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# ***GUIDE***

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## **BRAIN INJURY CAREGIVER**

### **Coping with brain injury** **A guide for caregivers and family**



The Ottawa Hospital | L'Hôpital  
d'Ottawa



***Disclaimer***

*This is general information developed by The Ottawa Hospital. It is not intended to replace the advice of a qualified health-care provider. Please consult your own personal doctor who will be able to determine if this information is appropriate for your specific situation.*

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# Section 1

## A guide for caregivers

### Caregiver: Is this me?

Yes. If you help take care of a person with a brain injury, you are a caregiver. Caregivers include professionals like nurses but they can also be family and friends who are there to help the person with the brain injury.

Adjustment to this role may be difficult for you and for the rest of your family.

The person's brain injury can affect the rest of the family too.

It may influence your relationships and cause everyone to feel stressed.

This booklet is designed to help you deal with your role as a caregiver. It can also help other family members to adjust.

Remember: It is normal to have trouble adjusting to these changes, especially if the concept of a brain injury is new to you.

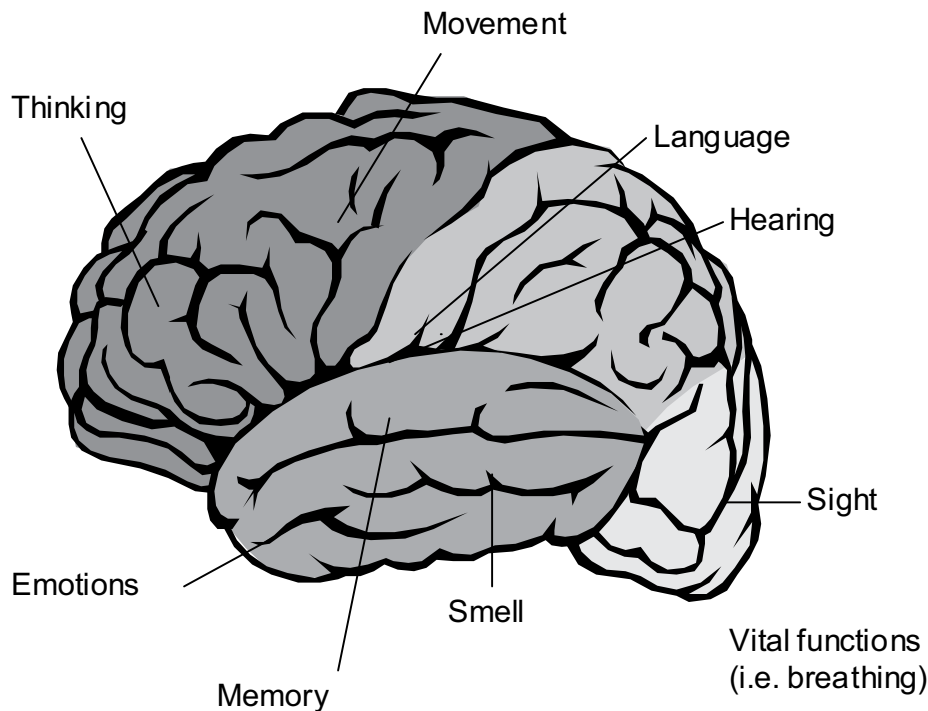
It includes important information about:

- Brain injuries
- What to expect
- Who to call for help
- Coping strategies
- Community Resources
- Things to remember

# The brain

The brain is a very complex part of the body.

It controls how we think, feel and move. When our brain is not working properly, it affects everything we do. For example, it affects how we drive our car and whether we are feeling happy or sad.



Each area of the brain is responsible for a different function. Therefore, the location and severity of the injury will influence what symptoms the person will experience.

## **Types of brain injury**

Our brain influences almost everything we do. For this reason a brain injury can change many things about a person.

### **What is an acquired brain injury?**

An acquired brain injury is damage to the brain that happens after birth.

There are 2 main types of brain injury: “Traumatic” or “Non-traumatic”

- If the person’s injury is caused by an event like a car accident or fall, he/she has a traumatic brain injury.
- If the person has a medical problem that results in brain damage (i.e. stroke or brain tumour), he/she has a “non-traumatic” brain injury.

Both types of brain injuries can result in similar symptoms.

# What to expect after a brain injury

The person may experience many physical, thinking and personality changes after his/her injury.

Below is a list of some of the common problems and/or symptoms that you may notice in the person. These problems can occur at any time during the recovery period.

You may also want to read through the patient information package for more information on each symptom/concern.

Physical	Behavioural/Emotional	Cognitive
<ul style="list-style-type: none"><li>• Headache</li><li>• Fatigue/drowsiness</li><li>• Balance problems</li><li>• Dizziness</li><li>• More sensitive to pain</li><li>• Bladder/bowel control</li><li>• Sensory changes</li></ul>	<ul style="list-style-type: none"><li>• Irritability</li><li>• Emotional instability</li><li>• Sadness</li><li>• Anxiety</li><li>• Changes in patterns of sleep</li><li>• Restlessness</li><li>• Agitation/Aggression</li><li>• Impulsivity</li><li>• Denial</li><li>• Lack of motivation</li><li>• Changes in sex drive</li><li>• Lack of initiation</li></ul>	<ul style="list-style-type: none"><li>• Slowed thinking</li><li>• Difficulty concentrating/paying attention</li><li>• Memory problems</li><li>• Difficulty with communication (i.e. speaking, information processing)</li><li>• Difficulty thinking: (planning, organization, problem solving and making decisions)</li><li>• Decreased awareness of limitations</li></ul>



# Helping the person: symptom management

## **Self-awareness**

After a brain injury, people are likely to experience many changes. Though these changes may be obvious to you, the person may not see them at all. It is important to recognize this as it could affect your role in the recovery process. Sometimes your help will be unwanted. The person might find you are being intrusive and demeaning even though you want to help.

### **What is self-awareness?**

Self-awareness is the ability to understand your own strengths and weaknesses and recognize how they impact your daily functioning and interactions with others.

### **Lack of awareness vs. denial**

A disturbance of self-awareness is not the same as denying a problem for emotional reasons. It is a direct result of neurological injury. However, both disturbances of self-awareness and denial can exist together and affect a person's adjustment to their brain injury.

Symptom	How to recognize	What to do
<b>Decreased self-awareness</b>	<ul style="list-style-type: none"> <li>• Will not accept help from others</li> <li>• Insists he/she can do things on his/her own</li> <li>• Has unrealistic expectations</li> <li>• Does not follow the recommendations made by health care providers</li> <li>• Is not worried about new limitations</li> <li>• Blames others for his/her condition</li> <li>• May seem confused when a problem arises</li> </ul>	<ul style="list-style-type: none"> <li>• Allow failures. With safety in mind, let the person try some things on his/her own to help him/her become aware.</li> <li>• Help him/her set realistic goals.</li> <li>• Avoid confrontation.</li> <li>• Know your love one will likely have reduced tolerance for stress; think about how to reduce stressors before episodes happen.</li> <li>• Be informative. Try to educate yourself so that you can provide helpful feedback (i.e. be constructive).</li> </ul>

# Physical concerns

Several physical concerns may arise while providing care for the person; some common physical concerns include pain, fatigue, balance problems, dizziness, and/or sensory changes.

Symptom	How to recognize	What to do
<b>Pain</b>	<ul style="list-style-type: none"><li>• Complaint of pain</li><li>• Change in posture</li><li>• Avoiding specific activities</li><li>• Irritable</li><li>• Guarding</li></ul>	<ul style="list-style-type: none"><li>• Use heat or ice as directed.</li><li>• Suggest an activity to take his/her mind off of the pain. If pain persists, see the doctor.</li><li>• Help him/her to do daily tasks and take medications at the same time every day.</li></ul>
<b>Fatigue</b>	<ul style="list-style-type: none"><li>• Often complains about being tired</li><li>• Has little energy</li><li>• Irritable</li><li>• Slowed thinking</li><li>• Daytime drowsiness, headaches, more emotional, cranky, more forgetful, attention problems</li></ul>	<ul style="list-style-type: none"><li>• Suggest a nap or break from activities.</li><li>• Help create a sleep schedule.</li><li>• Try to limit family/social demands.</li><li>• Allow for a specific rest period during the day.</li><li>• Help schedule appointments when most alert.</li></ul>
<b>Headache pain</b>	<ul style="list-style-type: none"><li>• Headache, stress, irritable, cranky</li><li>• Complaint of pain</li></ul>	<ul style="list-style-type: none"><li>• Encourage relaxation. Suggest a dark, quiet place for rest/sleep.</li><li>• Avoid possible triggers/things that make it worst including sunlight, alcohol and certain foods like chocolate.</li><li>• Try to keep track of headaches and share this information with the doctor.</li></ul>

Symptom	How to recognize	What to do
<b>Balance problems</b>	<ul style="list-style-type: none"> <li>• Is unsteady when walking</li> <li>• Needs help to walk or sit</li> <li>• Tends to fall</li> <li>• Uses furniture, walls, etc. for support when walking</li> <li>• Bumping into furniture</li> </ul>	<ul style="list-style-type: none"> <li>• Adjust your home (i.e. remove rugs).</li> <li>• Arrange to have someone there to help prevent falls.</li> <li>• Encourage use of aids (i.e. a cane).</li> <li>• Contact a physical therapist.</li> </ul>
<b>Dizziness</b>	<ul style="list-style-type: none"> <li>• Complains that things are spinning or moving</li> <li>• Nausea, light headedness</li> <li>• Balance problems, difficulty judging distance or speed</li> </ul>	<ul style="list-style-type: none"> <li>• Encourage patient to sit down and take a breath whenever he/she starts to feel dizzy. He/she should relax before getting up slowly.</li> <li>• Be aware of balance problems. Help to prevent a fall by moving/removing things in your home (i.e. area rugs, cords).</li> </ul>
<b>Sensory changes</b>	<ul style="list-style-type: none"> <li>• Trouble hearing/ringing in the ears</li> <li>• Problems seeing (blurry/double vision)</li> <li>• Sensitivity to light/noise</li> <li>• Changes in taste/smell</li> <li>• Sensitivity to physical pain</li> </ul>	<ul style="list-style-type: none"> <li>• Discuss these symptoms with your physician or specialist.</li> <li>• Encourage use of aids if he/she has them (i.e. glasses, hearing aids).</li> <li>• Have hearing tested and eyes checked.</li> <li>• Talk to a dietician about changes in taste and smell.</li> </ul>

## Emotional and behavioural concerns

Providing emotional support in addition to physical help is essential. The person may experience a wide range of feelings including anger, frustration, anxiety, sadness, or impulsivity. Avoid labelling or categorizing the person to prevent reinforcing any negative feelings.

Symptom	How to recognize	What to do
<b>Irritability/ Anger</b>	<ul style="list-style-type: none"><li>• Gets annoyed easily</li><li>• Has a tendency to overreact or get angry</li><li>• Impatient</li></ul>	<ul style="list-style-type: none"><li>• Avoid confrontation/retaliation, which is likely to increase anger.</li><li>• Try to reinforce/encourage anger management strategies.</li><li>• Discuss problems when both of you are feeling calm.</li><li>• Try to change the subject if it is causing anger.</li><li>• Try to identify what triggers the anger. Then, eliminate/avoid it.</li><li>• Don't take it personally! The person is angry because of his/her injury, not you.</li></ul>

Symptom	How to recognize	What to do
<b>Impulsivity</b>	<ul style="list-style-type: none"> <li>• Verbal or physical outbursts (i.e. cursing, hitting)</li> <li>• Saying or doing inappropriate things</li> <li>• Saying/or doing things that he/she normally wouldn't do</li> <li>• Does not seem to recognize how others view the behaviour or how the behaviour impacts them</li> <li>• Interrupting others</li> <li>• May appear self-centered</li> </ul>	<ul style="list-style-type: none"> <li>• Set guidelines for behaviour. Discuss which behaviours are appropriate and which are not.</li> <li>• Tell the person when he/she is doing or saying something inappropriate (preferably not in front of others).</li> <li>• Try to reinforce good/ appropriate behaviour.</li> <li>• Come up with a signal that you can use to let him/her know when his/her behaviour is inappropriate.</li> <li>• If acting inappropriately, stop him/her. Talk calmly with him/her about the possible consequences.</li> <li>• Remove dangerous items such as knives if violence occur.</li> </ul>
<b>Anxiety</b>	<ul style="list-style-type: none"> <li>• Often worries</li> <li>• May be jumpy, restless and/or irritable</li> <li>• Complains about having "racing thoughts"</li> <li>• Has physical complaints: sweating, shakiness, shortness of breath, racing heart</li> </ul>	<ul style="list-style-type: none"> <li>• If the person becomes anxious or restless when talking, try to change the subject.</li> <li>• Help him/her learn some relaxation techniques.</li> <li>• Suggest he/she keeps a diary or journal.</li> <li>• Discuss with him/her his/her problems and fears. You can then help him/her problem-solve</li> </ul>

Symptom	How to recognize	What to do
<b>Emotional instability</b>	<ul style="list-style-type: none"> <li>• Mood swings; may be happy one minute and sad the next, without any obvious reason</li> <li>• Emotional reactions don't seem to "fit the situation"</li> <li>• May not be able to control emotions effectively</li> </ul>	<ul style="list-style-type: none"> <li>• Try to understand why this is happening.</li> <li>• Try to help others understand the reason for mood swings.</li> <li>• If the person is becoming upset, try to change the subject.</li> </ul>
<b>Sadness</b>	<ul style="list-style-type: none"> <li>• Crying more often than usual</li> <li>• Lowered mood</li> <li>• Tendency to withdraw</li> </ul>	<ul style="list-style-type: none"> <li>• Try to talk to the person about his/her feelings.</li> <li>• Try to engage him/her in meaningful activities.</li> <li>• If sadness continues, encourage him/her to arrange an appointment with a family doctor.</li> </ul>
<b>Lack of initiation</b>	<ul style="list-style-type: none"> <li>• Stays in bed longer than he/she used to</li> <li>• Spends a lot of time lounging around and/or watching TV</li> <li>• Doesn't talk much unless he/she is spoken to</li> <li>• Says he/she wants to do things but doesn't follow through</li> </ul>	<ul style="list-style-type: none"> <li>• Keep in mind that this is not laziness. It is an effect of brain injury.</li> <li>• Avoid sarcasm or ridicule. To motivate the person, encourage them to do small tasks that they enjoy doing.</li> <li>• You may need to help him/her make initiate tasks and to complete the task.</li> </ul>

Symptom	How to recognize	What to do
<b>Change in sexuality</b>	<ul style="list-style-type: none"> <li>• An increase or decrease in sexual drive/interest</li> <li>• Becomes uncomfortable in intimate situations</li> <li>• Sexual behaviours in front of other people</li> <li>• Makes flirtatious or suggestive comments</li> </ul>	<ul style="list-style-type: none"> <li>• Provide verbal feedback when behavior or comments are inappropriate.</li> <li>• Use a signal to let him/her know when his/her behaviour is inappropriate.</li> <li>• It is important for partners to keep an open line of communication as they adjust to changes.</li> <li>• Find a way for the person to express his/her sexual feelings (i.e. in privacy).</li> <li>• Changes may be due to physical or emotional effects of the injury. Encourage the person to talk with his/her doctor or other healthcare provider.</li> <li>• You may also be adjusting to changes and the person may notice this... you and the person will need to talk about this.</li> </ul>



# Cognitive (thinking) concerns

Cognitive deficits are very common following a brain injury and will affect how the person thinks and processes information. As a result, he/she may have memory, communication and attention problems. Cognitive concerns can also hinder the ability to learn new tasks.

Symptom	How to recognize	What to do
<b>Attention problems</b>	<ul style="list-style-type: none"><li>• Is easily distracted</li><li>• Has trouble multi-tasking</li><li>• Has a shortened attention span</li><li>• Has a hard time shifting attention from one thing to another</li><li>• Has trouble completing tasks</li></ul>	<ul style="list-style-type: none"><li>• Encourage the person to work on one thing at a time.</li><li>• If having a conversation with him/her, try to limit distractions (i.e. turn off the TV).</li><li>• Try to avoid clutter.</li></ul>
<b>Memory problems</b>	<ul style="list-style-type: none"><li>• Has trouble remembering things like names and appointments</li><li>• Often misplaces things</li><li>• Often repeats the same things over and over</li><li>• Has a hard time learning new things</li></ul>	<ul style="list-style-type: none"><li>• Write things down.</li><li>• Repeat important information.</li><li>• Try to keep your home organized. Ask everyone to put things back in their place when they're finished with them.</li><li>• Label cupboards and drawers.</li><li>• Try to maintain a consistent routine.</li><li>• Explain only small amounts of new information at a time.</li><li>• Try to connect new information to things he/she remembers well.</li><li>• Ask him/her about his/her day. Talk about what he/she did or where he/she went.</li></ul>

Symptom	How to recognize	What to do
<b>Communication problems</b>	<ul style="list-style-type: none"> <li>• Speaks louder, softer or more rapidly than before</li> <li>• Has trouble finding the right words</li> <li>• Has trouble following your conversations</li> <li>• Takes long pauses or doesn't respond at all</li> <li>• Gets off-topic easily</li> <li>• Misunderstands what people say</li> <li>• Slurs his/her words</li> <li>• Has difficulty understanding what he/she reads</li> </ul>	<ul style="list-style-type: none"> <li>• Speak slowly and be as clear as you can (simplify information).</li> <li>• Talk about topics that the person is familiar with. Avoid changing subjects too quickly.</li> <li>• You may need to start the conversation. Asking open-ended questions can help.</li> <li>• Be patient. He/she may need time to think about his/her question and/or answer.</li> <li>• If he/she cannot find the right word, ask him/her to describe it (i.e. the thing we use to change the channel).</li> <li>• Try to make sure only one person is talking at a time.</li> </ul>
<b>Difficulty thinking (planning, organization, decision making, problem solving)</b>	<ul style="list-style-type: none"> <li>• Takes longer to make decisions, answer questions and understand things</li> <li>• Is more disorganized</li> <li>• Often late for appointments</li> <li>• Has a hard time starting a task</li> <li>• Finds it difficult to prioritize and/or set goals</li> <li>• Takes things too literally</li> <li>• Impulsive</li> </ul>	<ul style="list-style-type: none"> <li>• Recommend that the person start by doing small tasks.</li> <li>• Break activities up into smaller tasks.</li> <li>• Keep information simple.</li> <li>• Allow for extra time to complete the task at hand.</li> <li>• Try to eliminate distractions when he/she is trying to complete a task.</li> <li>• To help with decisions, discuss the pros and cons. Try to limit options.</li> </ul>

# Section 2

## Complications

### Potential complications

When the person has sustained a brain injury, he/she is at risk of having some serious problems.

### When should you get help for the person?

You should talk to the person and his/her doctor if any of the symptoms are getting worse or if they are interfering with daily or family life.

Seek immediate medical attention if you notice any of the following symptoms:

- Vision problems that gets worse
- Increased confusion
- Loss of feeling in arms, legs or body
- More pain than usual
- Headaches that will not go away
- Over or under eating
- Sudden change in behaviour
- Vomiting
- Fluid or bleeding from the ear or nose
- Black outs
- Slurred speech

These symptoms could mean that the condition of the person is worsening or that he/she has had another injury. A second brain injury could have a serious impact.

## **Other potential complications**

On the next pages you will find information about some of the other potential complications of brain injury including:

- Depression
- Seizures
- Loneliness
- Difficulty taking medications
- Alcohol and drug use
- Family problems

# Depression

Depression can be described as a condition of extreme sadness. People who are depressed may also feel hopeless or worthless. They may stop enjoying the things they used to like.

## Signs of depression

- Does not enjoy the things he/she used to
- Not interested in doing anything/decreased activity level
- He/she is sad for a long time
- He/she feels hopeless or worthless
- Fatigue
- Doesn't want to get out of bed
- Not happy with him/herself
- Sleeping more or less than usual
- Finds it hard to fall asleep
- Eating more or less than usual
- Crying more than before
- Drinking too much alcohol
- Does not finish what he/she starts
- Anger
- Anxiety and/or restlessness
- Has a hard time paying attention
- Loneliness
- **Has thoughts about killing him/herself**

## What can I do?

- Offer your support, understanding and encouragement.
- Talk with the person about his/her feelings and listen carefully.
- Remind the person that depression is not a sign of weakness.
- **Be aware of the signs of suicide. The person may need to see a doctor or psychologist.**

## **Signs of suicide**

A person who is thinking about suicide might:

- Make a will
- Start organizing his/her affairs
- Give away belongings
- Suddenly ask to visit old friends
- Start collecting medications
- Have a sudden, drastic change in mood
- Write a suicide note
- Talk about suicide

**Crisis Line phone number:**

- 1-613-722-6914 for Ottawa residents
- 1-866-996-0991 for outside of Ottawa

# Seizures

It is common for a survivor of brain injury to experience seizures. Seizures can develop soon after the brain injury or years later. The severity of the brain injury determines the risk of developing a seizure.

## Common types of seizures

Generalized seizures

- A problem in the circuits of the brain in which the entire brain is affected

Partial seizures

- A more subtle type of seizure in which the person elicits less severe symptoms

Epilepsy

- The condition of being highly prone to repeated seizures regardless of the type

## Signs and symptoms

- Loss of consciousness
- Body stiffness
- Jerking limbs
- Blanking out
- Changed perception
- Senses are altered
- Loss of bowel or bladder control
- Utter a cry
- Symptoms last approximately 2 minutes or less

Seizures can be determined by an electroencephalogram (EEG) or by a doctor

## **What can I do?**

- See a doctor as seizures can often be treated with anti-seizure medication.
- Record the date and important details about the seizure to share with the person's doctor.
- Limit alcohol consumption and prevent survivor from using illegal drugs.
- Avoid activities such as driving, or participating in risky activities such as working on ladders.



# Loneliness

Loneliness may affect the person despite the presence of caring family members in his/her life. Following the brain injury, the person may be unable to do the activities he/she enjoyed.

He/she may lose contact with friends and/or coworkers.

## Signs and symptoms

- Has a hard time engaging in a conversation
- Fatigue may limit activities hence resulting in loneliness
- Reports feeling misunderstood or alone
- Nervous when around other people because of fear of rejection
- Has a negative perspective on life
- Pushes others/help away
- Loses connections with friends, coworkers, or other contacts

## What can I do?

- Develop a list of plans and hobbies with the person that he/she is able to do exercise. For example, by going for walks with the person.
- Ask the person to help with tasks he/she is physically and cognitively capable of doing; this way the person is kept busy.
- Encourage communication by asking about survivor's feelings, opinions, and concerns.
- Search out a peer support system.

## **Difficulty taking medications**

Taking prescribed medication is extremely important for recovery. However, problems such as side effects, difficulty swallowing, and/or keeping track of when to take medications may contribute to the person's difficulty with taking medications.

Difficulty taking medications may derive from a series of smaller problems.

### **What makes it difficult to take medications?**

- Side effects of medication
- Finds it difficult to take medication in a timely manner
- Decreased lip or tongue strength
- May have problem swallowing
- Difficulty keeping track of multiple medications
- Impaired memory and concentration may make it difficult to keep track of when to take medications

### **What can I do?**

- Help the person with the medication calendar.
- Discuss medication issues with the person's doctor.
- Talk to a pharmacist, request instructions/information pertaining to the prescribed medication.
- Use a pill organizer.
- Help survivor to follow instructions and to understand the importance of his/her medications.
- Keep up with medication refills.
- Link medications with meals, for example, remind loved one to take medications each time he/she has breakfast or dinner.

## **Alcohol and drug use**

Using alcohol or non-prescription drugs can have a serious impact on the person. It may slow his/her recovery or stop him/her from recovering completely. It may even make the injury worse and increase the risk of re-injury.

### **Alcohol or drugs use after a brain injury may:**

- Diminish ability to regain old skills
- Worsen symptoms. For example, problems with balance, speech, depression, memory and concentration will be worsened.
- Increase likelihood to have a seizure.
- Cause prescription medications not to work as well.
- Cause trouble in the use of coping strategies learned.
- Increase risks of having another injury.

### **What can I do?**

- Alcohol and non-prescription drug use should be taken very seriously, not as a “phase”.
- Develop a plan with the person that will help him/her to cope with his/her problems (this may need to include contacting the family doctor or other health care professional).
- Consult a rehabilitation team member or a doctor if you think an alcohol or drug dependency exists.
- Motivate survivor to lead an alcohol/drug free lifestyle.
- Educate family members and friends about why they should not offer alcohol or non-prescription drugs to the person.

People who begin or continue using alcohol or drugs after a brain injury don't recover as quickly.

# Family problems

All family members are usually affected by the brain injury. Family problems can occur as a result of possible role changes, financial stress and miscommunication among family members following the brain injury.

## Possible causes of family problems:

- Role changes
- Changes in the person's personality
- Changes in the caregiver's ability to cope
- Less time spent with other family members
- Misplaced feelings/emotions
- Reduced awareness of survivor's limitations
- Family member feeling overwhelmed with additional responsibilities
- Changes in financial situation
- The injury continues to remain the focus of attention

## Resolving family issues

- Understand role changes.
- Make a list of the new responsibilities for each family member.
- Practice relaxation techniques.
- Communication with other family members is important. It can help you understand each person's point of view and can provide you with opportunities to problem solve together.
- Paying for external help may take away some of the stress on your family.
- Participate in a brain injury support group and/or consult a counselor.
- Make time for yourself as well as spending time with the other family members and friends.
- Let the person visit other family members or friends.
- Discuss any change you may have noticed in the person with family members and/or health care professionals.
- Allow other family members to take breaks from their duties.

# Section 3

## Health care providers/ Rehabilitation Team

### Rehabilitation team

#### Family physician

The family physician receives training that allows him/her to work with and treat both the patient (i.e. brain injury victim) and his/her family. They can act as a link to other health care providers. After the person leaves the hospital or rehabilitation centre, the family doctor will continue to monitor his/her condition in the community. If you or the person have any concerns, you can go together to see the family doctor. If he/she cannot address your concerns, he/she will be able to help or refer you to someone who can. The family physician assumes responsibility for medication after discharge from hospital and will receive information from the hospital following discharge.

Your family doctor's phone number is: \_\_\_\_\_

#### Nurse

While the person was in the hospital, he/she had 24-hour care provided by a nurse. In the hospital setting, a nurse is responsible for providing basic care, moral support and constant monitoring of the patient's condition so he/she can update other healthcare providers. A nurse can also help the patient and his/her family to adjust to changes and encourage them to follow recommendations.

Now that the person has left the hospital, the nurse probably plays a smaller role. Sometimes people will need to have a home care nurse who will fulfill a similar role that they did in the hospital but will do so within the home. Usually, there will also be a nurse who helps your family doctor.

## **Occupational therapist**

Occupational therapists' (OT) role is to help increase independence. They help people to learn new ways of doing things. For example, they can help by providing aids/equipment to compensate for limitations or teach you how to adjust to the person's environment to make living easier. They can also help the person decide whether or not he/she is ready to return to school and/or work. They may even help make a return to work plan. OT's can also help you to support the person's participation in these activities.

To contact an occupational therapist: \_\_\_\_\_

## **Physiatrist**

A physiatrist is a medical doctor who is specially trained in physical medicine and rehabilitation. The person's main doctor at the Rehabilitation Centre was a physiatrist. Usually, the physiatrist leads a rehabilitation team like the one at the Rehabilitation Centre. They will evaluate the patient's health and then decide on what kind of treatments he/she will require, making referrals as needed. Once a rehabilitation program has been designed, the physiatrist continues to work closely with other members of the rehabilitation team to monitor the patient's progress and effectiveness of treatment. Some patients who require follow-up will be seen in the out-patient clinic after discharge while others will follow-up directly with their family physician. You may need to contact the physiatrist if new symptoms, questions or problems related to brain injury arise.

To contact the physiatrist at the Rehabilitation Centre: \_\_\_\_\_

## **Physiotherapist**

Physiotherapists' job is to address their patient's mobility problems. They will evaluate one's physical condition and then come up with an appropriate treatment program to help the patient achieve physical independence. Usually, physiotherapists are concerned with issues like flexibility, balance, posture, coordination, and muscle strength and tone. They can help design an exercise program, decide whether or not the patient will need any special equipment (i.e. a walker or cane) and provide training to make sure he/she can use it properly.

If the person has difficulty moving around on his/her own, you may want to think about arranging an appointment with a physiotherapist.

To contact a physiotherapist call: \_\_\_\_\_

## **Speech language pathologist**

Speech language pathologists (SLP) treat people who have communication problems. They help their patients relearn communication skills (i.e. reading, writing, verbal expression, etc.) or show them how to communicate using new methods. If the person is having trouble in any of these areas, a SLP can help. SLP can also help if he/she is having a hard time swallowing.

To contact a speech-language pathologist: \_\_\_\_\_

## **Social worker**

Social workers (SW) provide patients and their families with counselling and practical assistance during the inpatient and outpatient rehabilitation process. They consider the individual's personal life and circumstances, especially from a family and socio-economic perspective. Social workers often serve as a connection between you and the other health care professionals. Also, they facilitate the patient's discharge from the hospital, give recommendations about community resources and make referrals for community services.

If you or the person have questions you can contact a social worker at:

\_\_\_\_\_

## **Recreation therapist**

Recreation therapists help patients achieve their therapy goals by allowing them to practice what they have learned in practical ways. For example, they might plan a community outing or help the patient to use his/her new skills to do something he/she enjoys (i.e. hobbies or interests). Recreation therapists help patients reintegrate into the community by helping them improve their abilities using recreational activities and by teaching them how to use community resources.

To contact a recreation therapist: \_\_\_\_\_

## **Rehabilitation therapist**

Rehabilitation therapists help patients in the recovery process by coordinating a treatment plan that focuses on the physical and cognitive well-being of the patient while also taking into consideration the goals of the family. Rehabilitation therapists act as a link between the patient, the family and the treatment facility.

To contact a rehabilitation therapist: \_\_\_\_\_

## **Neuropsychologist**

Neuropsychologists assess cognitive strengths and challenges of patients and provide treatment strategies to improve functions. They are able to test mental skills to determine the level of functioning of the brain (ex. short and long term memory, abstract reasoning, attention, concentration, executive functioning, motor skills and other cognitive and psychological factors). Neuropsychologists relate brain functioning to behaviour. Also, neuropsychologists provide treatment to assist patients with brain injury. Two main types of treatment are offered, restorative rehabilitation which helps with brain functions that have been impaired, and compensatory rehabilitation which teaches coping and compensation strategies for impairments that are likely to be permanent.

To contact a neuropsychologist: \_\_\_\_\_

## **Psychologist**

Psychologists help people who are experiencing personal problems. They can help the person if he/she is suffering from depression or having any other emotional and behavioural problems. They can also help friends and family members deal with the emotional issues they are experiencing themselves.

To contact a psychologist call \_\_\_\_\_



# Family adjustment after brain injury

Brain injury happens not only to the person who sustains the injury, but to the entire family. Every family member will be changed by the brain injury, not just the person with the injury. Not everyone experiences the process of recovery the same way. Different people, even in the same family, will react differently and move through the adjustment process at a different rate. Each family's recovery is unique and no definite time span can be assigned or anticipated.

After discharge from inpatient rehabilitation, the family members may face the following issues:

- Possible role changes and at times, increased dependency on family members.
- Possible need for physical care, cognitive and behavioural strategies and supervision for the person.
- Increased stress, increased demands on your time and energy.
- Challenges with balancing the needs of all family members, including your own.
- Increased responsibilities for financial management, legal and insurance issues, household management, parenting.
- Change in the breadth, openness and depth of emotional dimensions of relationship with the person.
- Change in plans regarding work, vacations, social and recreational activities.
- You may also experience grief, anxiety, anger, guilt and depression.

In order for families to adapt positively to the challenges resulting from the injury, changes in the injured and the family roles and relationships after discharge from inpatient rehabilitation, the following tips and strategies might be helpful.

## **Tips/strategies:**

- High levels of stress can result in physical symptoms, (e.g. high blood pressure, headaches, anxiety attacks), be sure to see you family doctor.
- Delegate responsibilities within the household.
- Ask for help /accept help from family members, friend and neighbours,
- Participate in a brain injury family education/support group, to receive support, understanding and encouragement as well as knowledge about coping strategies and community resources.
- If the family unit seriously deteriorates, consider counselling to enhance communication, sort out role changes, learn problem solving and stress management skills.
- Have the person with the brain injury do as much as possible for him/herself, always taking his/her safety and the safety of the environment into consideration.
- Keep in mind that most of the behaviour problems are due to the brain injury. Approach these behaviours as much as possible from a non judgemental standpoint. You might need to get professional help if behaviours become out of control.
- Ensure continued participation in work, social activities and hobbies.
- Seek individual counselling with a therapist to deal with grief and loss issues and work on redefining the relationship with the person.

If you have any questions regarding the impact of brain injury on you the caregiver or other family members feel free to contact your social worker: \_\_\_\_\_ at \_\_\_\_\_.

# Handling burnout

Burnout occurs because of accumulated stress. Emotional, mental, and physical exhaustions all contribute to burnouts when ignored long enough. It takes more time and effort to recover in later stages of burnout, hence, prevention is crucial.

## Signs and symptoms

- Disengagement or detachment
- A sense of hopelessness
- Lack of motivation
- A great deal of emotional damage
- Pessimistic views on life
- Constantly feeling dissatisfied
- Feeling overwhelmed
- Trouble relaxing even when help is available
- Constantly feeling exhausted
- Change in appetite
- Change in sleep habits
- Less energy to do all of your tasks
- Get sick easily or more often than usual
- Irritability and impatience toward survivor or others
- No longer able to take care of own needs

## **Tips/coping strategies:**

- Recognize your limits and do not push yourself beyond these limits.
- Beware of the warning signs of burnout and deal with them immediately.
- Try to understand and accept your feelings without compromising the person's well-being.
- Confide in someone you trust or attend support groups.
- Learn more about the person's condition – education encourages understanding.
- Incorporate relaxation rituals in your life. For example, take time to meditate or write your feelings in a journal
- Cut back on commitments and tasks by distributing them among others who are willing to help.
- Take care of yourself by making the time to do activities you enjoy.
- Grieve your losses and make new goals/dreams.
- Ask for help from family members, friends, and/or community resources that provide assistance.

## **Handling guilt**

Caregivers' guilt happens regardless of your efficiency in providing care. It is provoked by several feelings about oneself, including regret, anger, and self-blame. Feelings of guilt are often caused by a discrepancy between one's ideal self and one's current self.

### **Guilty feelings originate from:**

- Disappointment with oneself as a caregiver
- Thoughts of regret; for example, thinking that you could have done more to prevent the situation.
- Self-blame
- Feelings of anger about the injustice of the person's injury
- When your current actions do not reflect how you would like to be ideally
- Feeling you failed to help the person
- Comparing your health to the health of the person

### **Tips/coping strategies:**

- Recognize your feelings of guilt.
- Consider whether your values are aligned with your actions.
- Take good care of yourself as you can be more helpful if you are healthy.
- Revisit and reinvent your goals and values.
- Identify other feelings that might be related to your feelings of guilt.
- Guilt is not always bad; it can help you become the caregiver you want to be.
- Ask for help.

# Stress management

When there are too many pressures and demands, you may begin to experience stress if they are not dealt with properly. During stressful events, your body undergoes emotional, physical, and mental changes. If you are constantly stressed for long periods of time, it will affect your body's immune system, possibly leading to illness.

## Warning signs:

- Anger
- Unproductive worry
- Frequent mood swings
- Feelings of urgency and hyperactivity
- Agitation
- Sweaty palms
- Chronic fatigue
- Changes in sleep patterns
- Changes in eating habits
- Weight fluctuations
- Neck/back pains
- Over-engagement
- Overreacting
- Impulsivity
- Use of drugs and alcohol
- Loss of energy
- Distractibility

Stress occurs when there is a need to adjust to changes; hence, how you respond to the changes will determine how effectively you deal with stress

## **Tips/coping strategies:**

- Eat a healthy diet and exercise regularly.
- Do not try to control every situation, be able “to pick your battles”.
- Use relaxation tactics. Examples include breathing techniques, guided imagery, or behaviour changes.
- Set realistic goals and expectations.
- Communicate your feelings with others.
- Manage your time by making a set schedule.
- Build a social support system.





# References

Below you will find a list of sources that includes published materials and websites used to obtain some of the information found in this package. You may refer to these sources for more in-depth information on strategies for coping with a brain injury.

- Bergquist, T.F. *Changes in Self-Awareness Following Traumatic Brain Injury*. Communication Skill Builders Inc. 1994.
- *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans* (Module 2: Understanding the Effects of Traumatic Brain Injury and What You Can Do To Help). The Defense Health Board, The Defense and Veterans Brain Injury Center. 2010.
- Tombaugh, T. Ottawa Concussion clinic: *Head Injury and Concussion – Concussion and Memory: Information for Clients and Families; Head Injury and Concussion – Concussion and Fatigue: Information for Clients and Families; Head Injury and Concussion – Concussion, Personality Change and the Family: information for Clients and Families*.
- Sander, A.M. *Managing Problems with Thinking and Behavior In the Home: Strategies for Caregivers*. Presented at the 20th Annual Pacific Coast Brain Injury Conference, Vancouver BC. 2007.
- Brain Injury Association of Canada – Caregiver Challenges pages from <http://biac.aclc.ca/en/?s=seizures> (Search results seizures)
- *Alberta Brain Injury Initiative: Survival Guide*. 2006
- *Caregiver Stress Management*. (2009). American Brain Tumour Association <http://www.abta.org/index.cfm?contentid=198>
- Chakraborty, A., (Ed). (2009). *Stress Management Health Centre: Tips for Coping with Caregiver Stress*. WebMD, Inc.
- Smith, M., Jaffe-Gill, E., Segal, J., and Segal, R. (2008). *Preventing Burnout: Signs, Symptoms, Causes, and Coping Strategies*. [www.helpguide.org/mental/burnout\\_signs\\_symptoms.htm](http://www.helpguide.org/mental/burnout_signs_symptoms.htm)
- Faculty of the Harvard Medical School. (2006). *Generalized Seizures (Grand Mal Seizures)*. Harvard Health Publications
- Degeneffe, C. E. (2001). *Family Caregiving and Traumatic Brain Injury*. National Association for Social Workers



# Community resources

## Family and peer support

### **Brain Injury Association of Ottawa Valley (BIAOV)**

**613-233-8303**

211 Bronson Avenue, Room 300

The Brain Injury Association offers a number of programs in the community for adult survivors with brain injury, their family and caregivers. A Family Support Group, Peer Support Group and Peer Mentoring Program are available through the Association. The groups allow those coping with brain injury to connect with and learn from other individuals sharing similar experiences. Also, the Peer Mentoring Program offers the added opportunity to volunteer help to others by sharing your experiences.

**Email: [braininjuryottawavalley@bellnet.ca](mailto:braininjuryottawavalley@bellnet.ca)**

**Website: [www.biaov.org](http://www.biaov.org)**

### **The Ottawa Hospital Rehabilitation Centre**

**613-737-7350 ext. 77532**

505 Smyth Road

Family Brain Injury Education/Support Sessions are offered through the department of Social Work in the Ottawa Hospital Rehabilitation Centre (no referral needed). Also, individual counselling is available through the Psychology department (referral needed). If you were not previously a client of the Ottawa Hospital then you will need a referral from Dr. Marshall, at the Acquired Brain Injury Outpatient Clinic.

**Website:**

**<http://www.ottawahospital.on.ca/en/clinical-services/deptpgrmcs/departments/rehabilitation-centre/>**

## **Support services/Respite care**

### **Community Care Access Centre (CCAC)**

**613-745-5525**

100–1160 Cyrville Road

The Community Care Access Centre (CCAC) is a bilingual, charitable, non-profit corporation. It is funded by the provincial Ministry of Health and Long-Term Care. The CCAC provides in home personal care support and professional services. They also provide information and make referrals to community and long-term care services. CCAC also offers In Home Respite Services and can make respite bed referrals to Saint Vincent's Hospital as well as Nursing Homes. To find a Community Care Access Centre (CCAC) closest to you, within the Champlain District please call the local number: 613-310-2222

**Email: [info@champlain.ccac-ont.ca](mailto:info@champlain.ccac-ont.ca)**

**Website: [www.healthcareathome.ca/champlain/en](http://www.healthcareathome.ca/champlain/en)**

### **Pathways to Independence – Residential, Day, and Supported Independent Living Programs**

211 Bronson Avenue, Room 309

613-233-3322

Residential group homes offer 24 hours/day continuous staff support.

Day programs provide clients with supported leisure activities.

Supported Independent Living (SIL) program offers clients life skills support such (budgeting, household management ect.) in their own apartments in the community.

**Email: [laurieb@pathwaysind.com](mailto:laurieb@pathwaysind.com)**

**Website: [www.pathwaysind.com](http://www.pathwaysind.com)**

## **Vista Centre – Supported Independent Living (SIL)**

**613-234-4747**

211 Bronson Avenue. Room 214

Vista Centre provides long-term residential and community based support to adults living with the effect of brain injury through their Supported Independent Living (SIL) Program and Day program. The Vista Centre helps facilitate the enhancement of the individual's quality of life, relationships, personal abilities, and life skills, while assisting in the rebuilding of their life in the community.

**Email: [sil@vistacentre.ca](mailto:sil@vistacentre.ca)**

**Website: [www.vistacentre.ca](http://www.vistacentre.ca)**

## **Information services**

### **Brain Injury Association of Ottawa-Valley – Step Up Work Centre**

**613-233-0111**

211 Bronson Avenue, Room 300

The Brain Injury Association of Ottawa Valley provides support groups for individuals who have sustained a brain injury and their families. A resource centre is available, providing literature and video cassette information about brain injury and brain injury resources. The Association also provides a quarterly newsletter and special events/education sessions for the membership.

**Email: [braininjuryottawavalley@bellnet.ca](mailto:braininjuryottawavalley@bellnet.ca)**

**Website: [www.biaov.org](http://www.biaov.org)**

### **Champlain Health Line**

Online only

The Champlainhealthline.ca is a website developed by the Champlain Community Care Access centre (CCAC). It posts accurate and up-to-date information about health and community services across the Champlain region. Over 2100 service listings describe organizations and programs serving people who live in Ottawa, Renfrew county, Prescott and Russell, Stormont, Dundas and Glengarry and North Lanark and North Grenville. Users can search through services, events, news and careers.

**Email: [edit@champlain.ccac-ont.ca](mailto:edit@champlain.ccac-ont.ca)**

**Website: [www.champlainhealthline.ca](http://www.champlainhealthline.ca)**

### **Community Care Access Centre (CCAC)**

**613-745-5525**

100–4200 Labelle St.

The Ottawa Community Care Access Centre (CCAC) is a bilingual, charitable, non-profit corporation. They are funded by the provincial Ministry of Health and Long-Term Care. The CCAC exists to connect the people of Ottawa with the community and long-term care services they need. They provide personal and caregiver support by means of information, education as well as referrals to accessible brain injury resources. To find a Community Care Access Centre

(CCAC) closest to you, within the Champlain District please call the local number:  
613-310-2222

**Email: [info@champlain.ccac-ont.ca](mailto:info@champlain.ccac-ont.ca)**

**Website: [www.healthcareathome.ca/champlain/en](http://www.healthcareathome.ca/champlain/en)**

### **Citizen Advocacy of Ottawa**

**613-761-9522**

312 Parkdale Avenue

Citizen Advocacy is one of only a few Ottawa agencies supporting people with a wide range of disabilities. Citizen advocacy matches volunteers from the community with people who are isolated and vulnerable because of a disability. Citizen Advocacy sets up one-to-one matches between volunteer advocates and people with disabilities that can have profound effects on both. They offer services to the client by taking them out in the community and as a result giving respite to the caregiver during this community outing.

**Email: [info@citizenadvocacy.org](mailto:info@citizenadvocacy.org)**

**Website: [www.citizenadvocacy.org](http://www.citizenadvocacy.org)**