



FAMILY GUIDE:

Rehabilitation Phase
Post-Brain Injury

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A Family Guide to the Rehabilitation Phase of Brain Injury Recovery

When the tragedy of brain injury strikes, families must cope with the initial shock and struggle to make sense of a very distressing situation. Now that your family member's medical condition has been stabilized and there is reason to believe that a rehabilitation program can enhance further recovery, there are likely still many unanswered questions. Unlike other types of injuries and medical conditions, the course of recovery and potential effects of brain injuries can vary greatly from one person to another. The purpose of this guide is to provide some information that can help to further understand brain injury, answer some of your questions and in some instances, to give you an idea of the questions you can be asking of those providing services to you and your loved one.

This guide covers many of the issues that surface for injured persons and their families while recovering from brain injury. Included is some basic information as to how the brain works, the effects of injuries and how to manage some of these effects. While working with the health care team and even while reading these pages, you may encounter clinical language that may be foreign to you. The glossary of terms toward the back of the guide contains many of the terms you may hear or read about in the coming months.

For some people, this guide might have too much detailed information, for others, it may not be enough. For those who are suffering from "information overload", you may find it useful to first flip through the pages and read only the parts that seem important now. Keep the guide handy and as your family member progresses, you may want to return to sections of the guide as they become more important to you later. Some might find themselves wanting for information not already covered in these pages or would like more detailed information on a particular topic. If so, you can feel free to contact any member of the health care team or BrainTrust Canada with your requests.

Basic Brain Anatomy

The brain is the control centre for the body and the mind and is enormously complex in its functions. It is made up of nerve fibers and cells and covered by three layers of skin-like tissue called meninges. Generally speaking, the left side or hemisphere of the brain controls body movement and sensation on the right side of the body and vice versa. The brain is divided into lobes which each have different functions. Damage to any one part of the brain usually affects specific functions. If more than one part of the brain has been injured, the result can be more complicated because several aspects of brain function are interconnected. When the function of the different areas of the brain is discussed it is important to remember that the descriptions apply only in a general sense. As the brain is highly interconnected, damage to a particular area of the brain may affect the functions of that area as well as other functions performed by the brain.

Frontal Lobes

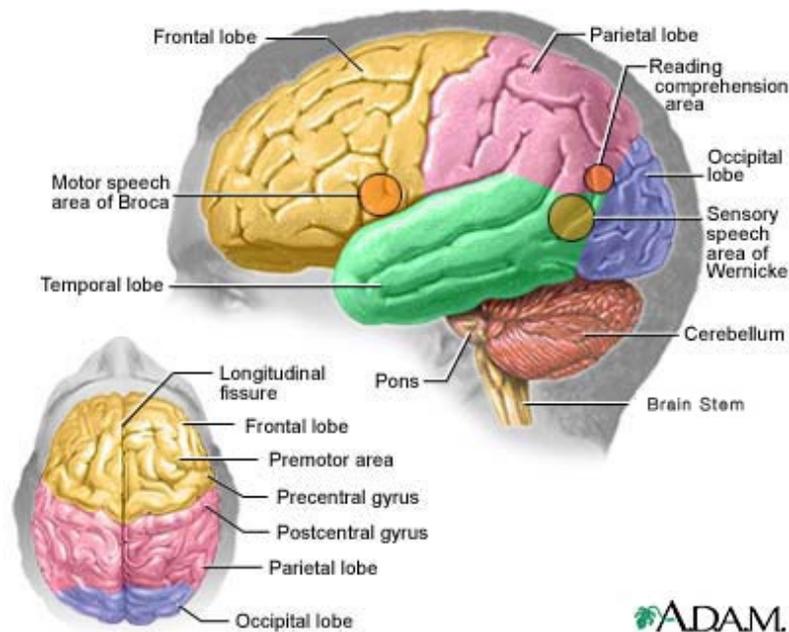
The frontal lobes are responsible for controlling emotions, behaviour and judgment. They are also the centre for decision-making, action planning and social skills. While these functions may be affected if injury occurs to this part of the brain, damage to the left frontal lobe can also result in speech difficulties as well as problems moving the right leg or arm. Damage to the right frontal lobe may result in problems with left arm or leg movement and may also affect the emotional aspects of speech.

Parietal Lobes

If the right parietal lobe has been injured, it may lead to problems making sense of maps, pictures and diagrams and may also cause a loss of sensation (feeling) on the left side of the body. If the left parietal lobe has been damaged, reading and arithmetic problems may be present as well as a loss of feeling on the right side of the body.

Temporal Lobes

Problems with understanding or remembering spoken language may result from damage to the left temporal lobe. The ability to understand and remember visual information such as diagrams, pictures and body language may be affected by damage to the right temporal lobe. Injury may also affect the interpretation of language and other sounds in the environment.



Occipital Lobes

If the left occipital lobe has been damaged, it may affect the ability to see things on the right side of the visual field. For instance, the person might eat only the food on the left side of the plate because he/she doesn't see the food on the right side of the plate. Damage to the right occipital lobe may affect the ability to see things on the left side of the visual field.

Cerebellum

Injury to the cerebellum may affect balance and coordination as well as the muscle tone of the legs, arms and hands.

Brain Stem

A wide range of physical and sensory problems may result if the brain stem has been damaged. It controls vital functions such as heartbeat and breathing and sends messages to the ears and eyes and the muscles of the face, throat, mouth.

How will we know how much damage has been done?

In the initial days or weeks after brain injury, swelling is usually resolved and blood from bruised areas is re-absorbed. As pressure in the brain decreases, normal blood flow can be restored and damaged sections of the brain can begin to recover. It is at this point that one can begin to see the effects of the brain injury begin to emerge. Procedures such as a C.T. scan and the EEG can give physicians a picture of the physical damage to the brain. However, these devices provide only a general indication as to which functions of the brain have been affected. For instance, a scan may reveal damage to an area of the brain associated with our capacity for judgment, but until the person with brain injury is placed in a variety of day to day situations which test his/her judgment, it may not be known to what extent injury has affected these abilities.

Brain injury affects people in varying ways depending on the nature and severity of the injury, the person's age and the condition of the brain prior to injury. The personality traits of the individual prior to injury may interact with the effects of the injury, producing outcomes unique to the individual and their injury. While persons with mild injuries may recover fairly rapidly and show few lasting consequences, more serious injuries tend to involve more areas of functioning with more severe and ongoing effects. Even mild injury can affect a person's ability to carry on with life as before in important ways. When injury is more severe, life as it was is never the same again and there are many changes in level of ability and challenges to cope with.

Although the physical problems that result from damage to brain tissue are frequently the most obvious, they are often not the most disabling. Many other factors may have more far reaching effects than the ability to move an arm or a leg. The thinking and emotional problems that result are often much more difficult to treat than physical problems and more directly impact the potential for successful community living and employment.

You may now begin to understand that questions about the severity and extent of brain damage are very difficult, if not impossible to answer, even for professionals who have worked with hundreds or thousands of cases in which brain injury has occurred. As mentioned above, many of the areas affected by the brain injury may not become obvious until the person is placed in day to day situations that put his/her various abilities to the test.

How does the Brain recover from injury?

What are the ideal conditions for recovery? A recovering person will need some stimulation and therapy but too much activity around him/her will be stressful. Undue stress during the recovery period should be avoided. Healing takes a lot of energy. Doing things that used to come easily may take more concentration and effort after brain injury. Too much activity and the loss of the ability to block out sights and sounds may cause a person to tire easily and feel stressed. While each person is unique and may respond differently to his/her surroundings, a few suggestions apply to most people who have recently had brain injury:

- ▶ he/she will tire more easily, needing more sleep at night and midday naps.

- structure and routine may help the person feel less prone to stress and/or anxiety.
- important activities should be done when the person is feeling his/her best - such as in the morning or after an afternoon nap.
- acknowledge the frustrations and struggles the person may be experiencing and reassure them that recovery moves along at it's own pace.
- encourage him/her to stay connected with friends and loved ones who support and want to understand the situation.

The Recovery Environment

When your family member is ready for the rehabilitation unit, it can be very unsettling to think about getting to know the new health care team, and leaving the acute care staff you have come to know and trust. Much energy and time has gone into building relationships with hospital staff in the acute care unit and getting to know the strengths of staff members. Now you must begin this process all over again. You can be comforted by the knowledge that a move to the rehabilitation unit shows faith in continued improvements and that the rehabilitation program will enhance the recovery process. It may also help you to be aware of some of the differences between acute medical care and rehabilitation so that you do not become unnecessarily concerned.

The rehabilitation unit employs a wide range of health care professionals who work to provide a coordinated program that will maximize your loved one's recovery. Unlike acute care treatment where the emphasis is on doing for the patient, the focus in rehabilitation is to help your loved one to do things for him/herself. It may be very difficult for you to watch your loved one struggle with frustrating tasks or activities. Yet, it is important to provide opportunities to re-learn skills and abilities that have been lost as a result of damage to the brain. Rehabilitation is also concerned with quality of life. So that when complete recovery is a questionable or long-term issue, people can be given the skills and special equipment that enable independence in many areas and keep lifestyle options open.

The rehabilitation team is comprised of a number of health care professionals who work cooperatively to provide care and an optimal program of recovery for your loved one. Each professional has a role which is briefly described below:



Nursing

The nursing staff essentially function as the glue that holds the program together. In addition to being responsible for tending to your loved one's general health care, registered nurses, licensed practical nurses and nursing aids provide a program of self-care skills, bowel and bladder programs, skin care, and hygiene. Each of these levels of nursing assume a different range of responsibilities.

The Patient Care Coordinator (PCC) organizes the nursing team and works with the physician(s) and other team members in managing health-care and treatment matters. The PCC is also an excellent source of information regarding your loved one's program and recovery progress.

Physical Therapy (PT)

The physical therapist assesses, plans and implements therapy to improve balance, coordination, muscle tone, strength and endurance. He/she ensures that the patient has the physical and neurological ability to perform and coordinate the movements necessary to sit, stand and walk.

Occupational Therapy (OT)

The occupational therapist plays a vital role in brain injury rehabilitation with the emphasis on activities of daily living (ADLs). To assist persons in regaining functional skills, Occupational Therapists implement programs devised to rehabilitate fine motor skills, perceptual abilities (seeing and hearing), eye-hand coordination and cognitive (thinking) skills as well as activities that have a carry-over to the domestic or employment settings. Where indicated, they may devise or obtain special equipment that can help people with tasks that challenge them. For example, a strap-on brush or a specially designed fork may make it possible for individuals to groom or feed themselves without assistance. Supports for sitting, wheelchair modifications and splints as well as consultation regarding home modifications are also provided by OTs.

Speech Language Pathologist/Therapist

The Speech Language Pathologist (SLP) is a primary resource for addressing communication problems. He/she will be concerned with difficulties related to the ability to comprehend or express oneself in written and oral language, such things as speech patterns, the ability to concentrate and make use of verbal reasoning and any physical problems that might inhibit swallowing, language reception and expression. There are several clinical terms used in describing language/speech difficulties (aphasia, anomia, apraxia, etc.), these are defined in the glossary provided and further discussed in the pages ahead.

Neuropsychologist

The Neuropsychologist is a psychologist with specialized training in dealing with problems that result from some form of insult or injury to the brain. He/she is often called upon to do extensive assessment of the areas of emotional, behavioural and cognitive consequences of injuries to the brain. A typical neuropsychological evaluation will assess areas such as memory, problem-solving skills, attention, concentration, sequencing skills, abstract reasoning, motor speed, planning, organizing, task completion and emotional/personality functions. This information is particularly important to rehabilitation following brain injury. The neuropsychologist can be available to consult

regarding cognitive and behavioural rehabilitation that may help your loved one and can offer counseling and guidance with regard to issues of recovery.

Patient - Family Counseling

The social worker is a key informational, support and counseling resource for family members and the person with injury. His/her role is to assess the needs and strengths of the family, help resolve issues that may have surfaced as a result of the injury and to assist patients and families in need of help and services. For instance, the social worker can speak with you about financial problems or help with patient or family worries that could get in the way of recovery. The social worker can also act as a "go-between" in communicating with the rehabilitation team and can help you or your loved one obtain the programs and services to which you may be entitled.

Often rehabilitation social workers continue to provide help and support long after the person with injury has returned home.

Family Members

The family may be the most important resource available to the rehabilitation team and can be the best source of information regarding the person with injury. Research shows that family involvement in the care, planning and rehabilitation of the individual aids the recovery process. As a family member, it is important to keep abreast of progress your loved one is making in rehabilitation. As a team member, it can be helpful to be open about your concerns, goals and expectations for your loved one and as much as possible, include the person with injury in that process. Family members may be called upon to participate in problem-solving and help the team develop program plans, particularly as the time draws nearer to leaving hospital. Such participation often serves to train and better prepare the family in some of the knowledge and skills that will be necessary in caring for the their loved one should he/she return home.

Immediate and lasting effects of brain injury

The following pages outline several of the potential consequences of brain injury that may be present now and/or may become evident over time. Although many of the effects noted below are common to brain injury, it is important to remember that each person's experience will be unique. The extent to which each person recovers and his/her ways of coping with the changes are also dependent on the individual. We have included ways of responding to the changes that may be helpful and therapeutic. The usefulness of these responses will again depend on the person. You may have some ideas of your own that seem to be working and if so, you may want to continue making use of them. On the other hand, if a response seems to repeatedly fail to get the desired result, it may be time for a different way of thinking or acting on it. Perhaps the best general advice is to build on strengths and do not do for them what they can do for themselves.

In the early stages, the person with brain injury may be confused and agitated while trying to make sense of where she/he is and what is happening in his/her surroundings. Even the slightest changes in his/her situation may provoke restlessness, aggression or verbal abuse. At this point, the individual's ability to process information is severely decreased, he/she is detached from the present and is often responding to his/her own internal confusion. Sometimes behaviour appears to lack purpose. He/she can have limited ability to focus attention, will usually tire easily, may speak incoherently and may be unable to perform self-care activities.

As recovery progresses, confusion may remain but the level of agitation decreases and the individual is usually able to follow simple directions. He/she may continue to be easily distracted, behaviour may appear random or disorganized and she/he may have no memory of the events surrounding the time of injury. The person with injury may not be able to remember things that happened a short time ago or things they learned long ago. Continued difficulties with processing complex and abstract information, limited problem-solving abilities and the inability to perform previously learned tasks may be evident. Learning new things is often very difficult.

In later stages of recovery, some of these problems may decrease or disappear but often difficulties with concentration, organizing thoughts, processing information and learning new concepts may continue to be present.

Possible responses to changes in thinking: As the person with injury regains consciousness family members may notice many of the above named early effects. Being aware of these can ease some of the distress and confusion as to what is going on with an injured family member. During this time family and friends can help to limit the amount of stimulation the person with injury is exposed to. An overload of information can produce more confusion, agitation and fatigue. Keeping the lights turned down, radio or t.v. off and the door closed during visits will be helpful. Limit the number of people in the room to two or three, with only one person talking at a time. When more than two visitors are in the room, it may help to have both on the same side of the bed. This will help minimize distractions and help the person focus his/her attention.

Especially during the early stages of recovery, the person with injury may have problems with sleeping, may tire easily and require frequent naps and rest periods as well as early bedtimes.

During this time the injured person may be very sensitive to disruptions, unexpected changes or surprises. It can help to create an atmosphere where there is quiet and things are as predictable and familiar as possible. Responding consistently, and providing structure and routine is important.

Familiar sights, smells and music can be soothing. Thinking problems may require the use of simple language and repetition when speaking with your loved one.

Signs of anxiety and changes in behaviour such as pacing and fidgeting may indicate early signs of irritability. If the person appears disoriented, it may help to use his/her name in conversation, repeat who you are, where you are and what is going on at that particular point in time. He/she may be frightened and therefore, structure and familiar faces can be comforting. It is also possible that your family member is feeling over stimulated. Speak in a calm, controlled tone at moderate volume. Moving slowly and using direct simple statements can help to prevent the person with brain injury from becoming more agitated. If the topic of conversation appears to be provoking irritability, change the subject and select topics known to be non-emotional, non-threatening and familiar to him/her. Offering a snack or drink can also help to redirect attention.

Personality Changes

Those close to a person with brain injury may note subtle or dramatic changes in behaviour and personality. Behaviour may be socially unacceptable and may seem immature and self-centred. The individual with injury often become more easily frustrated than they had before injury and can become easily agitated and irritable. Angry outbursts, swearing and shortness of temper are common. In general, some personality traits that were present prior to injury may become exaggerated. Your loved one may be far from the person you once knew so well. For some family members, this can be the most devastating consequence of the injury.

Possible responses to changes in personality: It may take quite some time for your loved one to re-learn social skills and behavioural control. He/she may require a great deal of guidance and ongoing support in order to achieve the desired results. The neuropsychologist and/or the social worker can provide assistance in dealing with these issues. If behaviour is of major concern on the unit, the team may develop a plan to address these issues.

Although persons with brain injury can usually re-learn social graces, some of the personality changes that result from damage to the brain may be long lasting. As a family member, the most difficult issue here is the loss of the person that once was and the ability to accept the person that now is. Coping with these changes is a difficult journey for the person with brain injury and family members. Many people benefit from participation in support groups and/or from professional counseling to help guide them through the process.

Issues with Swallowing:

Problems with swallowing are often referred to by the health care team as dysphagia and may occur as a result of damage to brain tissue or to the muscles used in swallowing. Tracheostomies or tube feeding may also cause swallowing problems. Signs of swallowing difficulties include choking, trouble chewing, food and saliva spilling out of the mouth, food coming up through the nose, gurgling and strained voice after swallowing. Where dysphagia is present it creates risk for food or fluids to go into the lungs instead of the stomach. This is called aspiration and is not only very uncomfortable but can cause pneumonia and can be life-threatening.

Swallowing problems also often call for the involvement of a Speech/Language Pathologist (SLP). The SLP and/or the physician may recommend a restricted diet in response to these kinds of problems. It is important to follow these recommendations even when swallowing seems to have improved, at least until the SLP can reassess swallowing and feels it is safe to allow a change in recommended fluids or solids.

Possible responses to swallowing problems: The nurses and speech therapists most commonly deal with the needs of the person with a swallowing problem. If your loved one has trouble swallowing, become familiar with the care and feeding procedures recommended by the nurse or speech therapist. Do not attempt to feed your loved one foods or liquids that are not recommended.

Speech and Language Problems:

Sometimes the ability to express oneself, to understand language and/or read and write may be affected. The nature, severity and duration of these affects will vary from one person to another.

Possible responses to speech and language problems: Allow your family member ample time to respond to you but help out if he/she appears to be getting quite frustrated. If the person is having problems understanding, facial and body language can help to get information across. Encourage him/her to use gestures if having difficulty forming or remembering words. Writing may be easier than speaking and it may be useful to keep a pen and paper handy. A supply of magazines and catalogues with pictures that depict feelings, actions, objects and ideas that are difficult to describe could be useful. Difficulties experienced in these areas can be as unique as the persons themselves. You may need to experiment with some different ideas and ask the speech therapist for suggestions.

Frequently, when persons suddenly find they are no longer as able to express themselves, they feel very self-conscious, are easily frustrated and/or feel helpless. It can be very demoralizing. You can show your support by acknowledging their frustrations, encouraging them to be patient with themselves and by being supportive when they do make an effort to express themselves.

Headaches and Dizziness:

It is not uncommon to experience headaches after brain injury. This can also occur due to bruised scalp, injury to sinuses, eye strain or tension. Dizziness may be the result of effects of injury on the sense of balance or upset in the circulatory system.

Possible responses to problems with headaches and dizziness: Muscle weakness in the eyes can mean that eyes tire easily and it may help to rest the eyes frequently and shorten activities such as watching TV or reading. If dizziness occurs when moving quickly to walking after lying flat, try changing body positions more gradually. Repeated problems with headaches, dizziness or faintness should be reported to the person's nurse or doctor.



Attention and Concentration:

Attention refers to the ability to be involved in an activity, conversation, etc. without being distracted. When problems of attention result from brain injury, the person may bounce from one topic to another in a conversation, easily lose their train of thought or get stuck on one thought or activity and be unable to switch to another topic or task. It may also involve the ability to concentrate on a task or topic for a sustained period of time. For example, the person may begin an activity and midway through, switch to something else.

Possible responses to problems with attention and concentration: Before giving instructions for a task or beginning a conversation, make sure you have your family member's attention by making eye contact with them. Use gestures and demonstrations to reinforce your message and limit background noise, interruptions and anything else that might distract him/her. Explain what you want the person to do and why. Begin with simple tasks and one step at a time, give short simple instructions. Don't give too much information and give him/her a chance to respond before moving to the next step. Talk the person through the process and provide feedback after each step (eg. "Good. Now that you've got your socks on, you can put on your shoes."). When faced with a decision involving a number of options a person with attention problems may be easily overwhelmed by too many choices. If this is the case, try to limit options to two activities. If your family member tends to get stuck on a thought or task, it is best to gently redirect his/her attention rather than confront or challenge this behaviour.

Sensory / Perceptual Deficits:

The individual with brain injury may have double vision, things may appear closer or further away than they are or may appear fuzzy and unclear. Injury may have affected the inner ear resulting in balance problems. Taste, touch and smell may also be affected.

Possible responses to sensory / perceptual deficits: If these difficulties are present, being aware of them will help you avoid unrealistic expectations of your family member. If vision or balance problems are evident, she/he may need the assistance of a person or special devices in certain activities. A specialist may be called upon to assess and assist with such problems and can suggest safety measures and ideas for getting around such problems.

Changes in Motor Function:

Brain injury may result in increased muscle tone, general or specific weakness or paralysis, posture or balance problems and effects to the range of motion in certain limbs. Persons may experience difficulty in coordinating or performing movements and may tire easily from physical effort.

Possible responses to changes in motor functioning: The P.T. and/or O.T. will be able to provide information on activities that will enhance rehabilitation outside the therapy room and be able to advise you as to what your family member should avoid while recovering from these problems. It is important to recognize that your family member may tire easily and not to pressure him/her into more activity when tired and stressed.

Seizures:

After brain injury, scar tissue can develop that will make a person more likely to have seizures or post-traumatic epilepsy. Persons with open head injury have a small chance of developing seizure disorder whereas someone with a closed head injury will have an even smaller chance. When seizures occur, they may do so within the first year after injury, however sometimes the first seizure does not occur until up to five years post-injury. If you are concerned about the possibility of your loved one having a seizure, it is best to ask your physician about it and what you can do. There are many kinds of seizures.

Possible responses to seizure activity: In almost all cases seizure activity can be controlled with drug therapy or anti-convulsant medications. When a moderate to severe brain injury has occurred, the individual will immediately be placed on anti-convulsant medication which may be eliminated or reduced as risk of seizures decreases. Should your loved one develop a seizure disorder, your physician or your local epilepsy society can be a useful source of information on how to respond.

Your loved one may not remember the injury or does not understand the effects of the injury and may want to do things he/she was capable of before injury occurred but cannot do now. While sometimes a lack of awareness is caused by damage to brain tissue, other times it can be a way of dealing with distress when the person with brain injury realizes that something is very wrong.

Possible responses to problems with self awareness: When a person with brain injury does not seem to understand how their injury has affected them, he/she may put their safety at risk. In cases where safety is a high risk, the health care team may use restraints to restrict movement of those who are in danger of hurting themselves. These are last resort precautions however, and usually gentle reminders about the effects of the injury, supervision and assistance are very useful. Self-awareness can return with time and often counseling can help the person with brain injury find solutions to this problem.

Lack of Insight:

Insight refers to the ability to look at oneself, to realistically assess strengths and weaknesses and understand one's own behaviour. A person with brain injury may have difficulty seeing and accepting changes in thought processing and behaviour that may have occurred due to injury. This may be the result of tissue damage to areas of the brain responsible for insight but sometimes there is a psychological component to this issue. Lack of insight may serve the purpose of protecting ourselves from painful and distressing changes we witness in ourselves and over which we have limited control. In a person with brain injury, this state may result in poor judgment and/or behaviour, taking unsafe risks and moodiness.

Possible responses to lack of insight: Provide frequent, clear and simple explanations of why the person is unable to do something. If he/she continues to deny or find excuses for these problems it may be better to change the subject rather than try to argue or reason with him/her. In this way, it is possible to leave intact the defenses needed to cope. In a clear and matter-of-fact manner, tell your loved one about some of the problems he/she is having that require rehabilitation and emphasize the things he/she can do. You can reassure the person with injury (e.g. "I know it must be very hard for you but try to understand that this will help") and support your loved one in making short-term, achievable goals and as insight develops, broader goals and plans can be made. Persons with injury often report that discussions with others who have survived brain injury is helpful. Hearing about the challenges and successes of others can open the doors to deeper insight and acceptance of the consequences of one's own injury.

Memory Problems:

One of the most commonly experienced consequences of brain injury is impaired memory. Rarely are persons not able to remember their lives before injury. However, when these remote memories have been affected it is referred to as **retrograde amnesia** and is generally short-lived as the amnesia can resolve over time.



When the short term memory has been affected, remembering people's names , appointments, the whereabouts of items in the home or getting lost around town can be problematic. Persons with severe injury may forget what has occurred from one day to the next.

Possible responses to memory problems: As with most effects of brain injury, memory problems tend to improve somewhat in the first few months. However, impaired memory usually continues to have some lasting affects for many persons with brain injury. The impact of memory problems can be minimized by developing ways to compensate for them. For instance, the person can carry a notebook to write down names, addresses, appointments and other important details. Buletin boards, calendars and visual reminders that are placed where they wil catch the eye can be useful in providing aids for memory. Some people have found it useful to pre-record daily messages on tape that remind them of steps in the tasks and routines planned for the day.

These types of strategies to compensate for memory problems should, if possible, be implemented with the assistance of a knowledgeable professional. Memory has many components and without appropriate assessment and training in their use these strategies will not be of use to the injured person.

Impulsive Behaviour / Lack of Inhibition:

Persons affected by brain injury can be very impulsive and/or act irresponsibly if they have lost the ability to stop and think before acting. This can lead to sily mistakes or potentially dangerous or embarrassing situations. For example, he/she may disregard courtesy rules, make inappropriate remarks, swear a great deal, or behave in ways that put him/herself and/or others at risk.

Possible responses to impulsive behaviour/ lack of inhibition: Supervision around potentially dangerous situations (ie. crossing roads, operating equipment, etc.) may be needed at first. As time goes on, the recovering person can be supported in controlling impulses. It often helps to clarify what is acceptable and unacceptable in a given situation. You can help your loved one control disinhibition by targeting one simple behaviour to start with. Explore with him/her other ways of behaving that might be more useful. Have the person repeat back to you the alternatives he/she will try and give praise when she/he has demonstrated these alternatives. Try to give rewards immediately at first and then gradually delay praise as the person successfully curbs the undesirable behaviour. A person with brain injury sometimes has difficulty seeing the affects his/her behaviour has on others. Feedback and role modeling from peers can sometimes be much more effective than that given by family and therapists.

Problems with Irritability / Temper Outbursts:

This issue is related to impulse control and the unpredictable mood swings and exaggerated emotional reactions that are also a common effect of brain injury. Persons with brain injury may often have a low tolerance for frustration. They may become agitated or angry in situations such as being kept waiting for an appointment, exposure to busy social situations, difficulty with task completion, etc. and their anger may be disproportionate to the circumstances. Your family member may become aware that skills and abilities that once came easily are now difficult or unmanageable. Such experiences can create frustration and anger that may be directed at others or at the self.



Possible responses to problems with irritability / temper outbursts: It is important to remember that these problems are related to brain injury. Don't take anger directed at you personally and try to be calm and consistent in your response. It may be useful to direct the person with injury away from the anger provoking situation, leave the room yourself, or change the focus to another topic. It can be useful to help the person become aware of the situations that seem to increase irritation of anger. It is best to discuss this issue at a time when he/she is relaxed and to do so in a gentle manner. If possible, try to identify the situations that seem to agitate and frustrate your family member and help him/her avoid them if you can. Sudden changes in routine and unexpected events may provoke agitation and anger. It is useful to give as much warning and explanation as possible prior to changes or uncontrollable situations.

Given time to reflect, a person with brain injury is often remorseful about the outburst. Let him/her know that you are willing to help. Rather than criticizing, explore other ways of dealing with a difficult situation that have worked before or come up with some new possibilities that give the person a sense of control. Look for times when your family member improves the way he/she manages a situation that has proven difficult and praise him/her for these efforts.

While coping with these situations can sometimes get the better of any of us, it usually makes matters worse to retaliate with one's own anger. It can help to let off steam with a supportive peer, friend or counselor. Educate all friends and family members to react consistently when the person with brain injury becomes irritable or aggressive.

Problems Talking Excessively / Repeating Information:

This difficulty is linked with injury to the areas of the brain (usually frontal lobe) that help a person regulate, monitor and evaluate behaviour. Repetition may also be the result of agitation and anxiety.

Possible responses to talking excessively / repeating information: Listen to the person and let him/her know that you have heard what is being said. If need be, the individual's attention can be redirected by changing the subject and gently letting him/her know that you have something else to discuss.

Problems With Socially Inappropriate Behaviour:

Brain injury may affect social judgment. A person with brain injury may be inappropriately familiar with others physically or emotionally due to damage to the areas of the brain that affect judgment.

Possible responses to socially inappropriate behaviour: When a person has exercised poor judgment while interacting with others, those people can ask that the person to stop the behaviour using a quiet, non-threatening tone and offering alternatives that would be more acceptable. For example, a hand shake can be suggested instead of touching or holding which may be offensive to another. It can also be helpful for family members to provide some coaching to the person with injury prior to participation in social situations. Inappropriate sexual comments can be responded to by quietly letting the person know that you do not like what they have said, changing the subject or walking away if they persist.

Problems with Decision Making and Planning:

Executive functions are the abilities that involve planning and responding to problems and decisions that we encounter in day to day life, be they small or large. Included is the ability to size up a problem and determine what is required, developing an action plan from among possible choices,

carrying out the plan, getting information on how the plan worked and making the adjustments needed to reach the goal. When injury disrupts this process, the person may not think to begin an activity, plan future tasks and goals and/or may only be able to react to events that occur in his/her surroundings.

Possible responses to problems with decision making and planning: We learn these skills slowly over time, beginning in early childhood. By the time we reach adulthood, we have planned and carried out so many decisions that the steps we take through the process become second nature and we give little conscious thought to them. Remember now that your family member may have lost these skills as a result of the injury and may need to re-learn them all over again. Here are some guidelines to help your family member re-learn these skills and build confidence:

- ▶ explain tasks and activities before you begin;
- ▶ depending on your family member's abilities, begin with simple, one-step tasks and gradually move on to multi-step tasks to promote success and build confidence;
- ▶ talk through each step while guiding the person as he/she carries out the task, repeating and explaining the steps as you go;
- ▶ once your loved one is able to handle multi-step tasks, he/she can go on to participate in the planning and organization of a new task. Have the person write down the steps involved to guide him/her through the task before following through;
- ▶ go back and review how your family member managed the task. Be sure to acknowledge successes and be matter-of-fact about mistakes.

Difficulty Learning New Concepts:

Due to impaired memory, and especially in the early stages of recovery, a person with brain injury may have some difficulty retaining information and in learning new concepts, skills and knowledge.

Possible responses to difficulty learning new concepts: It is important to be aware of abilities and areas of strength prior to injury and to be mindful that, for the time being at least, the person will not be able to do things he/she was not capable of or did not do well before the injury. The learning of new skills and information should be reserved for the later stages of the recovery process or when the individual demonstrates the capacity to absorb and retain new concepts and information. Effective learning usually occurs

as a reaction to real events and requires the use of both sides of the brain. In order that these conditions be present, the individual should ideally be relaxed. It is generally not helpful to pressure a person with brain injury in the pursuit of learning.

However, when the person is ready, it helps to structure learning experiences beginning with simpler skills. If success is not forthcoming on the first few attempts, it may help to break tasks into smaller steps to ensure success. Consistency and repetition are usually essential for new learning.

Brain injury creates significant loss experiences for injured persons and those closest to them. The survivor may gradually become aware of the loss of abilities in areas where they had previously been quite capable. There may be chronic changes resulting from injury that prevent the person from activities that once gave a sense of value and meaning to their lives. Family members may need to come to terms with persistent personality changes that mask the many aspects of the person they knew and loved prior to injury. While some persons may regain much of their pre-injury functioning, others may have lasting effects. The realization of such losses is often in rapid succession, presenting ongoing challenges to them and their families to adapt and accept changes and new limitations. Thus, the person with brain injury and their family members are often forced to face an ongoing string of losses and transitions and do not have the opportunity to complete the grieving and adjustment process. Under the circumstances, it is not uncommon for the person surviving brain injury as well as family members to experience grief reactions or depression and for these experiences to subside and re-emerge over time.



There may also be a biological basis for the emotional reactions. Cell death is often accompanied by hormonal changes. Changes in brain chemistry can cause or increase depression. At first, the person with injury may not be able to make sense of their emotions. But as the brain begins to function better, the person can begin to sort through feelings and thoughts and be able to gain from their experiences.

Possible responses to loss and feelings of depression: It is usually helpful to listen and acknowledge feelings of sadness, guilt, frustration, helplessness and anger that often accompany loss and depression and to appreciate that such experiences are part of the healing process. Some people need more time to do this than others as these emotions come and go. Keep the person with injury as well as other family members informed of progress and support their participation in planning and

decision making. This can aid in combating feelings of hopelessness and give one a greater sense of control.

While it may be important to let these feelings run their course, supporting feelings of hopelessness and helplessness on an ongoing basis may not be useful. Rather than dwelling on what is lost, recognizing growth and building on strengths and abilities fosters a sense of competence. Get ideas from rehabilitation professionals as to activities your family member can manage independently. Try to avoid doing things for your loved one that he/she can do for him/herself. Encourage the person to make his/her own decisions whenever possible. Allowing him/her to handle family and community responsibilities promotes feelings of belonging and can provide a sense of purpose, personal worth and self-determination.

When hopelessness and depression seem to be hanging on, a counselor, social worker or psychologist will know how to help. If the person begins to talk of plans to end his/her life, it is important to contact one of these people or the family doctor.



Family health and adjustment

Considering the demands of living with a person who has had serious brain injury, it is not uncommon for family members to become over stressed and exhausted. The effects of brain injury may require drastic lifestyle changes resulting in changed family roles and increased responsibility for all family members. Problems that existed for the family prior to the occurrence of injury may now be all the more difficult and demanding. Family members often experience feelings of guilt, self-blame, anger and despair or they succumb to emotional numbing so as to keep highly charged feelings under wraps. These are hardships and stressors that can pile up and intensify the stress that family members face. The following suggestions have been useful to many families:

EDUCATE YOURSELF - Learn as much as possible about brain injury. The more information you have the better prepared and in control you will feel. You will also find it easier to participate as a decision-maker and team member when you are well informed. Don't be afraid to ask questions.

COMMUNICATE - Talk with the appropriate health care team members about your concerns. Share information with other family members. Keeping a journal of questions, concerns, information and notes can help put things into perspective and can be used to jog the memory under stressful conditions.

BE AWARE OF YOUR FEELINGS - Under the circumstances, tempers can flare easily and emotions can be "dumped" onto others which can add to family strains. Discussing your experiences with another family member, a friend, a support group or a professional can help to generate new ideas and diffuse highly charged emotions.

REACH OUT TO OTHERS - Many people seem to have difficulty asking for help, yet when others reach out to them, they think no less of the person asking and are glad they could lend a hand. There are several professionals who have the ability to help with the many issues you are confronting now. Any member of the health care team can be a good source of information and support. The staff of the Patient/Family Counseling and Psychology Departments are there to assist you with information, support and counseling. BrainTrust Canada can also help with these issues through the Family Support Coordinator and a family support group. You may also have a network of relatives and friends through your church, work, leisure and neighbourhood who would be pleased to lend a hand.

TAKE CARE OF YOURSELF - Although this may seem like a time when the person with injury is in great need of your undivided attention, it is important to remember that the demands on the family will not be resolved when your loved one is released from the hospital. Often quite the opposite is true, particularly if there are plans to have him/her come home to live with you as he/she continues to recover. At least for awhile, your loved one may still have many of the care needs he/she had while in the hospital. In some cases, in-home care and assistance can be provided but in other cases little or no help may be available. You could be the all purpose care provider and coordinator in addition to the other responsibilities you now have in the family. You will need all of the energy you can muster, so while your loved one is in hospital you may want to consider this a good time to catch up on all the sleep and self-care you can. Even if your loved one may be going directly to a residential rehabilitation program, the demands and extra responsibilities can be ongoing and will begin to take their toll on you. The road to recovery from a serious brain injury is usually a long one. If you allow yourself to "burn out" early in the process you might soon find yourself unable to adequately attend to the many responsibilities you have.

LET YOURSELVES "LIVE" - The initial crisis is over and rehabilitation is beginning to wind down. You stop for a moment and look back on your life and that of your family since the injury occurred. You realize that in the past several months, or perhaps even years, everyone's life has revolved around dealing with the consequences of the injuries. If you are like many family members, you put your lives on hold while responding to the immediate needs and concerns related to the injured person's recovery. You have realized how fragile life is and now more than ever, may want to protect your loved ones from any further suffering. While some of the damage may linger, it may be time to think of rebuilding. You may begin to recognize that life goes on in spite of the devastation that has occurred in your family. Although the losses may be undeniably great, you have been left with something that is still worthwhile and perhaps discovered strengths in your family you might otherwise not have found.

There will come a time when you can allow each other, including the recovering person, the dignity of risk, the opportunity to rediscover the rich possibilities life can still offer. There may be fear but if you stay with it, joy will revisit your lives once again.

Practical issues affecting the family

Brain injury in the family may raise concerns that require important decisions affecting the present and future welfare of the injured person and the rest of the family. Identifying and acting on these concerns early can reduce stress and prevent a crisis from developing in the future. The social worker in the rehabilitation unit can help you address the following issues:

Legal Issues: In some cases it may be advisable to consult a lawyer. Most lawyers experienced in brain injury cases do not charge for an initial consultation regarding the family's rights. Before discussing your case, the family should ask if there will be a fee for the initial meeting. You are not obligated to retain the lawyer after an initial consultation. You may want to check with a few to see with whom you are most comfortable and who has the most court experience with brain injury cases. Your nearest Brain Injury Organization can suggest pertinent questions to ask when choosing legal counsel.

Financial Issues: Your family member may need help with financial affairs and decisions that may require the involvement of the public trustee. The injuries may have resulted in the loss of a major source of personal or family income and financial assistance may be required. The B.C. Medical Plan will cover many of the costs of rehabilitation and you may be eligible for disability pensions or insurance. There are other programs for which you may qualify if in need.

Community Resources: A person with brain injury may not be able to return home directly after release from the hospital and a placement in a community-based rehabilitation program or supported living environment may be required. He/she may not be able to return to independent living without extra help, or may require assistance in vocational rehabilitation. There are community resources that may be available with respect to these matters that you can inquire about.

Personal and Family Issues: You or your family member may have personal, marital or family problems that require attention. You can ask for some assistance with these matters.

Many of these issues may present concerns for you at this time and you needn't feel you must tackle them alone. Talk with the social worker in the rehabilitation unit or the Family Support Coordinator of your local Brain Injury Organization to get more information and/or assistance with these matters.

Glossary of Terms

Family members of a person with brain injury will encounter many professionals during hospitalization and rehabilitation. When discussing treatment plans and recovery progress they will often make use of clinical terms not often understood by the lay person. The following list provides definitions of some of the terminology frequently used by health care providers working with persons with brain injury.

agraphia	the inability to express thoughts in written form.
anomia	the impaired recall of words with no impairment of comprehension or the capacity to repeat the words
anoxia	occurs when blood flow to the brain is reduced, depriving the brain of oxygen and causing damage.
aneurysm	a weak section in an artery wall. Immediate treatment is required if pressure from blood flow causes the aneurysm to balloon out and perhaps even rupture.
anterograde amnesia	loss of memory for events occurring after the injury.
aphasia	also referred to as dysphasia. It occurs when the ability to express or understand language is lost or reduced. Receptive aphasia is the inability to understand written or spoken language and is often related to injury to the temporal segment of the brain. Expressive aphasia occurs when the ability to express oneself verbally or in writing has been affected. While some individuals may be unable to form the words they are thinking, others may be able to form sounds but the words do not make sense. Expressive aphasia is frequently linked to damage to the left frontal area of the brain.
apraxia	the inability to execute movements when paralysis is not present. For example, the person may not know what to do when handed a shovel or how to put together the movements necessary to open a door. <u>Verbal apraxia</u> refers to the inability to control the sequencing of muscle movements used in speech (the lips, tongue, jaw muscles, vocal chords). It may result in laboured speech, sound reversals and incomplete formation of sounds.
ataxia	occurs when the ability to coordinate muscle movements is impaired or when muscle movements are irregular. The ability to walk, eat, talk and groom oneself can be affected.

brain stem	the lower segment of the brain connecting it to the spinal column. It is responsible for many of the body's vital operations such as blood pressure, pulse and breathing.
burr holes	holes drilled into the skull to drain a hemorrhage. Burr holes may also be made as the first step in performing a craniotomy.
cerebellum	concerned with coordinating balance and movements and is the brain segment located just below the cortex.
concussion	a change in brain chemistry within brain cells that result in impairments to brain function
contusion - bruising	When the brain hits the skull resulting in bruising, it is called a <u>coup</u> injury. If, upon doing so the brain bounces off the wall of the skull and then against the other side of the skull, causing multiple contusions, it is called a <u>contra coup</u> injury.
cognition	the act or process of knowing, perceiving, remembering and awareness based on a learned set of rules and procedures on which thinking is based.
coma	an unconscious state lasting for more than a brief period where the individual is unresponsive and/or cannot be aroused.
cortex - cerebrum	is the large, top portion of the brain. It is comprised of two sides referred to as hemispheres which are connected by a band of tissue. It is responsible for most of our cognitive functions.
craniotomy	a surgical procedure involving the opening of the skull allowing the surgeon to operate on the brain.
cue	a verbal or visual hint or reminder.
diplopia	double vision.
disinhibition	an inability to maintain control over impulses and control behaviours that may be contrary to social norms.
disorientation	being unaware of who you are or where you are in time and space. Clinicians sometimes use terms such as "oriented in all three spheres" or "oriented three times", meaning the awareness of person, time and place.
dysarthria	a slow, laboured, uneven rate of speech usually resulting from the inability to control muscles needed for speech.

dyscalculia	when brain injury or disease has interfered with the ability to do mathematics.
dyslexia	reading difficulties related to the brain's ability to interpret written symbols
dysphagia	difficulty in swallowing or in moving food from the mouth to the stomach.
dyspraxia	a breakdown in a persons ability to deliberately perform a movement/ function even though he/she may be able to do it absent-mindedly.
egocentrism	the tendency to be absorbed with one's own needs and wants to the point where the experience of others is of little concern.
emotionally labile	refers to swift and radical changes in emotions such as rapidly becoming sad, angry, giddy or happy and displaying these emotions with intensity.
Glasgow Coma Scale	a commonly used test which measures the severity of injuries based on level of consciousness related to three factors: eye opening, motor and verbal responsiveness.
flaccidity	a clinical term used to describe reduced muscle tone which causes limpness. <u>Muscle tone</u> is the resistance of a muscle to being stretched. When nerve damage occurs in the brain or spinal cord, the flow of information that allows muscles to 'know' how much tension to release or maintain in the muscle is disturbed.
haematoma	an abnormal collection of blood either inside or outside of the brain tissue.
hemianopsia	blindness involving one-half of the visual field in one or both eyes.
hemiparesis	occurs when injury to the areas of the brain that control motor functions create weakness on one side of the body or part of it.
hemorrhage	internal bleeding that occurs when blood vessels inside the skull or brain have been damaged.
hypotonic	less tension in a limb than normal. The limb feels very heavy and is susceptible to joint damage as a result of reduced muscle tension.
hypertonic	more tension in a limb than normal. One feels increased resistance when trying to move the limb.

incontinence	the inability to control the functions of the bladder or bowels.
inhibitory techniques	special therapeutic methods that are used to improve abnormal muscle tone (flaccidity or spasticity).
limbic system	the set of structures (thought to be contained within the temporal lobe) that play a major role in attention, memory, behaviour and emotions.
motor control	the operations of the nervous system that regulate the timing and the amount of contraction of muscles necessary to produce smooth and coordinated movement of the body. <u>Fine motor control</u> refers to precise and subtle movements such as in threading a needle or rolling or stacking of coins. <u>Gross motor control</u> involves large strong movements such as walking, reaching and grabbing, etc.
muscle tone	the amount of tension in the muscle when it is at rest. Normally, a person's body or limb will feel easy to move when relaxed. When brain injury affects the control of muscle tone, this can cause hypotonicity (less muscle tone results in the limb feeling heavy and floppy) or hypertonicity (too much tone makes limbs feel tight and stiff).
perseveration	involves being stuck on a word or a task and unable to switch back and forth or onto the next word or task.
post-traumatic amnesia	discrimination and memory loss that occurs with injury and may persist for weeks or months and is usually regarded as an indicator of eventual recovery. It affects the organization and retrieval of information about events occurring after the point at which injury occurred.
premorbid	a person's condition before the occurrence of injury.
proximal instability	refers to a pronounced reduction in strength or muscle tone in the trunk, shoulder or hip girdle. It can affect posture, the ability to sit up, hold the head up, and can cause abnormal movements in the limbs.
quadripareisis	a weakness of all four limbs that are not paralyzed.
Rancho Los Amigos Scale of Cognitive Recovery	a tool that is used to determine various levels of functional recovery from traumatic brain injury.
retrograde amnesia	loss of memory for events preceding the injury. It is not usually complete but rather, some things may be remembered while others are not.

spasticity	an abnormal increase in muscle tone which causes them to become stiff and resist being stretched.
spontaneous recovery	healing of injury which occurs with or without therapy in the earlier stages of the recovery process. It is often difficult to determine how much recovery is spontaneous and how much results from rehabilitation.
stimuli/stimulation	anything that can cause a response in the nervous system, sensory system, feelings, thoughts etc. of a person.
ventricles	brain cavities containing cerebrospinal fluid which function as cushions that absorb shock from impact to the brain. The ventricles may enlarge when tissue damage has occurred or if the flow of cerebrospinal fluid is impeded. This can result in a condition known as hydrocephalus.
visual field deficit	occurs when a person is not visually perceiving information in a particular area of the visual field. It commonly involves either the left or right portion of the visual field.

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BRAINTRUST CANADA

A Family Guide
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Reprinted through the generous support of the Sunrise Rotary Club, Kelowna BC.



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