the person would have changes in how he feels touch or pain, his vision, or temperature changes on his right side.
- Damage to the right parietal lobe may lead to problems with spatial tasks, like making sense out of pictures, diagrams, and reading maps. Damage to the right lobe may cause changes in sensation on the left side.

**Frontal lobes**
Damage to either frontal lobe may lead to problems with emotional control, social skills, judgment, planning, and organization.
- Damage to the left frontal lobe may cause problems with speech and moving the right arm or leg.
- Damage to the right frontal lobe may cause problems moving the left arm or leg.

**Temporal lobes**
- Damage to the left temporal lobe may cause problems in understanding and remembering language.
- Damage to the right temporal lobe may cause problems in understanding and remembering non-verbal information such as pictures, diagrams, body language cues, and other visual messages.
**Brain stem**

The brain stem is the control centre for breathing and for the heart beat. Damage to the brain stem can cause many physical and sensory problems. The brain stem gives commands to the muscles of the face, eyes, mouth, and throat.

**Cerebellum**

Damage to the cerebellum may cause problems with co-ordination, balance, or muscle tone in different parts of the body.

**Resources**

To learn more about brain injury and the anatomy of the brain, see chapter 2 at:  
www.braininjury101.org
Injury Worksheet

Ask your healthcare provider to review the area(s) of the brain that have been injured.
What is an Acquired Brain Injury?

Acquired brain injuries (ABI) are the medical conditions that happen to the brain (usually after childhood) that change how it works. There are two kinds of ABI:

- traumatic brain injury
- non-traumatic brain injury

**Brain swelling (cerebral edema)**

Just like if you hit your thumb with a hammer and it swells up, swelling in your brain happens as a normal response to an injury (trauma) or irritation (non-trauma).

There is a balance of brain, cerebrospinal fluid (CSF), and blood within the vessels of the brain. The skull is a fixed compartment; this means that any increase in either the size of the brain or the amount of blood or CSF puts pressure inside the skull (called intracranial pressure or ICP), which can be dangerous. Pressure on the brain tissue reduces blood supply, which means the brain gets less oxygen, damaging the brain.

**Traumatic brain injury**

Traumatic brain injuries involve physical trauma like an accident, brain surgery, or a head injury.

The brain may hit the skull at the point of impact, bounce against the other side of the skull, while also twisting quickly. This is also called a closed head injury. A brain contusion is a bruise to the brain, just like if you were to hit bump your knee and got a bruise.

An open head injury is a head injury in which the dura mater, the outer layer of the meninges, is damaged. If there is a fracture in the skull, especially at the base of the skull, (a basal skull fracture), the CSF fluid can leak.

A penetrating injury is one that’s caused by objects such as bullets, knives, and other objects that push the skull bone into the brain. If the skull pieces push into the brain covering it’s called a depressed skull fracture.
**Diffuse Axonal Injury (DAI)**

Diffuse axonal injury is one of the most common types of traumatic brain injury, where the damage occurs over a more widespread area of the brain.

When the brain moves around the skull upon impact the brain tissue stretches and tears. This causes the brain cells (the axons) to twist, stretch, and snap (Figure 6). As some of the badly injured brain cells die, they release chemicals that irritate the surrounding brain tissue and cause the brain tissue to swell. This is called cerebral edema.

Since axons connect brain cells, when they are injured, it can slow how fast messages are sent from one part of the brain to the other.

For example, if the main road through a city is closed, you can still drive across the city but it takes much longer because you have to travel on smaller, slower routes. You also need to learn the new route! This is the same effect as DAI.

![Diagram of axons](image)

**Figure 6**: This diagram shows the axon twisting when the brain moves around the skull after an impact.
**Hematoma**

Whenever the brain is shaken hard or twisted the brain tissue tears. If blood vessels are broken, bleeding may continue until a pool of blood (hematoma or hemorrhage) builds up, causing pressure on the brain (Figure 7).

- An epidural hematoma is blood between the dura and the skull.
- A subdural hematoma is bleeding below the dura layer.
- A subarachnoid hematoma is bleeding under the arachnoid layer of the brain.
- An intracerebral hemorrhage is bleeding inside the brain.
- An intraventricular hemorrhage is bleeding into the ventricles.

**Figure 7: Two types of bleeding in the brain**

**Figure 8: Where the different types of bleeding are found.**
**What are some causes of non-traumatic brain injuries?**

Some causes include:

**When the brain doesn't get enough oxygen (hypoxia/anoxia)**
- Hypoxia is when the brain cells aren’t getting enough blood (therefore oxygen).
- Anoxia is when the brain cells aren’t getting any oxygen.

**Infection of the brain (encephalitis/meningitis)**
- An infection or inflammation of the brain that affects the membranes and CSF surrounding the brain.

**Changes in the body’s chemistry or toxins**
- Can affect the way the brain normally works (metabolic/toxic encephalopathy).
- The abnormal brain function is caused by abnormalities in the balance of electrolytes and other chemicals in the body (for example, blood sugar levels that are too high or too low).
- Toxic changes caused by poisons such as carbon monoxide, alcohol, or drugs can also injure the brain.

**Stroke**
- An *ischemic* stroke is when the blood supply to a part of the brain is interrupted. The artery may be blocked by a clot (embolism) or become too narrow for blood to flow through it (thrombosis, or hardening of the arteries).
- A *hemorrhagic* stroke is when there is bleeding in the brain. This type of bleeding is usually caused by high blood pressure, which weakens the blood vessel’s walls until the wall breaks and blood enters the surrounding brain tissue.

**Aneurysm**
- This is when an artery wall has a weak section; this weak section balloons out under the pressure of blood flow and may burst or leak, causing bleeding inside the brain (intracerebral hemorrhage).

**Some kinds of brain tumours**
- This is an abnormal growth of cells within the brain tissue. As the tumour grows, it takes up more space in the skull, pushes on the brain, causing swelling, which can affect the blood and oxygen supply to healthy brain tissue.
Resources

To learn more about the anatomy of the brain and brain injury, see chapters 3 and 4 at www.braininjury101.org
Recovering after a Brain Injury

It may takes weeks, months, or years to recover from a brain injury. The longer it’s been since the brain injury, the slower the recovery. More functions usually come back as the brain heals.

Some people make a full recovery, some have mild, long-term problems, and some may need extra care and services for the rest of their lives.

In the days and weeks after a brain injury, the brain tissue is often affected by swelling, bleeding, and/or changes in brain chemistry. Recovery may also depend on the bad the injury was, where in the brain the injury is, the person’s age.

Sometimes blood that has built up has to be removed to reduce pressure and/or swelling. As the swelling in the brain improves, function may improve.

Sometimes other body systems have also been injured. The effect of other injuries can affect how the brain recovers. For example, losing a lot of blood may mean that the brain doesn’t get all the blood and oxygen it needs to heal.

More is being learned about how the brain heals itself. It’s believed that the brain tissue that’s left can learn how to do some jobs that damaged or destroyed brain cells used to do.

Glasgow Coma Scale (GCS)

The GCS is used to assess and monitor how well the brain is working. It’s also used as a way of learning how bad the injury is. This scale can help the team decide how much care the person may need.

The total score is out of 15:

- 8 or below: severe brain injury
- 9 to 12: a moderate brain injury
- 13 to 15: a mild brain injury
Amnesia

*Anterograde* is when there is no memory of things that happen after a brain injury.

*Retrograde* amnesia is when there is no memory of what happened before the brain injury.

*Post-traumatic amnesia (PTA)* is when there is no memory of what happened at the time around an injury. This is because the brain couldn’t make new memories at the time of the injury.

How long the PTA lasts, the first GCS number, and how long a person is unconscious afterwards helps the team understand how bad the brain injury is. It also helps the team give the person or the family an idea of what the chance of recovery may be and how much he may recover.

The First Few Weeks

The person may be in a coma. This means he is unconsciousness, and doesn’t seem to respond to things like sound, touch, and light. The eyes stay closed and he may not show signs that he’s aware of what’s going on around him.

As brain function improves, he may open his eyes, follow sleep-awake cycles, follow commands, respond to people, and speak. It’s common for the person to be confused and disoriented. You may find that he has trouble paying attention and learning or that he seems agitated or restless. He may not sleep well.

Some days will be better than others. For example, the person may follow a command (like squeezing your finger), then not do it again for a while. Try not to become too anxious about the ups and downs—they are normal.

You can help by keeping the person’s space calm and quiet. Examples include limiting the number of people in the room, turning off the TV, or turning down the lights.

Be sure to speak with the healthcare team if you have questions or concerns.
Treating the Brain Injury

Depending on the injury or their overall condition, some people begin their recovery in an intensive care unit (ICU) or acute care unit.

During the early weeks after the brain injury, the treatment focuses on stabilizing the physical condition, dealing with medical issues, and preventing complications like pneumonia and blood clots.

When the healthcare team feels the person is ready, the rehabilitation process will begin. Rehabilitation (rehab) encourages the body’s natural healing process through:

- stimulating and enhancing physical and thinking abilities
- teaching new skills to make up for lost skills (includes physical, thinking, and behaviour)

The therapy focuses on making the person more aware of his surroundings. For example, he may have to re-learn the date, time, where he is, and understand what happened to him.

As thinking skills and physical abilities improve, rehab focuses to also improve thinking skills, mobility, and becoming more independent in self-care.

The way for the person to relearn is by practice. The person with the injury spends only a few hours a day in therapy. What happens for the rest of the day is very important to recovery.

How much and what rehab the person with a brain injury gets depends on things like how aware he is, what other injuries he has, how much rest he needs, and how much he can take part in therapy.

Rehabilitation

Rehab is treatment to help the person work on the thinking and moving skills that were affected by the injury. Rehab itself is very different from acute hospital care. Even though it may start in the hospital, it often continues after discharge.

The fastest change is usually seen in the first 3 to 6 months. People will still make gains for months and a couple of years, but this change will happen more slowly.

Rehab is hard work. It’s done with the person, not to the person.
He must be willing and able to work with rehab services during active treatment and, later with caregivers or by himself when he’s discharged.
**Important points to remember about rehab**

- The goal of rehab is to help patients be able to do as much as they can on their own (reach their functional goals).
- Most rehab services last days to weeks; some can last months.
- Rehab can happen at home and in-between therapies. Doing everyday tasks, even when not in active treatment is still rehab.

**Factors that affect rehab progress**

As we have said, rehab is hard work. Along with how alert the person is, his medical status, where he is in his recovery, and how well he can tolerate and take part in therapy can affect progress:

- *How much he is willing to work at rehab (motivation):* People differ when it comes to motivation. A brain injury may also affect the person’s insight, awareness, and motivation. The person’s personality is also a factor. Family can also help by talking with the healthcare providers about how he has dealt with other life challenges. Also, helping to identify what he enjoys doing or was important to him will help to create goals that have meaning.

- *Relationship with therapists:* The person will likely work with many healthcare providers. Of course, each has his or her own style. Let each healthcare provider know what style you’ve noticed works best and write this into the treatment plan.

- *Expectations:* One of the hardest parts of rehab is being realistic about how much function a person can get back. Some people make a full recovery and function as they did before the injury. Other people will improve just a little. This mostly depends on how bad the injury was. He may need to learn new ways of doing everyday tasks, while staying hopeful that things will keep getting better.

- *Feelings:* People can have a lot of feelings during rehab. These can be feelings about the injury itself, how much their rehab is going to help them, or how much they expect to recover. Feeling tired, angry, discouraged, or overwhelmed is normal and part of the rehab process.

A brain injury can make these feelings even stronger. Talk with the healthcare team if you think these feelings are so strong that they may affect his rehab progress. As a family caregiver who is watching or being part of the rehab process, you will also have many strong feelings. It may help to talk with the social worker, or ask the team who can help you.
As family and other support people know what the treatment goals and activities are, they become partners with the person with the injury and the rehab team to help him get back as many skills as he can and become as independent as possible.

If you have questions, even years after the brain injury, you are welcome to speak to the brain rehabilitation team.

It’s hard to know how a person’s thinking will be affected by a brain injury. However, we do know that there is usually a pattern to recovery that starts soon after a serious brain injury. One scale that is often used to describe cognitive disability and recovery is the Rancho Los Amigo Scale.

**Resources**

To learn more about brain injury recovery and rehabilitation, go to:  
[www.msktc.org/tbi/factsheets/Understanding-TBI](http://www.msktc.org/tbi/factsheets/Understanding-TBI)
The Rancho Los Amigo Scale: Levels of Cognitive Functioning

The Rancho Los Amigo Scale is a scale that describes the general pattern of recovery after most brain injuries. It has 10 levels.

Everyone is different. People
• don’t always move quickly or clearly from one level to another
• may show traits of more than one level at the same time
• may move quickly through levels, or may move slowly or not past a level (because of how bad the brain injury was)

Understanding the level the person is at gives you tips to how to help him while he’s at that level, as well as care for yourself.

Please talk to the healthcare team for more tips on how you can help, as well as how they can support you through this time.

Level 1: No response

Total Assistance
• Will seem to be asleep. Isn’t suffering or in pain.
• Doesn’t respond to sound, touch, or see things.
• Will likely be in the intensive care unit (ICU).

Level 2: Generalized response

Total Assistance
• Will still seem to be asleep most of the time, but does sometimes respond (but not on purpose) to some stimulation, such as sound or touch.
• Responses are limited and often the same, even to very different stimulation. Pain will likely cause the first response.
• Thoughts or feeling aren’t well developed.
Level 3: Localized response

Total Assistance

- Will seem more alert for short periods.
- Will begin to respond more consistently to general stimulation.
- May follow simple commands, such as closing his eyes or squeezing your hand.
- Will begin to respond to discomfort (for example, by turning away when being suctioned or by pulling at the catheter or feeding tubes).

How you can help: Level 1, 2, and 3

The first 3 levels are usually a time of low activity. The goal is to first begin to develop responses to sensory information (touch, sound, smell, and sight) and then to slowly increase how often he shows a response, how often, how long the response lasts, and what type of response it is. Go slowly—over-stimulating won’t make the brain heal any faster. Your healthcare team can help you decide how to do this.

- Talk to him in a calm, slow, normal voice. Say the things that are important to both of you. Don’t expect him to remember the things you say.
- Each time you see him, say who you are. Tell him the day and the date and that he’s in the hospital. Tell him how he was hurt and that now he is getting better.
- Explain what you are about to do before you do it (for example, “I’m going to move your leg.”).
- Speak in reassuring tones. Hearing often comes back before understanding. The tone of voice is more important than what’s being said. Even though it may be hard to have a relaxed tone of voice in these early stages, this can be more meaningful than it may seem.
- Even though he can’t understand everything being said, don’t talk about him or his condition as if he isn’t there. It’s a bad habit to start.
- Show affection in whatever way you can.
- Talk to him about people and things he knows, names of family, friends, school, etc.
- Play the radio music he enjoys once in a while. Don’t leave it on all the time as it can be over-stimulating to a brain that is still healing.
- Keep a journal so you keep track of his progress. The journal can also be a way for the family and the healthcare team to communicate.
Taking care of yourself as a family: Level 1, 2, and 3

- Especially in the very early stages of his recovery, you may be afraid to leave the hospital because you’re worried and you want to help or you may be afraid that he won’t survive. Take care of yourself.
- It’s important to learn to pace yourself early. Get enough sleep. Do some things that you find relaxing, and get some exercise. Remember to eat healthy meals every day.
- Work out visiting schedules with other family members and friends so that you don’t have to be there all the time. Let people help you with things that they can do, like making meals ahead of time and freezing them.

Level 4: Confused – agitated

Maximum Assistance

This stage is very different and can be frightening for the family.
- Will shift from being underactive to overactive.
- Behaviour can be unpredictable and strange; he may scream or cry for no apparent reason, or he may be aggressive or agitated.
- May be very confused and frightened. Restraints may have to be used to keep him safe.
- Speech may be unclear and/or not make sense.
- Doesn’t remember new information well. The brain may “make up” stories to fill in the gaps (called confabulation). The only memory is for things that happened before the brain injury.
- Can’t pay attention for very long.
- Will likely need a lot of help with self-care (like combing his hair).

How you can help: Level 4

- Remember that this is a stage, a sign that his brain is healing; it’s not a personality change.
- Remind him often what day and time it is, and where he is. If he argues or doesn’t believe this, don’t argue back. Try changing the subject.
- Limit visitors to 2 at a time.
- Cut the number of things going on at any one time. For example, don’t talk to him, play the radio, feed him, stroke his arm, and visit with other visitors all at the same time. He needs structure and order. Too many things happening at one time will confuse him even more.
• Communication is an important part of recovery. If he isn’t speaking yet, use another consistent way of communicating, such as trying to get him to nod or shake his head or tap his finger to show “yes” or “no”.

• When he becomes agitated, don’t walk out on him, or ignore him. Having family with him and reassuring him will usually soothe him. Touch him, wash his face or body with warm water, or play soft music.

• Be patient—he doesn’t usually know what he’s doing or saying. It’s very normal for family to get impatient and frustrated. If he swears at you, or gets agitated and acts out, don’t take it personally. Remember, it’s the brain injury swearing at you, not him.

**Taking care of yourself as a family: Level 4 and beyond**

By this stage, family members are often tired by the range and strength of emotions they’ve gone through. Feeling the “low” from the fear of losing the person, to feeling the “high” from seeing him start to recover is part of the process.

By this stage, family usually know that he may have some disability because of the brain injury. Family know that his rehabilitation is going to be a very long and slow process.

This awareness may make you feel depressed or afraid. It’s very normal to feel this way. It is quite common for family members to get counselling to help cope and adjust to these changes. You may feel better if you talk about your feelings with a member of the healthcare team.

**Level 5: Confused – inappropriate**

**Maximum Assistance**

• Is alert and can pay attention to activities around him.
• Will still have trouble focusing on the important parts of an event.
• Will have lost of lot of his memory, which affects his new learning.
• Is easily distracted and can’t focus his attention.
• May seem to forget how to use objects he knew how to use before the injury.
• Will confuse the past and present.
• May be able to follow simple, everyday conversations.
• May be able to answer, “I’m fine, how are you?” but get “lost” if the conversation becomes harder to follow.
• May say things that aren’t appropriate (for example, he may swear even though he never swore before).
• Will depend on others to direct or cue him.
• May now be able to do simple self-care activities, but will still need some help.

**Level 6: Confused – appropriate**

**Moderate Assistance**

• Behaviour is purposeful.
• Can follow simple directions.
• Can follow a schedule with some support but changes in his routine can confuse him.
• Still needs direction
• Problems with memory problems that can lead to poor judgment and errors.
• Recall of memories he had before the injury are generally accurate.
• Can pay attention and concentrate better. He usually knows where he is, the time, the date, etc.
• May now recognize staff. He may become very attached to family members (may phone home often).
• Is easily overwhelmed with too information.
• Can’t plan or foresee events.

**How you can help: Levels 5 and 6**

• Be patient and repeat information as needed. Help him learns ways to remember things.
• Go over information about family and friends. Use a photo album to stimulate memories.
• He may laugh or cry easily and not always appropriately. Usually, the best thing to do is to ignore it, distract him by suggesting another activity, or change the topic until he calms down.
• Help him with homework or assignments his therapists give him. Encourage him to make his own entries in the journal, phone, or other electronic device.
• For basic tasks, give him the structure he needs by giving step-by-step instructions.
• Slowly increase his independence by gradually decreasing the amount of help you give for certain activities.
• Within limits, use every situation as a learning experience. Everyday tasks will still be hard for him. Help him count money and make change. Ask him about the steps involved in making coffee or doing the laundry, and then have him do the task he has just described.

**Level 7: Automatic – appropriate**

**Minimal Assistance**

By this time he may “seem” normal at first glance.
• Can do everyday tasks with little or no confusion.
• Very aware of staff, family, and surroundings.
• Knows that he has a brain injury but may not know the details.
• Can learn, but not as fast as he did before the injury.
• Memory has improved there are still gaps.
• Judgment, problem-solving, and planning are still poor so he still needs some supervision. He has limited insight into these issues. If interested in an activity, he may do it without someone suggesting it.
• Can do his own self-care (like brush his teeth and wash himself).

**How you can help: Level 7**

• Talk about things in the home that could be dangerous and have him tell you what he has to do to stay safe.
• Encourage him to write in his journal every day, or use an electronic reminder such as a phone.
• Make sure that your words and body language match.
• Support him as needed when he’s making decisions.
• Be patient and be creative. He may still be slow to answer questions, start conversations, or start an activity.
• Help him think of other things to do. He may seem to be unmotivated or “lazy” because he can’t think of anything to do but watch television.
• Encourage him to continue with therapy or get counselling as needed.
Level 8: Purposeful – appropriate

Stand-by Assistance

Unless they knew him before the injury, others often don’t notice any issues he may still have as a result of the injury.

- His memory for past information is good, while memory for recent events and new learning may still seem foggy or fuzzy.
- Is able to learn new information, although not as much or as fast as before the accident.
- Can follow routines with your help as needed and make changes with little help.
- Likely has less ability to reason, tolerate stress, or use good judgment in emergencies or unusual situations.
- Often social, emotional, and intellectual abilities are still less than before the injury, but are good enough to function in most social situations.

How you can help: Level 8

- Encourage him to be involved in the home, school, or job within his thinking and physical limits. Help him pace himself.
- Help to manage the medicine he takes (this may mean just supervising). The goal is to help him be as independent but as safe as possible.
- Measure improvement starting from the time of brain injury, not how he used to be.
- Learn to appreciate this “new” person; one who is likely different in many ways since the injury, for example you may notice changes in his personality and behaviour as well as his likes and dislikes.

Remember that he still needs your support, affection, and companionship.
Level 9: Purposeful – appropriate

Stand-by Assistance on Request

By this stage he should be able to recall past and recent events and connect them.

- Can re-learn higher level tasks like driving and job training.
- Can carry out routines on his own, but may ask for help if he’s not sure how to do it.

Level 10: Purposeful – appropriate

Modified Assistance

By now he should be able to finish activities on his own, even though he may need more time.

- Is able to set his personal and work goals.
- Can monitor himself in social situations.
- Can acknowledge other people’s needs and feelings.

Although he may seem back to normal, he may feel depressed once in a while. Living with a brain injury is a life-long process and he’ll need support from his family and friends just like anyone else.

How you can help: Levels 9 and 10

- Keep offering emotional support and encouragement.
- Let him make her own choices; however, be ready to help if asked or when needed.
- Be patient and tactful.

It’s a delicate balance to encourage the person to be independent but still be there for support when he’s dealing with the world. Congratulate yourself whenever you’re successful!

Resources

To learn more about the Rancho Los Amigos Scale go to:
www.rancho.org/research_rancholevels.aspx
Thinking and Memory Changes after a Brain Injury

The kind of changes in thinking (cognition) that a person has after a brain injury depends on many factors:

- the part(s) of the brain that was damaged
- how much damage the injury caused
- the stage of recovery
- pre-injury factors like personality, age, intelligence, education, and work background

Talk to your healthcare provider, such as an occupational therapist, speech therapist, or neuropsychologist for more ideas on how to treat changes in thinking.

Changes in attention and concentration

Attention is being able to focus on what’s important and not get distracted by what isn’t important. The changes in attention that can happen after a brain injury can make it hard to follow a conversation, hard to work, or make it unsafe to cook a meal or drive.

Terms you may hear:

- *Alternating attention*: This lets you to switch from one task to another without losing track of what you’re doing, and to keep track of several things at once.

- *Attentional capacity*: This is how much information you can take in at once without getting overloaded. For example, the average adult can hear and repeat a 7-digit phone number but usually won’t remember it 5 minutes later.

- *Sustained Attention*: This is how long you can concentrate on an activity or task. It depends on the task, how tired you are, etc.

- *Selective attention*: This is being able to ignore distractions. Examples of this may include having trouble with having a lot of visitors/people talking at the same time, or being easily distracted while driving. Other examples include forgetting what you were going to get from the bedroom, or trouble preparing a three-course meal.
In the early stages of recovery, the person may not be alert enough to communicate. He may not be fully aware of his environment. If he is able to sustain his attention, it may only be for a short amount of time. He may be restless.

At times, one small detail or focus on the wrong information may distract him. These distractions could be internal, as he might be distracted because he needs to go to the bathroom. Or the distraction could be external, for example, while talking with you, his attention may be on your tone of voice or your earlobe, rather than what you are saying. Or, he may be trying to pay attention to your words, how you look, noise from the street, and other activity in his room, all at the same time.

If he can’t concentrate, it’s hard to finish a task. He may know what he needs to do, but can have trouble keeping track of what he’s doing. We all have problems concentrating, especially when we’re tired or don’t feel well. For the person with a brain injury, it can be so hard to concentrate that he can’t do even the simplest task, like washing his hands or dressing.

Since it’s common to feel very tired (fatigued) after brain injury it can also be the reason why he seems to be so up and down during the day.

**Tips to help with concentration and attention**

- Reduce distractions; have only one person in the room, turn off the TV or radio.
- Break tasks into small steps.
- Take away time pressures. Don’t rush through a task or expect it to be done perfectly.
- Be sure you have his attention before starting a talk or task.
- If his mind is wandering, use your voice to try to keep his attention. Show excitement in your voice and use gestures to bring his attention back to the task. If he seems to be withdrawing from you, try a quiet, soft-spoken approach.
- Give new information in small bits and repeat it often. Have him repeat back the information to be sure he’s actually listening.
- Encourage hobbies or activities that he enjoys and can do. Card games, puzzles, and reading help develop concentration.
- Praise him when you see that he can pay attention longer (either listening or doing a task).
- Make sure he doesn’t get too tired. People who have trouble focusing may get tired quickly. Make sure he takes short breaks to give his brain a rest.
Changes in memory

Losing the ability to make new memories can be a huge loss. Losing your memory can range from mild, like sometimes forgetting a name, to severe amnesia where something that happened a few seconds ago isn’t remembered. The person may make up a silly or absurd story to fill memory gaps; he isn’t trying to lie. This confabulation is automatic and unconscious.

Problems with memory can affect progress in all areas. If memories fade quickly, he won’t able to learn from new experiences or he may not remember that he’s making changes or improving. This can have a huge impact on rehabilitation. In therapy, the person is learning ways to walk, to use assistive devices, and to communicate and think. If the person has trouble remembering what he’s learned from one day to the next, treatment may bring only a small improvement.

A brain injury doesn’t affect all types of memory. Even when other kinds of memory are greatly affected, many people can still learn new habits and routines allowing them to become independent. During the assessment stage of therapy, different types of memory will be looked at. Therapists test memory for events that happened:

- before the accident (remote memory)
- in the past few seconds (immediate memory)
- a few minutes, hours, or days ago (recent memory)

Immediate and recent memory tends to be more affected by a brain injury than remote memory. Memory recovery is often slow and incomplete, but there are ways to help overcome or make up for this.

Tips to help with memory

- Have clocks and calendars around the house and in his room, and mark today’s date.
- Encourage using a journal, notebook, or electronic device (for example, iPad) to record important information. When family or friends visit, write the date and activities in the notebook. These memory aids should always be kept in the same place.
- Put a radio in his room so he can listen to his favourite station and hear the news and time. Don’t keep it on all the time as this can make him tired.
- Follow a routine or schedule at home. Put it in a spot that’s easy to see, like the fridge or a dry erase board.
• Remind him of the time, names, appointments, and so on. Try to add this information into your social conversation.

• Gently remind him of correct details of past and present events. Check with others to make sure the information is correct.

• Use short sentences and simple words when talking to him.

• When giving new information, repeat it often and write it down for later reference. Have him repeat new information back to you to be sure he understands and remembers it.

• Have him use a voice recorder (these are common on most smart phones or devices), so he can go back and listen to them again later.

• Whenever possible, do activities that he knows and can do—like playing cards.

• People with memory problems do best in familiar and routine situations that don’t make them adapt to changes.

• If his memory is very bad, you can buy devices that shut off stoves and other appliances automatically. This can help to prevent safety hazards.

**Changes in judgment and problem-solving**

Problem-solving and judgment may be impaired after a brain injury. He may have trouble judging a situation and figuring out what the right response should be. He may act on his first impulse.

His thinking style may not be flexible—once he’s made up his mind, it can be hard to change it. Once he has an idea or plan, it may be hard for him to think of alternatives. Because of poor judgment he may not make decisions that are in his best interest.

**Helping with judgment and problem-solving**

• Involve him in making decisions whenever possible.

• Encourage him to plan and reason out loud so you can help with his decisions and gently correct errors in his thinking.

• Point out important things to think about when making a decision. Encourage him to write these down.

• Give him choices, instead of asking for a suggestion or opinion. For instance, ask if he wants to go for a walk, practice his exercises, or watch TV, instead of asking him what he wants to do.
• Give him feedback about his behaviour; on both what was a correct response and what wasn’t. Tell him if his behaviour or ideas are appropriate or realistic. You can ask your psychologist, occupational, or speech therapist for ideas on how to do this.

• Help him remember similar problems or situations from the past. Reduce distractions and demands, and give him extra time to problem-solve.

### Changes in planning

Many people with a brain injury find it hard to plan, begin, and finish an activity. He may seem like he’s not interested, not motivated, or even depressed; this isn’t usually done on purpose.

He may not be able to think ahead. He may lack follow-through to finish a task. His thinking may be disorganized and incomplete. This may show up as repetitive movements or comments.

He may act impulsively by doing something quickly, without thinking. He may also need a lot of time to understand information and respond the right way.

### Tips to help with planning

• When possible, have him help with household chores (as much as he can do). Things like setting the table, washing the dishes, or preparing a salad need planning but may be familiar enough to him that he can do the task. Help only when he needs it.

• Use a checklist so that he can check off each step of a task as he does it.

• Break down the task into small steps and give guidance at each step. For example, when making a salad, tell him to prepare the lettuce. When this is done, tell him how to make the dressing, and so on.

• Reduce distractions, reduce the demands, and give him extra time to problem-solve.

• He might be able to finish a task if you prompt him. Clearly and briefly explain the activity before he starts.

• Limit distractions, such as noise or too much equipment on the table.

• Give instructions or directions slowly to give him time to understand and respond.

• Routines and schedules outlining future events help him organize better. Set a time to do these tasks in.

• Use a calendar so he can see what is coming up so he can get ready for it.
Changes in self-awareness

It’s common after a brain injury for the person not to be as self-aware as he was before. For example, he may not be aware of what he can’t do anymore. He may not notice or remember the changes in himself. He may be in denial or grieving the changes in himself. Or he may feel pressure to return to home or work whether it’s a good idea or not. This may lead him to overestimate his abilities and underestimate his problems.

To help someone with impaired self-awareness

Talk to your therapist:

- to learn ways to help set limits with clear explanations to make up for poor judgement and to reinforce accurate self-statements
- to learn ways to help him predict how a task will go, then review how it went
- to identify the best person to help him learn ways to become more self-aware (for example, he may not take feedback from his mother but will listen to his brother)

Give lots of supportive but realistic feedback.

Resources

To learn more about cognitive changes after brain injury, go to:
www.msktc.org/tbi/factsheets/Cognitive-Problems-After-Traumatic-Brain-Injury
Communication and Language Changes after a Brain Injury

Let’s look at some of the things the brain normally does when we communicate. What must happen if, for example, someone asks a question, and you answer?

1. You hear the speaker’s voice and focus on it.
2. You create meaning from the speech sounds.
3. You match the meaning of what you’ve heard with information stored in your brain.
4. You make a mental image of your reply.
5. In your mind, you put your response into words.
6. You activate the muscles controlling voice and speech.
7. You hear your answer and judge if it is what you wanted to say.

The brain usually does these functions quickly.

A person with a brain injury may find it harder to use speech or language. This can be very frustrating for him. It also makes it harder for others who are trying to help.

We know that more than one part of the brain can be injured. This means that there could be more than one issue affecting communication at the same time. For example, the person may have damage to the language areas of his brain or damage to the area that controls pronunciation.

Damage to other brain areas may cause issues with the thinking skills you need to be a good communicator. The person may be confused, disoriented, and impulsive, talk too much, or be withdrawn and silent. These cognitive and behavioural issues can make conversation sound inappropriate. He may have trouble staying focused on an appropriate topic and his speech may ramble disconnectedly (language of confusion). He may repeat his speech (can’t control this) or activity. This is called perseveration.
Of course, not many people will have all of these issues at once, but it is possible for several to be combined, especially early in recovery. If the person a lot of trouble communicating, he may need another way to communicate, such as using a computer or picture board.

Please speak with your healthcare provider, such as a speech-language pathologist, for tips on how you can help with communication problems.

**Changes in Understanding (comprehension)**

It’s very hard to understand what is being said if, because of a brain injury a person can’t:
- hear the speaker’s voice and focus on it
- get meaning from words or use speech sounds to make words
- match the meaning of that being heard with information stored in the brain

Problems understanding can range from only affecting the person at certain times (like when he’s tired) to being very bad. A person with a comprehension problem may have trouble reading.

**Changes in Expression**

To communicate with others we need to be able to:
- come up with what we want to say
- put our response into words in our mind
- activate the muscles controlling voice and speech
- judge whether we are being appropriate

It’s important to be able to form words to share thoughts. If the brain injury has damaged the part of the brain responsible for expressive language the person may have trouble making sentences or finding the right words.
Changes in Speech and Voice

Sometimes all stages of communication work as they should, except the process of making the sounds of speech. Damage to certain areas of the brain can interfere with messages to the muscles of the tongue, lips, jaw, voice box, and other areas. The result may be a weak, breathy voice, or slurred speech sounds. Sometimes the brain gets a mixed message of how a word should sound. The person might struggle to get the right sounds in order or have trouble speaking at all.

Tips to help with communication

The speech-language pathologist (speech therapist) working with the person will show you ways that you can help. There is no one size fits all, but there are a few guidelines.

One of the most important things you can do is to keep your natural relationship with the person, rather than becoming too much of a teacher. Always remember that communication involves two people. You need to help the person with the brain injury to understand you and to express his thoughts as many times as he needs to try.

- Create an easy, non-demanding atmosphere where he feels free to communicate without feeling he’s under pressure to perform.
- Reduce background noise and other distractions when talking with the person. Get his attention before speaking. Limit the number of people in the room, especially if he has a comprehension problem.
- Speak in direct, clear, short sentences. Keep an adult tone of voice and vocabulary.
- Ask yes/no and multiple choice questions.
- Emphasize important information.
- Use hand movements, writing single words, or act out what you mean if your message doesn’t seem to be getting through.
- If he has trouble expressing himself, give him time to communicate in the best way he can. Give him your full attention until he finishes the thought. Don’t finish sentences for him, although you may repeat or paraphrase his message to make sure you understand it.
- Don’t ask too many questions at one time. Wait for a response to one question before asking more.
• When you have to, give cues to help him find or express the words he wants.

• He may talk non-stop and not give the listener a turn to speak. If this happens, politely interrupt and say that you would like to speak.

• If all else fails, be honest and admit that you didn’t understand and ask him if it’s really important or suggest he tell you later (often he will).

Resources

To learn more about communication changes after a brain injury, go to:
www.msktc.org/tbi/factsheets/Cognitive-Problems-After-Traumatic-Brain-Injury#Language
Vision, Hearing, and Dizziness after a Brain Injury

Vision

Problems with vision make life harder for the person with the injury. Because it can take many months for the brain to recover, it may be a while before we know what, if any, problems the person will end up with.

An eye doctor will decide what, if any treatment is needed (like surgery or glasses). Sometimes the person has to learn new skills to adjust to the change in his vision. An occupational therapist can help teach these new skills.

Normal vision depends on the functions below working together. The brain controls all these functions. If something goes wrong at any point, vision will be affected:

- the eyes must move together and focus on something
- nerve receptors at the back of the eye (retina) must then send messages back along the optic nerve
- the occipital lobe at the back of the brain must catch or capture these messages

Some vision problems that can happen after brain injury

Blurred vision: This can be like being near-sighted. Things close up may be clear, but things that are further away tend to blur into the background.

Double vision (diplopia): This happens when the eyes don’t move exactly together, causing the person to see two of everything. This makes it hard to decide exactly where objects are.

Someone with double vision is likely to bump into furniture or drop or spill things. Sometimes an eye patch or glasses with prism lenses are prescribed.

To help someone with this problem, things such as furniture need to stay in place and not be moved without telling the person first.
Drooping eyelid (ptosis): A drooping eyelid may block vision in the affected eye. It may take awhile for vision to adjust even if the eyelid stops drooping.

It’s hard to judge distances using only one eye. The person with the brain injury may:

- feel dizzy
- not see where steps are
- not be sure about how fast things and people are moving towards him
- have trouble pouring liquids from one container to another

Hemianopia: Blindness involving one-half of the visual field in both eyes.

Vision loss: Damage to some part of the nervous system that sends messages from the eye to the brain may cause vision loss. This loss can range from some vision loss to complete vision loss. Often some part of the visual field may be missing. For example, he may not see things to his left, but be able to see things on his right.

People with some loss of their visual field may:

- suddenly notice objects that seem to appear or disappear as they can’t see that part of their environment
- bump into objects on the affected side
- not see food on the side of the plate on the affected side
- turn their head toward the unaffected side
- lose track of the last place on a page where they were reading or writing
- cut words in half when reading, which can make it hard to figure out what the word is
- turn their head toward the unaffected side
- lose track of the last place on a page where they were reading or writing
- cut words in half when reading, which can make it hard to figure out what the word is

To help someone with visual changes

- Remind him to look around the environment, especially on the affected side.
- Mark “on” and “off” switches of items that are used often (like the TV and kitchen appliances) with bright pieces of tape so the person can tell when equipment is on or off.
- Put bright objects or favourite things on the affected side and him to turn his head until he sees the objects.
- Make the font or print size bigger.
- Draw a straight, brightly coloured line down one side of a book or notebook as a cue to show the edge of the page. Do this on the right side of the page if the right side is affected and on the left side if the left side is affected.
**Hearing**

A hit to the outer ear can injure the eardrum, or break or dislocate the small bones in the middle ear. The inner ear can also be damaged, which affects the nerves that help us hear. Damage to the outer and middle ear can usually be fixed.

If the part of the brain that controls hearing is damaged, it can cause problems with the brain’s ability to change sounds into meaningful messages. Damage to the nerves of the inner ear and to the part of the brain that controls hearing can’t be fixed. This damage may be permanent and may not get better.

A hearing specialist (an ear, nose and throat (ENT) doctor or audiologist) may be asked to do an assessment such as a hearing test to find the type of injury and how bad it is.

**Dizziness**

The same hit to the outer ear can also affect the way the ear works to help us keep our balance. Other causes can include damage to certain parts of the brain, or as a side effect of medicine.

The person with the injury may say he feels light-headed or dizzy if his sense of balance or his circulatory system is upset, such as if his blood pressure is low, especially with sudden changes in posture such as lying to standing.

He should change positions (like going from lying flat to walking) slowly. Taking time to sit before standing gives the body time to adjust to changes in position.

Our vestibular system, deep in our inner ear tells us how we are moving in relation to the environment and gravity. It relies on sensory receptors in the inner ear.

The person may be referred to an ENT doctor and/or a physiotherapist who can assess and treat balance disorders.

**Resources**

To learn more about visual changes and brain injury, go to:  
www.brainline.org/content/2009/07/introduction-to-vision-and-brain-injury-.html
Changes in Perception after a Brain Injury

How we perceive or “see” something depends on how much we know about our own body and how it moves, and how well we take in information from our senses (what we see, hear, and feel). It also depends on how well we can compare new sensory information to information stored in our memory from past experiences. We can then use the combined information to make decisions about how to respond to new situations. This processed information builds over a lifetime. It lets us do the complicated tasks we do every day, like getting dressed, cooking, driving a car, or reading.

Damage to the areas of the brain that help us to understand our body and how it moves, as well as what we see, hear, or feel affects perception. Damage to the area of the brain involved in memory, thinking, and reasoning can affect how well sensory information is collected and stored. The damage can also affect how information is used to make decisions in new situations. Any of these changes can affect how well a person is able to do everyday tasks.

The following are some of the common perceptual problems that happen after a brain injury, how they affect everyday activities, and some ways of helping people with these problems.

Please talk to your healthcare provider, such as a physiotherapist or occupational therapist, for tips on how to help with perception problems.

Unilateral Neglect

Unilateral neglect is when the brain ignores body parts or objects on either the right or left side. A person with unilateral neglect may only dress one side of the body or shave one side of the face. He may bump into things on the neglected side. He may also tend to turn his head toward the unaffected side.

To help make the person more aware of the neglected side:

- sit on the neglected side when talking to him
- touch or hold the hand on the neglected side
- remind him to watch his neglected side as he goes through doorways or around furniture
- put objects that he wants or needs on his neglected side
- when he’s dressing, have him dress the neglected side first
Changes in spatial relations

Sometimes a person has problems relating to space after a brain injury (for example, he has trouble understanding where an object, like his arm or leg, is in space). This is called proprioception. An example of this is confusion would be up/down, in/out, and front/back.

It also includes having trouble judging distance between two or more objects.

People with a spatial relations syndrome may have trouble:

- finding a hairbrush in a cluttered drawer
- finding the brakes on the wheelchair
- telling a knife from a fork or finding the silverware beside the plate
- finding the way to a room
- judging the height of steps
- judging distance, such as reaching for things on a table or counter

**Tips to help a person with spatial relations changes**

- Organize drawers and cupboards and keep everything in the same place.
- Encourage him to slow down and look at areas carefully by looking and feeling. Have him practice locking and unlocking the brakes on the wheelchair when transferring.
- Remove all extra cutlery from the sides of the plate. Give him the correct utensil to use with the type of food.
- Leave a light on in the bedroom or bathroom and remind him to look for the light. Labelling rooms with a sign or coloured arrow may also help.
- Have him use both hands to feel for objects.
- Have him move slowly, feeling for the edges of steps with his toes when going up and down stairs. Brightly-coloured tape across the edges of each step on the stairways may also help.
- Gently ask him to move if he’s standing too close or too far away.
Trouble organizing movements (apraxia)

Apraxia is when someone can’t do a skilled movement even though his muscle strength, co-ordination, and sensation are normal.

The person knows and understands what he wants to do but can’t organize the movements to do it. He often uses objects incorrectly. He may have trouble:

- writing
- folding towels
- putting a letter into an envelope
- putting a belt through the belt loops
- using eating utensils
- putting clothes on in the right order and on the right body part
- recognizing the front and back of clothing
- telling the difference between a toothbrush and a hairbrush and what to do with them

Tips to help someone with apraxia

- Have him practice writing something he knows, like his name.
- Have him practice using clothing labels to tell the back from the front.
- Put your hand over his and move it through the correct motions to do a task.
- Keep things in the same place in the bathroom at all times.
- Put the belt through the loops before he dresses.
- Be supportive. Explain the problem to him and let him know you understand how hard it is for him.

Trouble recognizing familiar things (agnosia)

Agnosia is when you can’t recognize familiar things using your senses (seeing, hearing, or touching).

A person with agnosia may have trouble recognizing:

- words, even though he may be able to recognize the letters within the word
- faces he knows, such as those of family or friends
- sounds he knows (for example, being able to tell the difference between the sound of a car engine running and a vacuum cleaner)
- objects by touch (for example, trouble telling the difference between a toothbrush and a comb)
Tips to help a person with agnosia

- Bring pictures of family and friends to the hospital and practice naming the people in the pictures. Help him look for clues to help him tell people apart.

- Encourage him to use whatever sense is working. For example, if he can’t recognize things by sight, have him feel things to identify them. If he can’t identify things by touch, have him use his vision as much as possible. Use labels in the form of written words or pictures to best describe
Physical Changes after a Brain Injury

A brain injury may damage the pathways that have to do with movement. If this is the case, a physical therapist will assess the person’s physical status and abilities.

After the assessment, a treatment program is created that fits the person’s needs.

The areas assessed are:

- sensation
- inner ear function
- muscle tone and strength
- range of motion
- posture
- endurance
- motor control, balance, and coordination
- functional mobility—bed mobility, transfers, walking, stair climbing

Sensation

Sensation tells us about how we are moving, what we’re feeling, and what’s going on around us. Forms of sensation include light touch, pain, temperature, moving joints and muscles, and vision.

This may involve being able to sense movement or position, to feel changes in temperature, or to feel touch to the affected part of the body.

It also makes it harder to re-learn movement, since the sensation of movement is gone. Movement information must be sensed by thinking about the movement first.

Losing sensation can be a very serious safety issue because he may not be able to feel an injury.

It’s important to know what types of sensation have changed to help him stay safe. For example, if he can’t feel hot or cold, ask him to use his unaffected body part to check the water temperature before a shower.

Your healthcare team can help you learn ways to manage sensation changes.
Muscle tone, strength, and coordination

Muscle tone is the amount of tension in a muscle when at rest. When muscle tone is normal, the limbs and body feel easy to move. A brain injury may damage the normal control of muscle tone. This may cause decreased muscle tone—the limbs feel floppy and heavy (hypotonicity) or more than normal muscle tone—the limbs feel stiff and tight (hypertonicity). Both affect the person’s ability to control movement.

After a brain injury, muscles may show different degrees of weakness. Some muscles may be stronger in one limb than another. Damage to certain parts of the brain may result in slow, jerky, or uncontrolled movements.

You may hear the terms:
- hemiparesis: muscle weakness on one side of the body only
- hemiplegia: muscle paralysis (no movement) on one side of the body only

Posture

The head and neck give the eyes, mouth, and tongue a stable base. The trunk (the body between the shoulders and hips) gives us a stable base so we can use our arms and legs.

To move normally, the head, neck, and trunk need to be properly positioned when standing and sitting.

A brain injury can affect the muscles that control head, neck, and trunk positions. It can also affect the sense of what is midline or upright.

This may be caused by wrong information coming from the senses about position, limited range of motion, abnormal muscle tone, pain, or weakness. It can also be caused because the person had a poor posture before the brain injury.

If posture is abnormal or poor, you can help by asking the person to concentrate on what he feels, reminding him to visually check how he’s sitting, or standing, or by physically helping him into the correct posture.
Balance

Our brain and nervous system is always making adjustments so that we keep our balance. If the ability to balance is affected after a brain injury, the person may react too fast, too slow, or not at all. To improve balance, therapy may involve practicing in different situations (for example, walking on different surfaces like carpets, tile, rough concrete, and snow).

Endurance

Endurance is the strength one has over time. It can be measured how well the person tolerates a treatment or an increase in the treatment (for example, first make him walk further then make him walk faster).

Please talk to your healthcare provider, such as a physiotherapist or occupational therapist, for tips on how to help someone who has physical changes after a brain injury.

Resources

To learn more about changes in balance after brain injury, go to: www.msktc.org/tbi/factsheets/Balance-Problems-After-Traumatic-Brain-Injury
Swallowing Changes after a Brain Injury

Trouble swallowing or moving food from the mouth to the stomach is called dysphagia. Dysphagia can put the person at risk of choking or having food go into the lungs (aspiration) instead of the stomach. Besides being very uncomfortable, aspiration can cause pneumonia and can be life-threatening. Symptoms of dysphagia can include:

- choking, gagging, coughing
- trouble chewing
- food spilling out of the mouth or coming through the nose
- sneezing a lot while eating
- eyes water when eating
- gurgling and/or having a strained voice after swallowing
- feeling like food is stuck in the throat after swallowing
- a congested chest, a lot of mucous
- hurts to swallow

The brainstem and the frontal lobe coordinate swallowing. The brainstem sends messages to and from the mouth, tongue, and throat. The brain’s frontal lobes control the muscle action of the mouth, tongue, and throat.

There are factors that can affect how a brain injury affects swallowing. These could be physical (trouble with muscles), related to the position of the body, or can related to problems with thinking skills. Anyone of these areas can affect the ability to swallow properly and safely.

Swallowing can be affected by one or more of the following:

- poor head or upper body control
- less lip, tongue, and throat strength, range of motion, and coordination
- trouble concentrating on eating
- impulsive behaviour when eating (for example, takes bites that are too big)
- can’t follow proper techniques when swallowing either because he forgets what he’s been told or that his brain has trouble remembering how to finish the movement for a safe swallow (apraxia)
A person who has trouble swallowing may need to get his nutrition through a nasogastric (NG) or gastrostomy tube (G-tube). An NG tube is a feeding tube that goes up the nose and down to the stomach. A G-tube is a feeding tube that goes to the stomach.

Just because he has a feeding tube doesn’t always mean he can’t eat by mouth. The tube just makes sure that he gets the proper nutrition and fluids until he can eat and drink well enough on his own, if this is possible. How long that takes is different for everyone.

Exercises, treatments, and positioning may help improve how well a person can chew and swallow. A speech-language pathologist will teach him and his caregivers how to do these exercises and techniques. It’s important to only follow the exercises or treatments you are shown. As a caregiver, your support and help with the swallowing program are important. Many people do get back their ability to swallow after brain injury.

Please talk to your healthcare provider, such as a speech language pathologist or dietitian, for tips on how to help with swallowing problems and helping the person meet his nutritional needs.

Resources

To learn more about swallowing safety, go to:  
www.brainline.org/content/2010/08/swallow-safely_pageall.html
Bowel and Bladder Changes after a Brain Injury

Brain injury may affect bowel and/or bladder function. After a brain injury, the person may need help re-establishing and maintaining regular bowel movements and/or emptying the bladder.

Managing the bowel

The goals of bowel management include creating a regular emptying pattern, not leaking stool (incontinence), and managing diarrhea or constipation.

Constipation can be caused by less physical activity, not eating or drinking enough, and confused nerve messages to and from the bowel.

Bowel problems can happen if the person with the brain injury can’t:

- recognize that his bowels are full and he needs to have a bowel movement
- plan ahead to give himself enough time to get to the bathroom
- control his bowel movements
- ask for help to get to the bathroom
- walk to the bathroom
- eat enough food with fibre and drink enough fluids
- eat enough food with fibre and drink enough fluids

For a healthy bowel function, he should eat at regular times, eat foods high in fibre, drink the amount of fluids recommended by the dietitian or doctor, and be as active as possible.

He may be asked to follow a bowel care schedule, which includes trying to have a bowel movement at the same time every day and eating at regular times.

At certain stages of recovery, he may need to use other methods for bowel emptying (fibre supplements, stool softeners, suppositories, and/or laxatives). These methods aren’t used regularly because it makes it harder for the bowel to regulate itself. Some of these methods may also be habit-forming.

Most people with a brain injury don’t end up with a permanent problem managing their bowels.
Managing the bladder

The goal of managing the bladder is to keep the kidneys healthy. Some of the reasons for bladder problems after a brain injury are because of the damage to the parts of the brain that control behaviour and memory.

The person with a brain injury may have a problem with emptying his bladder while his brain is healing. Managing the bladder is an important way to prevent bladder infections.

Damage to these areas may mean the person can’t:
- recognize that his bladder is full
- remember when he last passed urine
- control passing urine
- ask for help
- plan ahead to get to the bathroom
- walk to the bathroom in time

Early in the care of someone with brain injury, the bladder may be drained through a catheter (a tube that is inserted and left in the bladder). The urine empties through the catheter into a drainage bag, which also allows the urine output to be measured. The catheter is usually taken out as the person gets better.

Problems that were there before the injury (for example, an enlarged prostate in men) may add to bladder problems after a brain injury.

Problems with managing the bladder may include:
- not being able to pass urine
- leaking urine (incontinence)
- strong urge to pass urine
- passing urine more often
- not emptying the bladder completely
- skin problems because the urine touches the skin for too long

If the person can’t sense the need to empty his bladder, other ways to manage the bladder are:
- keeping the catheter in the bladder
- inserting and removing a catheter at set times so that the bladder is emptied regularly (intermittent catheterization)
- scheduling attempts to pass urine
- using an external condom catheter for men
- using an adult diaper

To keep the kidneys healthy, the person with a brain injury should drink fluids as recommended by the dietitian or doctor.
It may help to meet with your nurse or doctor to create a plan to manage the bladder. Most people with brain injury don’t end up with a permanent problem managing their bladder.
Weight Changes after a Brain Injury

Some people may lose weight after a brain injury because:

- the type and texture of food they’re allowed to have may be less appetizing, especially if they have trouble swallowing
- they’ve lost some or all of their ability to smell so food doesn’t taste the same

Some people may gain weight after brain injury because:

- there can be changes in the messages the brain gets about feeling full
- a side effect of medicine they take may cause weight gain

The body needs more calories to heal after a brain injury. The dietitian makes sure that the person is getting the calories and other nutrients needed during recovery.

Small meals eaten often (and high in calories and protein) are recommended if losing weight is a problem. If the person starts gaining too much weight, a lower calorie diet may be needed.

Once he has a better appetite, he may go through a period when he eats all the time. He may lose the ability to feel full or may feel hungry even though he just ate.

If the control centre of the brain (the hypothalamus) was damaged, he may have less control over his actions and emotions. This often gets better over time.

Please talk to your healthcare provider for ways to manage changes in weight.

Resources

For information on Canada’s Food Guide to healthy eating, go to: http://hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php

For useful tools to help improve nutrition, go to: www.dietitians.ca/Your-Health.aspx
Skin Changes after a Brain Injury

A brain injury can cause changes to hormones (for example, cause the oil glands in the skin to overwork). Sometimes medicine he takes can cause skin changes. These may cause acne on the face, back, and chest. Washing with a mild soap and water is important. If needed, antibiotics or other medicated skin lotion may be prescribed.

Because of the loss of sensation that often happens with a brain injury, check his skin regularly for scrapes, red areas, and sores.

It’s important to check the back of the head, buttocks (bum cheeks), tailbone, knees, ankles, elbows, and anywhere there is a bone that doesn’t have a pad of muscle or fat to protect it.

Talk to you healthcare provider if you have questions about any skin changes you see.
Using Alcohol and Drugs after a Brain Injury

A brain injury can affect how people think and manage emotions. If a person with brain injury drinks too much alcohol, uses illegal drugs, or takes more medicine than prescribed, it can damage the cells and nerves in the brain, making the effects of the brain injury become worse.

Tips for family members:
• Take the substance abuse seriously—it’s not a phase.
• Support him to lead an alcohol- and drug-free lifestyle.
• Help him find ways to cope with things that had him abuse alcohol or drugs before the brain injury.
• Practice ways he can avoid these situations.

A rehabilitation psychologist, social worker, or addictions counsellor can help to decide if a drug or alcohol problem exists. There are alcohol and other drug treatment programs that can help. Talk to any rehabilitation team member or doctor if you have concerns.

Alcohol and drugs can trigger seizures and affect:
• alertness and concentration
• judgement
• self-awareness
• perception
• memory and learning
• emotions
• reasoning, planning, and problem-solving
• speech and language
• motor control
• social interactions or social behaviour
• motivation

Resources

To learn more about using alcohol after a brain injury, go to:
www.msktc.org/tbi/factsheets/Alcohol-Use-After-Traumatic-Brain-Injury

If you are concerned about drug or alcohol abuse, call the 24-Hour Help Line at 1-866-332-2322 or go to www.albertahealthservices.ca/addiction.asp
Seizures after a Brain Injury

Sometimes a person with a brain injury will go on to have seizures. We don’t always know who will develop post-traumatic epilepsy (PTE) after a brain injury. We do know that the risk goes up the worse the head injury. You can develop the PTE even years after the head injury.

There are many types of seizures. Some of the actions/behaviours you may see during a seizure include one or more of the following:

- the eyes may be open and/or roll back
- may lose bowel and/or bladder control
- may pat a part of his body or pick at his clothes while looking like he’s daydreaming
- jaws and hands may become clenched
- may jerk involuntarily or shake one of his body parts; this jerking or shaking may spread to other body parts and become

- He’s not usually aware of any activity during the seizure.
- If his breathing sounds like he’s snoring, it means that the seizure is almost over.
- When the seizure is over, he may be confused, his speech may be slurred, he may feel sleepy, or may say he has a headache

Keep a diary of all seizures. Write down the date, time of day, what he was doing before, during, and after the seizure, and how long the seizure lasted. This information can help the doctor who’s treating him for his seizures.

**Medicine to control seizures (anti-convulsants)**

Medicine is the main way to stop, reduce, or control seizures. Blood work has to be done for some of the medicines used to check the level in the body. All medicine can have side effects; it’s important to know what they are. The benefits of taking the medicine are weighed against the risk of not taking the medicine.

Ask your nurse, doctor, or pharmacist for more information on how to safely take anti-convulsant medicine.

**Resources**

To learn more about seizures after brain injury, go to:
www.msktc.org/tbi/factsheets/Seizures-After-Traumatic-Brain-Injury

To learn how to help during a seizure, go to:
https://myhealth.alberta.ca/health/pages/conditions.aspx?hwId=ty7150spec
Fatigue after a Brain Injury

Fatigue is the feeling of being very tired or having no energy. It’s common in people recovering from a brain injury. It can also last a very long time.

Fatigue may be caused by the injury, or from the extra physical and mental effort needed to do tasks that once were done with little or no effort.

How long one can do something physically, attention, concentration, memory, and communication can all be affected when someone is tired.

He will tire easily. He may sleep more and/or take naps during the day. He may have headaches or be irritable—these can all be caused by fatigue.

Too much activity or no longer being able to block out sights, sounds, or movements can also cause fatigue.

He may feel embarrassed and say that he’s not tired. The trouble is that he may then push himself to the point where he’s over-tired, which could slow his recovery.

When a person with a brain injury goes home for the first time, it can be hard to know how much he can or should do. Often during this transition, he and his family may become discouraged how slow the recovery seems to be going, changes in responsibilities, or they may try to do or expect too much.

This is just one step in the recovery process. In time, his energy level likely will improve, and he’ll be able to do more activities and for longer.

To help someone with fatigue

Rest and sleep

- A regular day/night routine is important.
- Set a schedule for regular rest breaks or naps. Make sure the room is quiet and there are no distractions. This includes turning the TV or radio off as this is just more information for the brain to process.
- Rest breaks or naps shouldn’t be longer than 1 hour. Try not to let him nap in the evening.
- Schedule a nap before visitors come or before going out.
**Tasks**

- Start with tasks you know he can do without becoming too tired.
- Encourage breaks, even as often as every 5 minutes during tasks, before, or as soon as he shows signs that he’s tired.
- Watch for signs of fatigue, such as not paying as much attention or not concentrating as well, repeating tasks or comments, becoming irritable, or making more mistakes.
- Gradually increase how hard the task is, making sure he takes breaks as needed.
- Slowly make the breaks shorter and fewer as he is able to tolerate activities better.

**Activities and visitors**

- Important activities should be done when he’s feeling best, often in the morning. If an activity is planned for later in the day, he may need to rest first.
- Limit his with visitors or make sure he has a rest break during visits.
- Plan ahead for activities that you know will tire him, such as visitors, trips, or going out.
- Resume activities gradually, over weeks or even months. Ask your healthcare provider for ways to do this.
- Write things/appointments, etc. in a smart phone, calendar, or planner.
- If the healthcare team recommends, use assistive aids (for example, a cane or a wheeled walker).

**Resources**

To learn more about fatigue after a brain injury, go to:  
[www.msktc.org/tbi/factsheets/Fatigue-And-Traumatic-Brain-Injury](http://www.msktc.org/tbi/factsheets/Fatigue-And-Traumatic-Brain-Injury)
Headaches after a Brain Injury

It’s important to find out the type of headache pain, where it is, and how often the he has it before treating it. It’s normal to have headaches after a bad head injury because of the injury itself.

Headaches can also happen after a brain injury after the first healing has taken place. There are many reasons for these headaches:

- a change in the brain caused by the injury, or neck and skull injuries aren’t fully healed
- tension and stress
- fatigue
- side effects of medicine

Make sure the brain injury team is told if he’s having headaches. If you can, also tell them how often, what you think the triggers may be, and if anything (like taking a pain medicine) helps relieve them.

Resources

To learn more about headaches after brain injury, go to:
www.msktc.org/tbi/factsheets/Headaches-After-Traumatic-Brain-Injury

For an example of a headache diary go to:
https://myhealth.alberta.ca/health/_layouts/healthwise/media/pdf/hw/form_aa164142.pdf
Social and Emotional Changes after a Brain Injury

Behaviour and personality

Sometimes, personality traits may become exaggerated or more intense after a brain injury. For example, the quiet person may become even quieter; the assertive, active person may become aggressive and even more outspoken. The opposite can happen too, where a normally quiet person becomes very outgoing or outspoken.

Brain injury can cause the person to have poor emotional control. This can be seen by mood swings that often don’t seem to be related to what’s happening. There may be strong emotional outbursts triggered by minor frustrations. Or he may seem demanding, self-centred, irritable, or impatient. Even a person with a mild brain injury can be irritable and impatient while his brain heals. Finally, a person with a brain injury may lose interest in hobbies or activities he used to enjoy.

Mood swings and managing anger

Being irritable and having trouble controlling anger are common personality changes seen in a person after a brain injury. There are several reasons for this. It could be due to the areas of the brain that were damaged.

He will often get frustrated very easily. Where he may have been able to keep quiet in a situation before the injury, he may now have trouble doing so. He may blurt out angry words before he knows it or before he is able to stop himself from saying hurtful things.

Sometimes a person is irritable after a brain injury because he’s frustrated because he can’t do things as easily as he could before the injury.

As a result, he may become angry over things that don’t seem like a big deal to us. Like anyone else, the person with a brain injury may direct the anger he feels towards himself or those who are closest to him. Don’t take it personally.

Don’t blame him for his short temper or to tell him that if he only tried harder he could control his temper.
**Strategies that can help to manage mood swings and angry outbursts**

- Stay calm when he’s having an outburst.
- After he calms down, ask him to write down what happened to make him angry, what he thought and did when he was angry, and what happened after he was angry. In this way he will have a record of what happened. He can then look back at his written notes, alone or with someone else and see more clearly what is happening and what can be done about it.
- Respond right away to ideas that aren’t appropriate and stay focused on the original topic.
- Suggest other ways he could behave. Praise and reward the behaviour you want to see.
- Have him take a “time-out” when he starts to get angry or frustrated. When he starts to feel like he might be getting angry, he can say “I am beginning to feel angry and I would like to take a time-out.” He can then go for a walk or sit somewhere quiet until he isn’t as angry or frustrated.
- Listen to him and let him know you want to understand what he’s feeling.

Family and friends need to be told ahead of time that the he may need to take a time-out to help prevent anger outbursts. Time-out is not a sign of weakness, nor is he trying to run away from his problems. Time-out is a way of preventing angry outbursts. When he’s calm, the problem that made him angry can then be dealt with more reasonably.

Other ways of reducing chances of anger outbursts include:
- making sure he gets enough sleep
- avoiding drinks with caffeine or alcohol
- telling yourself that “this isn’t the end of the world” or “it’s not worth fighting about”
- identifying situations that seem to lead to anger and calmly change or avoid them

**Depression**

Feelings of sadness, frustration, and loss are common after a brain injury. These feelings are often seen during the later stages of recovery, when confusion decreases and self-awareness improves. However, if these feelings become too much or affect recovery, he may become depressed.

Depression can happen while the person tries to adjust to a temporary or lasting disability caused by a brain injury. It can also happen if the injury was to parts of the brain that control emotions (changes in the brains structure or chemistry).
Being depressed is not a sign of weakness, and it’s not anyone’s fault. Depression is an illness. Depression doesn’t go away just because you want it to, or if you use more willpower, or “toughen up”. Fortunately, medicine and other therapies can help most people with depression.

These can be symptoms of depression:
- a feeling of sadness that doesn’t go away
- irritable, anxious, moody, or big mood swings
- not interested in things anymore or don’t feel pleasure
- eat or sleep more or less
- feel tired, no energy, no motivation
- feel helpless, worthless, or hopeless
- physical symptoms such as headaches or chronic pain that don’t get better
- want to be by yourself
- thoughts of death or suicide

If the person with brain injury has symptoms of depression, please let his healthcare provider know. There are very good treatments that can help.

If he says he wants to die or says he’s going to hurt himself, call 9-1-1!

**Lowered self-esteem**

How a person sees himself (self-esteem) is often affected by a brain injury. The more aware the person with a brain injury is, the more likely there will be changes in how he sees himself.

Don’t label, categorize, or stereotype a behaviour or communication skill that was changed by the injury. Learning as much as possible about brain injuries and being patient and kind are good steps toward understanding and helping raise the self-esteem of someone with a brain injury.

**Tips to help with lowered self-esteem**

- Focus on the positives—don’t criticize.
- Re-direct conversation to positive or neutral thoughts.
- Let him express his feelings. Give caring, realistic feedback.
- Tell him you are concerned and want to try to understand what he’s feeling.
- Point out his successes, even partial successes.
- Let him be as independent as possible.
- Help him plan ahead to help him be as successful as possible.
- Choose activities and tasks that he can do well.
Social Situations

A person with a brain injury may find it hard to be in social situations. He may act impulsively, such as speaking out without thinking about the consequences. He may not always be sensitive to social boundaries or his behaviour may not be the right one for the situation. He may act out of place in social or public settings he’s not familiar with.

Tips to help with socializing

What to do before an event

• Tell him what behaviour is expected in that social setting or things such as a job interview, a funeral, or in church.
• Plan and practise social interactions so that he will be familiar, predictable, and consistent.
• Decide on a signal (like a word or movement) that will cue him to stop and think.

What to do during the event

• Have him slow down and think about how he’ll respond.
• Have him thing about the result the behaviour will have.
• Give positive feedback for correct behaviour.
• Take a break if you see him getting frustrated or tired.
• If undesired behaviour happens, calmly address the behaviour in private. Be objective and explain that it’s the behaviour that isn’t appropriate, not him.
• Reassure him and make sure your expectations are realistic.

What to do after the event

• Go over the behaviour, how well the cues work, and the overall success of the outing.
• Make sure he knows what behaviour, responses to cues, and redirection was appropriate.

Effects due to stress

The stress caused by the physical and changes in thinking after a brain injury can often lead to emotional problems. If he has problems with his memory or can’t control his emotions well, he may feel that he’s losing his mind, instead of telling himself that that these changes are because of his brain injury. He may react by becoming depressed, anxious, or frustrated. Out of fear or confusion, he may deny that he has any problems and the result they may have.
Some people feel angry about their condition and take their anger out on their family. Others may give up hope and become depressed and withdrawn. The way a person adapts to his disabilities depends on the injury, what his personality was like before the injury, and the attitude of family and friends. Adjusting to the changes created by a serious brain injury can take many years.

**Tips to help manage stress**

- Encourage the person with the brain injury, their family, and close friends talk about their fears and concerns.
- Help him set realistic goals.
- Keep up hope for continued recovery.
- Find out if there are programs that may help you cope.

**Resources**

To learn more about depression after a brain injury, go to: [www.msktc.org/tbi/factsheets/Depression-After-Traumatic-Brain-Injury](http://www.msktc.org/tbi/factsheets/Depression-After-Traumatic-Brain-Injury)

To learn more about behaviour after a brain injury, go to: [www.brainline.org/landing_pages/categories/behavioralsymptoms_results.php?types=article](http://www.brainline.org/landing_pages/categories/behavioralsymptoms_results.php?types=article)
Recreation and Leisure Changes after Brain Injury

Leisure activities are a very important part of recovery for anyone with a brain injury. They are great ways of letting go of stress, learning skills, enjoying life more, and feeling satisfied. Leisure activities can range from light fun to more serious activities that add meaning and quality to life.

The focus of recreation therapy is help the person become as independent as possible when doing leisure activities and to help him ease back into his community.

The goal of recreation therapy is to help the person develop skills, knowledge, and to find resources that will allow him to take part in activities that add quality and meaning to his life.

A brain injury may result in some lifestyle changes. Below are some of the issues that may be seen:

- He may suddenly have a lot of free time; especially if he can’t go back to work or become the activities he did before the injury.
- He may lose interest, motivation, or the ability to think about a leisure activity to do. Remind him that leisure activities are an important part of recovery.
- He may have poorer social skills or not be able to do leisure activities because of a physical problem or may have trouble communicating.
- He may have trouble things such as attention, concentration, planning, and problem-solving.
- There may not be many recreational resources around (like a recreation centre, programs, or adaptive equipment) where he lives.

Increasing leisure activities

- Encourage him to take part in both hospital and out-of-hospital recreational activities (families and friends are always welcome).
- Let him try new things and decide what he’d like to do. Give him two or three ideas—too many can be confusing and frustrating. (The recreation therapist can give ideas and give more information on recreation activities.)
• Help him plan recreational activities on weekends and passes. If he needs it, break things down into steps so that they are easier to understand. Try to get him to do as many of the steps as he can.
• Be patient and understanding. A person who suddenly can’t do the things he used to may find it hard to start doing them again, or to try new ones.
• Make sure he has things such as puzzles, books, pictures, and a radio/music player, both in the hospital and at home.
• Be a role model – do the activities with him.

Resources

For a guide to explore leisure as part of recovery, go to: https://patienteducation.osumc.edu/Documents/leisure-recovery.pdf
Life after a Brain Injury

The best time to start planning for discharge is just after the person is admitted to the hospital. This may seem too soon to think about going home, but planning early gives you more time to prepare. The healthcare team may not know yet how long he is likely to be in the hospital. When he does leave the hospital, he might be discharged:

- home, with no needed services
- home, with help from a family caregiver
- home, with help from home care
- a rehabilitation setting for longer term rehabilitation
- a supportive living environment such as a personal care home, assisted living, or long term care

Many people with a brain injury will need outpatient rehabilitation services once they leave the hospital.

Going home

The process of rehabilitation begins in the hospital and continues at home.

Outpatient therapy usually lasts much longer than inpatient therapy. Members of the healthcare team develop rehabilitation goals that will help him function to the best of his ability and become as independent as possible.

Having realistic goals and expectations for yourself as a caregiver is important throughout the recovery process. The rehabilitation team is there to answer your questions and to support you as everyone adjusts to life at home.

Tell the team that you are the family caregiver. Meet with the social worker as soon as you can to talk about discharge. This is a good time to talk about:

- how much time you can spend being a family caregiver
- whether you will provide all or some of the needed care
- whether you can keep working or have to take time off
- whether you have any health problems or issues, such as not being able to lift
- whether you have other commitments, such as caring for young children
- all your other questions and concerns about being a family caregiver
Resources

For a copy of the Alberta Brain Injury Survival Guide:

To learn more about becoming a family caregiver, go to: www.nextstepincare.org
Caring for the Caregiver after a Brain Injury

Along with the physical care a person with a brain injury may need, he may also need companionship and emotional support. Because caregivers also may have many other responsibilities, like working outside the home and caring for children, being a caregiver can be overwhelming and challenging. There are groups and programs (such as home health care or respite care) that support caregivers.

Suggestions for the caregiver

- Ask for help when you need it. Sometimes, caregivers try to handle everything on their own. Don’t be afraid to ask for help.
- Set limits. There are only so many hours in the day and only so many things you can do. Some things can wait.
- Take time for yourself. Taking an hour, a day, a weekend, or a week away can do wonders!
- Stay in touch with friends and family.
- Learn relaxation techniques such as breathing exercises, meditation, or progressive muscle relaxation.
- Take care of yourself. Caregivers are at risk of illnesses related to stress. If you’re concerned about your health, talk with your doctor.
- Take time for exercise. Exercise relaxes you, improves your mood, keeps your body strong, and makes you feel better about yourself. These are reasons enough to make exercise a part of your limited time.
- Join a support group. Support groups are a great way to share problems and concerns. People with understand what you are feeling.
- Keep your sense of humour. Laughter is a great stress reducer!

Resources

To learn more about taking care of yourself as a caregiver, visit:
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=847

To learn about coping strategies, visit:
www.brainline.org/content/2009/09/caregiver-coping-strategies.html
Intimacy and Sexuality after a Brain Injury

Love, affection, and sexual feelings are healthy human desires. If these desires aren’t understood or expressed, it’s normal to feel confused or uncertain. Sexuality is how males and females express their identities through sexual actions, attitudes, and behaviour in relationships. From childhood on, we become aware of sexual differences. We are taught both directly and indirectly how to behave with the opposite sex.

Most people have trouble talking about sex. The person closest to the person with the injury is usually best one to help him re-learn how to express sexual feelings properly. This is when you may want support and ideas to help address sexual issues.

The goals of rehabilitation include helping the person be as independent as the brain injury allows, and healthy personal relationships. Being able to develop and maintain social relationships may be the most important measure of a successful rehabilitation. Therefore, recognizing and talking about concerns about love and sex are important.

Acceptance and trust are very important for intimacy and in a sexual relationship. If his personality has changed, you may have to get to know him again. As well, if there are also physical changes, both of you will have to adjust to these changes.

Sometimes a brain injury causes the person to forget how to properly express these learned behaviours. For example, the adult with a brain injury may not understand when it’s the right time to kiss, hug, or touch you or other people.

A person with brain injury may not be able to recognize sexual cues anymore. He may lose interest in sex, be less able to fantasize, or lose the ability to be sensitive to his partner’s needs. It’s unusual for there to be a physical reason for sexual problems after a brain injury (such as not being able to have or keep an erection or to have an orgasm).

If the person with the injury is now more dependent, his partner may have to take the the lead in the sexual relationship. It’s okay to give the person with the brain injury directions and cues.

Touching, caressing, cuddling, and resting together can help you feel close. Hospitals don’t give you much privacy, but you can ask for private time in the hospital room or ask for a day or weekend pass.
Talk about your feelings with a member of the rehabilitation team or someone you trust. Although you may not feel comfortable talking about sexual matters, the rehabilitation team members are used to dealing with these issues and understand your feelings.

Social workers, rehabilitation nurses, and rehabilitation psychologists can also support you.

**Resources**

To learn more about sexuality and brain injury, go to:  

To learn more about relationships and brain injury, go to:  
Going Back to Work after a Brain Injury

Going back to work depends on the person and the brain injury. A brain injury can cause many changes in behaviour, emotions, communication, and thinking skills.

It may be hard for him to do the job he did before the injury. Even if he can’t work after the injury, there will be other things he can do to keep busy and feel fulfilled. This might be the time for him to volunteer or find new hobbies or activities.

Work is a big part of most people’s lives. Work makes us feel like we’re doing something positive, it makes us feel responsible, it gives us financial independence, it lets us interact with others, and it gives us structure. People who are able to work after brain injury are usually healthier and feel better about themselves than those who don’t.

Some agencies or outpatient rehabilitation programs can help people with a brain injury reach the goals they need so they can go back to work. This may include re-training or learning a new job, help with assistive devices, and finding a job. They work with the rehabilitation team to learn what the best fit is for the person.

Going back to work after a brain injury can be challenging and rewarding. You have to look at the person’s interests, skills, and finances. The rehabilitation team works with the person to help him regain or develop job skills.

Talk to a health professional such as a physiatrist or occupational therapist to learn more about going back to work.

Resources

To learn more about going back to work after a brain injury, go to Chapter 10 of the Alberta Brain Injury Initiative Survival Guide:

Going Back to School after a Brain Injury

School is important for social and educational growth. Along with learning, people find friends, support, and learn social skills. Sometimes the effects of a brain injury aren’t seen at first but become more noticeable later, when thinking and social demands increase at school.

Most colleges have an office for students with disabilities. Schools can help by:

- giving extra time for tests for slower thinking or information processing
- giving tests privately and in a quiet environment if you have trouble paying attention or concentrating
- putting you in classrooms with less noise and distractions
- voice recording lectures if you have trouble paying attention, concentrating, or problems with memory
- letting you review the teacher’s or a classmates notes if you have trouble listening and taking notes at the same time
- writing down assignments for problems with memory and concentration
- having a place where you can take a break or rest if you get too tired or start feeling frustrated
- offering tutoring

In many cases, parents and family members become advocates to assure you get the services you need to be successful at school.

Parents and family also serve as go-betweens to make sure that rehabilitation providers and school personnel meet to develop a plan for a successful return to school. Members of the brain rehabilitation team can help by letting you know about resources the school system or healthcare services offer.

Talk to your physiatrist, speech therapist, or occupational therapist for more information about going to school.

Resources

To learn more about going back to school after brain injury, go to:
www.msktc.org/tbi/factsheets/Returning-To-School-After-Traumatic-Brain-Injury
Driving after a Brain Injury

Driving can be affected by a brain injury in many ways. After a brain injury you may be left with issues that make driving unsafe, such as problems with attention, concentration, visual scanning, making fast decisions, and/or quick reaction times.

By law, a person with a medical condition that could affect his ability to drive must be reported to the Driver Fitness and Monitoring Branch of the Alberta Government or any registry office. Your healthcare team will be able to tell you if your condition should be reported. In some cases, the healthcare team may submit a report for you.

When reporting a disability, you must have a Medical Examination for Motor Vehicle Operators form filled out by a doctor. The Alberta Registry may suspend your driver’s license or put it on a medical hold. You’ll get your license back when it’s felt that you’re medically ready to start driving again.

Your doctor may refer you for a pre-driving assessment by an occupational therapist. If you are referred, you will be asked to have your vision tested to make sure that you meet the visual standards for driving in Alberta. If you do meet standards, you will take the first part of the pre-driving assessment in a clinic setting, not on the road. The pre-testing could include:
- a brief physical review to make sure you are physically able to drive
- an assessment to see if you need any equipment modifications in the car (for example a left-sided gas foot pedal)
- testing to see how you think, problem-solve, and if you can think ahead
- testing your reaction time

Your doctor will get a report of the results. The Driver Fitness and Monitoring Branch will decide if you are ready to start driving, if you need driving aides, or if you need to do another road test.

You may need to give more medical information in the form of a report to Driver Fitness and Monitoring. Talk with a healthcare provider such as a physiatrist, family doctor, or occupational therapist if you have questions about being able to drive again.

Resources

To learn more about medical conditions that may affect safe driving, go to: www.transportation.alberta.ca/2560.htm

To learn more about the Alberta Driver Fitness and Monitoring Branch, go to: www.transportation.alberta.ca/542.htm
Leaving the Hospital after a Brain Injury (Discharge Planning)

Discharge Checklist

<table>
<thead>
<tr>
<th>While in the hospital I know:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ my planned date of discharge</td>
</tr>
<tr>
<td>☐ if I need help when I get back home</td>
</tr>
<tr>
<td>☐ if I need my doctor to sign a “time off work” letter</td>
</tr>
<tr>
<td>☐ who will drop off the insurance papers at the doctor’s office</td>
</tr>
<tr>
<td>☐ if I need equipment (e.g., bath stool) before I go home and who will set this up</td>
</tr>
<tr>
<td>☐ If I need a home exercise program from my therapist(s)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A few days before discharge I know:</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ my diagnosis</td>
</tr>
<tr>
<td>☐ if I need to see my family doctor after I’m home</td>
</tr>
<tr>
<td>☐ if I need prescriptions</td>
</tr>
<tr>
<td>☐ If I re-start the medicine (including supplements) I was taking before my brain injury</td>
</tr>
<tr>
<td>☐ the reason for any change in the medicine I take</td>
</tr>
<tr>
<td>☐ if I need a follow-up appointment and who will call me</td>
</tr>
<tr>
<td>☐ who to call if I have questions once I’m home</td>
</tr>
<tr>
<td>☐ if or when I can drive</td>
</tr>
<tr>
<td>☐ if I drink alcohol or use recreational drugs</td>
</tr>
<tr>
<td>☐ if I need a home exercise program from my therapist(s)</td>
</tr>
<tr>
<td>☐ if there’s anything I shouldn’t do when I get home (restrictions)</td>
</tr>
<tr>
<td>☐ what my discharge teaching sheet says because the nurse went over it with me</td>
</tr>
</tbody>
</table>
Getting Ready for a Successful Discharge

No one may know the exact date early on. You and your team will know more as you recover. Your therapists will assess your progress while you are in therapy.

Your nurses, therapists, and doctors will start talking about your discharge almost from the day you arrive. That is because everything we do is to get you ready to return to your life before your injury.

You may go home, or to another site for more rehab, or you may stay in the hospital until you can be moved to long-term care.

Wherever you end up, your rehabilitation team makes sure you and your family know what has to be done so that you can keep working toward your goals after your discharge.

For many of you, your rehab will continue as an outpatient. How often and how long your outpatient rehab is will depend on many things (like where you are in your recovery to date and your needs).

- Will you feel 100% ready when it is time to go? Maybe not.
- Will you have some worries and self-doubt? Probably.
- Will it be hard giving up the security of a call bell and medical team on hand? Maybe.
- Will there be some inconveniences? Very likely.
- Will your family feel somewhat uncertain about how all of you will cope once you leave the hospital? Maybe.

Resources

To learn more about planning for discharge, see:

- “Home-to-Hospital Discharge Guide” or “Rehab-to-Home Discharge Guide”, Next Step in Care: www.nextstepincare.org
Resources and References

The Calgary Brain Injury Program at www.albertahealthservices.ca/cbi.asp has links to resources in Alberta, and across Canada.

Along with the Calgary Brain Injury Program, Alberta Health Services has links to community groups that offer support for people with brain injuries and their families.

References

Some sections were taken or adapted from:

- “Coping with the results of brain injury”, The Glenrose Rehabilitation Hospital, Alberta Health Services
- “Planning for inpatient rehabilitation services”, Next Step in Care, www.nextstepincare.org
- The Rancho Levels of Cognitive Functioning, Rancho Los Amigos National Rehabilitation Center www.rancho.org
- “Understanding brain injury: A guide for the family”, Mayo Foundation for Medical Education and Research

This passport was created by the Patient and Family Education working group of the Calgary Brain Injury Strategy and the Calgary Brain Injury Program.

We would like to extend a very special thank you to the survivors, family members and care providers who inspired and helped to put this passport together.