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# THE BRAIN INJURY BOOK

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## A GUIDE FOR PATIENTS AND THEIR FAMILIES

Created by the Patient and Family Education Working Group, Calgary  
Brain Injury Strategy, 2012

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### A Very Special Thanks

To the Glenrose Rehabilitation Hospital in Edmonton, Alberta  
for their permission to adapt their booklet:  
“Coping with Brain Injury”

Also,

To the survivors, family members and care providers, the  
members of the “Patient and Family Education” working group  
of the Calgary Brain Injury Strategy, who put this book together.



# Introduction

## Key Messages

- Brain injury affects virtually every area of a person's life.
- The relationships, roles, and responsibilities of friends and family will experience a period of adjustment.
- It is crucial for family members and close ones to maintain strong support for each other as well as for the injured person throughout these changes.
- Adjustments are best made in small steps with the instruction and guidance of health care team members.

Brain injury is a life-altering event which affects every area of a person's life — including his or her relationship with family members and others close to him or her. The phrase **acquired brain injury** refers to medical conditions that occur to the brain (usually after childhood), changing its function. These conditions include stroke, traumatic brain injury, tumor and other diseases of the brain.

It is virtually impossible to give an early prediction of the final outcome after a significant brain injury. The after effects of brain injury can be cognitive, psychosocial (psychological, emotional, and social) and physical. Often there is no clear relationship between how much disability is experienced by the injured person and the visible, physical damage. This can lead to misunderstanding by the family members and friends. Sometimes there is the belief that if the injured person just tried harder, he or she could get better. Another common belief is that because the person looks alright physically, everything else should be okay.

Family members and others close to a person with brain injury may struggle to cope with behavioural changes caused by the brain injury. It is common for family members to experience a number of feelings as a result of the injury — shock, numbness, fear, anger, anxiety, depression or guilt. If the injury is serious and the injured person's disabilities lead to a significantly reduced quality of life, family members may find themselves thinking that given the choice, the injured person may have chosen not to survive the injury.

As a result of the brain injury, roles and responsibilities often change within the family. Family members and others close to the person may feel stressed, burdened, even depressed by the major changes in activities, responsibilities, daily schedules, leisure and support that are required to adjust to the consequences of acquired brain injury.

Most people with brain injuries are able to go home after rehabilitation. At this time, family members may find that they have to do many of the tasks that were once done by the injured person. Long term dependence on family members is likely if there is prolonged social, vocational or cognitive disability.

This immense adjustment can't be done alone, so it becomes very important to enlist the support of family, friends and community resources. It is important for the family members to look after themselves and their own needs by using personal support contacts, professional support, social service agencies or help through a church affiliation. People need to have useful support while developing new resources to cope with all the changing circumstances in their lives.

For any person who was independent, active in the community, participated in sports or hobbies, held a job, or

had frequent contact with friends - the loss of any of these activities due to the injury can be very difficult to accept. Often the injured person feels useless and depressed. The family becomes his greatest source of support. This support is particularly important during the rehabilitation process.

For the injured person, it is sometimes hard to accept that there may be significant and lasting changes. The seriously injured person may not have the insight to see himself as having any limitations. Because the outcome of significant brain injury is often uncertain, the family may have unrealistic expectations for recovery. Whatever the situation, adjusting to the changes can be stressful.

Often, major adjustments are best made in small steps. Simple changes may help the person with brain injury, family and friends to find more enjoyment in their relationships and activities. By taking each stressful situation one step at a time, the person with brain injury and family may feel that life is becoming a little more “normal” again.

Recovery from brain injury is a process that takes time. In recent years, brain rehabilitation as a specialty has advanced in its understanding of ways to encourage and maximize recovery. Your team will use all available knowledge and techniques while caring for your loved one. Consult any member of the health care team to address your concerns and questions.

This book is dedicated to family members who are caring for a person who has a brain injury. The **Brain Injury Resource Book** clarifies and hopefully starts to answer some questions caregivers must face.

Throughout the rehabilitation process, the injured person and the family will meet with a number of health care

professionals. **Chapter 1** lists these professionals with a brief description of what they do.

**Chapter 2** describes the recovery process and what the family should expect for treatment.

Understanding how the brain functions is one of the first steps in putting brain injury into context. **Chapter 3** specifically examines the structure, functions, and areas of the human brain.

Step- by- step, **Chapters 4 to 8** walk the reader through all of the major problems and disabilities that can occur because of a brain injury.

**Chapter 5** is devoted solely to studying various types of seizures and how caregivers can watch for situations that can trigger seizures.

**Chapter 9** addresses social and emotional issues.

Life after brain injury can be a struggle for both the injured person and their family. **Chapter 10** serves as a guide for maintaining and improving the injured person’s quality of life.

Please note the **Resource** section towards the end of the book. Finding support, networking, and asking questions are necessary tasks when one is caring for a person with a brain injury. Although there are few local services in some regions, this section does cover some critical resources that are available.

For ease of writing and to avoid the awkwardness of he/she, we have used male pronouns throughout the book. This was done for ease, not to imply any gender bias.

## 2. A Team Approach

### Key Messages

- The health care team is dedicated to helping a person following brain injury and their family.
- Patients, families and friends are important members of the team, because they are the true experts.

The health care team is an important source of information and support to the injured person and family. The team can recommend a treatment plan and help to learn skills to meet specific needs.

Family, friends and the person with brain injury are important members of the health care team. Active participation in treatment and rehabilitation is essential to recovery. The involvement of other family members, caregivers, friends and co-workers also can help the person with brain injury successfully return home and to the community.

Health care team members may include:

- **A primary care physician**

The doctor is responsible for medical care and treatment. The attending doctor may have residents, fellows, and clerks working with him or her, making up your “team” of doctors.

- **Nurse practitioner**

A nurse practitioner (NP) is an advanced practice nurse who works with the physician team. They are able to assess and

treat, including ordering tests and investigations and prescribing medications. The NP works closely with the nurses and therapists and are often the “eyes and ears” for the physicians.

- **Physiatrist**

These are physicians who specialize in physical medicine and rehabilitation, including brain injury rehabilitation.

- **Nurses**

Nurses have training and expertise in brain injury care, rehabilitation and discharge planning. The nurse monitors a person’s vital signs and neurological status and performs assessments and interventions. The nurse also assists with daily care such as taking medications, bathing, dressing and using the toilet. Through rehabilitation, they help a person do the things learned in therapy, to increase their independence while in the hospital and prepare for discharge and reintegration into the community.

- **Psychologists and Neuropsychologists**

These are professionals with training and expertise in evaluating and treating thinking, behavioral and emotional changes caused by a brain injury.

- **Physiotherapists**

They are professionals who evaluate and treat changes in physical abilities. Some activities may include strengthening, conditioning, walking, and balance training.

- **Occupational therapists**

They are professionals who evaluate and treat thinking and perception problems, and help an injured person maintain or learn independent living skills (for example: eating, dressing, managing money and safety awareness).

- **Speech language pathologists or speech therapists**

These are professionals who evaluate and treat communication and swallowing problems. They focus on improving social skills as well, and look at cognition as it relates to communication.

- **Recreation therapists**

These are professionals who help a person with brain injury explore and participate in leisure activities. They help to find new leisure opportunities and learn new ways to do previously enjoyed activities.

- **Brain injury coordinators and case managers**

These are nurses and therapists who help coordinate care of patients with brain injury and support and educate their families about the injury and recovery process.

- **Social workers**

These are professionals in the hospital and outpatient settings who help guide the adjustment to acquired brain injury. They provide information on discharge planning, assessment of financial resources, and community resource referrals. They may also assist in addressing stress management and the development of effective coping and adjustment strategies.

- **Dietician**

Makes sure nutritional needs are met. They provide nutrition teaching in the hospital and will also help make food choices at home.

- **Transition coordinator or home care coordinator**

Nurses who provide information about home care services and other options for supported living. Help may be available for activities of daily living, to assist with rehabilitation and goals to maintain or increase independence and for surveillance. A home care therapist may make a home visit prior to discharge from the hospital to identify and organize any equipment or changes in the home that will make it safer and easier.

- **The survivor, family and friends**

This is who makes decisions about a person's care and rehabilitation including their goals and plans. Family and friends can speak for the survivor if they are not able to speak for themselves about their goals and plans and feelings and beliefs. Family and friends can give emotional support and can help practice new skills and techniques to help meet the survivor's needs.

The healthcare team meets regularly to discuss healing, progress and make ongoing plans. In addition to regular, informal updates, a family conference can be scheduled to bring everyone together. If you have concerns, speak with any member of the team.

## 2. The Recovery Process

### Key Messages

- Recovery from a brain injury is a process that takes time.
- Various treatment options and coping strategies can help life gradually feel “normal” again.
- The medical community is gradually realizing how a damaged brain recovers. Current treatment methods are based on a growing understanding of the brain’s recovery processes
- Most adults with a brain injury progress through common recovery stages.
- The length and outcome of each stage cannot be predicted.
- During recovery, a person may shift back and forth between stages; Inconsistency is common

Recovery following a brain injury may be measured in weeks, months or years, and slows with the passage of time. Some of the effects of brain injury can be long-lasting and recovery may be incomplete. Although some people with severe brain injuries experience only mild long-term difficulties, others may require care or special services for the rest of their lives.

In the days and weeks immediately following brain injury, the function of surviving brain tissue is often affected by swelling, bleeding and/or changes in the brain’s complex chemistry. Sometimes blood accumulation must be removed surgically to reduce swelling and pressure within the brain. Controlling swelling and allowing time for the brain’s blood

flow and chemical systems to recover will usually lead to improved function.

In cases of traumatic brain injury, trauma often occurs to other parts of the body, with associated bleeding, swelling and changes in function. The effects of these other injuries can prolong overall recovery and maybe even further damage the brain. For instance, excessive bleeding may deprive the brain of needed blood and oxygen. Prompt treatment of associated injuries may help limit brain damage.

In the first few weeks after a brain injury, swelling, bleeding or changes in brain chemistry often affect the function of healthy brain tissue. The injured person’s eyes may remain closed, and the person may not show signs of awareness. As swelling decreases and blood flow and brain chemistry improve, brain function usually improves. With time, the person’s eyes may open, sleep-wake cycles may begin, and the injured person may follow commands, respond to family members, and speak.

A period of confusion and disorientation often follows, during which the person’s ability to pay attention and learn stops and agitation, nervousness, restlessness or frustration may appear. Sleeping patterns may be disrupted. Overreaction to stimulation and physical aggression may result. This stage can be disturbing for family because the person behaves so uncharacteristically.

Inconsistent behaviour also is common. Some days are better than others. For example, a person may begin to follow a command (lift your leg, squeeze my finger) and then not demonstrate this behaviour again for a time. This stage of recovery may last days or even weeks for some. However, once demonstrated, behaviour usually appears again. In this stage of recovery, try not to become anxious

about inconsistent signs of progress. Ups and downs are normal.

Family and friends can help by creating a calm, quiet environment (for example, limiting the number of people in the person's room, turning off the television and dimming the lights). In addition, ask questions of the nurses and others on the health care team, who are responsible for keeping you accurately informed. You are encouraged to ask questions to stay abreast of your loved one's progress.

Exactly what happens in the brain during the later stages of recovery is not clear, but some parts in the process are becoming clearer. New research is shedding light on brain tissue and its capacity to repair itself. Many things can occur that help restore surviving brain tissue to maximize function. For example, although the total number of brain cells may not change, it is thought that surviving brain tissue has the capacity gradually to learn how to perform some functions of destroyed cells.

Later stages of recovery can bring increased brain function. The person's ability to respond may improve gradually. New research is investigating the body's ability to replace damaged brain tissue. Other parts of the brain, however, may slowly learn to assume functions of the damaged tissue.

Factors such as age and the severity and location of a brain injury can affect, but do not entirely predict, the outcome of recovery. For example, some people with significant brain injuries experience only mild long-term difficulties, while others need lifelong, special care.

## Treatment of Brain Injury

### Key Messages

- A broad range of therapy, testing, and other treatment options are available to help people after a brain injury.
- Treatment for brain injury is tailored to meet individual needs.
- Members of the health care team determine when the rehabilitation process will begin.

Depending on the nature of the brain injury, some people begin treatment in an intensive care unit (ICU) or a general hospital unit, and may be transferred later to a rehabilitation unit. After they leave the hospital, therapy as an outpatient may continue. Some need regular follow-up appointments with a health care provider while some will receive therapy, tests and monitoring on an outpatient basis.

During the early weeks after injury, treatment focuses on stabilizing the person's physical condition, preventing complications such as pneumonia and blood clots, and addressing medical issues that arise (for example, removing blood or other fluid build up to reduce swelling and pressure in the brain).

When the health care team determines that the person with brain injury is ready, the rehabilitation process can begin. Rehabilitation encourages the body's natural healing process through:

- Stimulating and enhancing physical and thinking abilities.
- Teaching new techniques to compensate for lost physical, thinking (cognitive) and behavioural skills.

Early on, therapy strives to keep the person safe and increase awareness of his or her surroundings. For example, the health care team may need to help the person relearn date, time and location and understand what happened with the injury.

As cognitive and physical abilities progress, the focus shifts to improving attention span and mobility, coping with memory and thinking problems and increasing independence in self-care skills. The person may participate in stretching, strengthening, balance and range of motion exercises. Community outings to practice skills learned in the hospital may be included.

How much and what rehabilitation therapy the person with brain injury receives depends on factors such as level of awareness, other injuries such as fractures, the need for rest, and the ability to participate in therapy.

If you have concerns about your loved one's thinking, behaviour or emotions, even years after a brain injury, contact a member of the brain rehabilitation team

### **The family's role in therapy**

What is the role of family and friends in the recovery of the brain injury survivor? The key to relearning more normal movement is **practice**. The injured person spends only a small portion of their day in therapy. What happens during the rest of the day affects recovery. Therapists may have specific advice about exercises or activities that can be done with the injured person on the ward and at home. The safest and easiest methods of doing transfers are a good example of this. "Transfers" refer to moving from a chair or wheelchair to another seat, such as a bed, toilet, bathtub or car. Family and friends can also learn to assist the person when he is walking, managing on stairs and mobilizing in his wheelchair. The goal

is always to enable the person to be as independent as possible while ensuring the safety of themselves and the helper(s).

There is no "normal" or "standard" way of moving. How we do things depends on our age, body build, habits and pre-existing medical and physical well-being. It is important to keep in mind that each brain injury is unique and, therefore, expected outcomes are specific to the brain injury survivor.

When friends and family members are aware of treatment goals and activities, they become partners with the patient and the rehabilitation team in optimizing the rehabilitation process.

## 3. The Brain

### Structure

The brain is the body's control centre. It is made up of billions of nerve cells, called **neurons**, which are arranged in patterns that work together to control thought, emotion, behaviour, movement and sensation. For example, how we think, feel, see, taste, touch, move, control our breathing, heart rate and regulate blood pressure.

Each neuron gives off chemicals that trigger an action in other neurons. These chemicals are called **neurotransmitters** and are substances like epinephrine, norepinephrine, or dopamine. Each cell can send a message to other cells. The speed of the message varies depending on the path to the cell and the connections between them.

How well the brain is working depends on:

- How well each part of the brain is working
- How well the connections are working
- How quickly the messages are sent between the connections of the cells

Information goes through many nerves which connect to certain parts of the brain. One major route from the brain to the rest of your body is through the spinal cord. Messages sent to your brain tells it about things such as hot and cold, pressure, pain, and where arms and legs are positioned. Other nerves carry information from the eyes, ears, tongue and muscles on the face to the brain. These are called cranial nerves. The brain then sends messages to the muscles through a different set of nerves so a person can do things like move, walk, talk and swallow.

The brain is covered by three membranes (skin like layers). These are called the **dura, arachnoid and pia mater**. The brain and spinal cord sits in a clear fluid that bathes the brain and circulates into the **ventricles** of the brain. This is called the **cerebrospinal fluid** or **CSF**.

Several major arteries supply the brain with oxygen and other nutrients. The two vertebral arteries follow the spinal column up into the brain. The two carotid arteries come up on either side of the throat. These four major arteries branch and join to form a network that carries oxygen, nutrients, and blood to the entire brain.

The brain is divided into two halves that look nearly the same but differ in many functions. The halves are called the **cerebral hemispheres**. For most people, the left half of the brain controls verbal functions including language, thought and memory involving words. The right half controls nonverbal function like recognizing the differences in visual patterns and designs, reading maps and enjoying music. The right hemisphere also is involved in expressing and understanding emotions.

Although each half of the brain has distinct functions, the two parts actually work closely together to control the activity of the body. The left side of the brain controls movement and sensation in the right side of the body and the right side of the brain controls movement and sensation in the left side. Thus, damage to the right side of the brain may cause movement problems or weakness on the body's left side.

Left Side	Right Side
<b>Listening, reading, speaking and writing</b>	Judging the position of things in space and knowing body position in space
<b>Memory for spoken and written messages</b>	Understanding and remembering things we do and see
<b>Detailed analysis of information</b>	Putting bits of information together to make up an entire picture
<b>Controls the RIGHT side of the body</b>	Controls the LEFT side of the body
<b>Receives sensation signals from the RIGHT side of the body and space</b>	Receives sensation signals from the LEFT side of the body and space

### Areas of the brain and results of damage

The cerebral hemispheres are further divided into four separate areas called **lobes**. Each lobe has different functions. Damage to different parts of the brain can cause different problems. The specific nature of the problem or problems depends on which part of the brain is injured.

#### Occipital Lobe

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

#### Parietal lobes

Damage to the left parietal lobe may lead to problems in reading and arithmetic. As well, damage to this lobe may cause a loss of sensation on the right side of the body. This means that the injured person has alterations of touch, pain, vision or temperature changes on his right side. Damage to the right

parietal lobe may lead to problems with spatial tasks, like making sense out of pictures, diagrams and reading maps. Damage to the right lobe may cause alteration of sensation on the left side.

#### Frontal lobes

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

#### Temporal Lobes

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

#### Brain stem

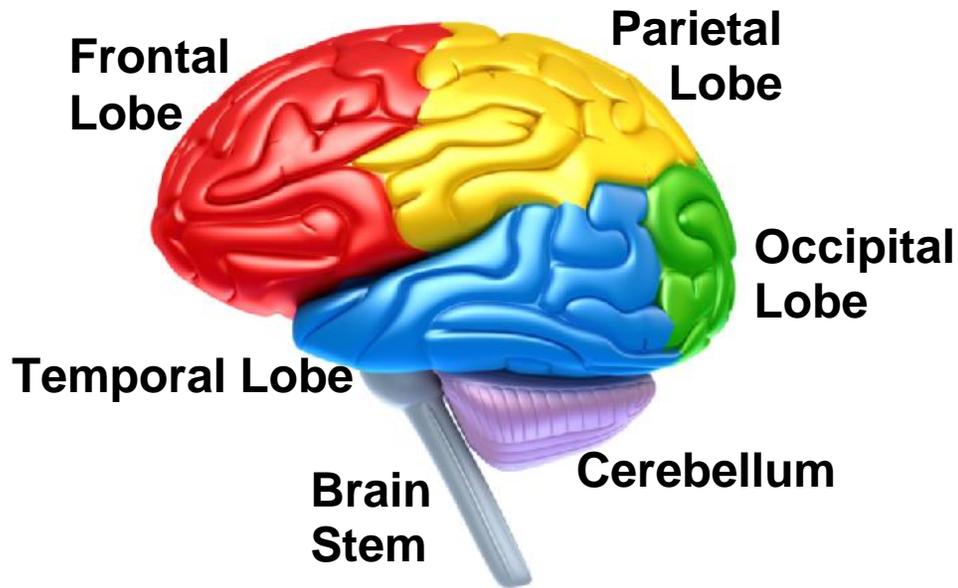
Damage to the brain stem may cause a wide variety of physical and sensory problems. The brain stem is the control centre for breathing and for the heart beat. It gives commands to the muscles of the face, eyes, mouth, and throat. Damage to this part of the brain may also result in the injured person not being able to swallow food.

#### Cerebellum

Damage to the cerebellum may lead to problems in coordination, balance or muscle tone of various body parts.

No two people will be affected in exactly the same way by a brain injury. This is partly because we are all unique and respond differently. Another reason is our nervous system is complex and it's not yet possible to completely predict what will

happen as a result of a brain injury, even when we know what part of the brain is damaged.



### Types of Acquired Brain Injuries

**Acquired brain injury**, or ABI, is an injury to the brain that does not occur at birth. It does not include disease processes that are progressive. ABI can be a **traumatic brain injury**, by causes such as a motor vehicle collision, fall or assault.

ABI can also be non-traumatic, where the brain is injured from an **anoxia** and **metabolic/toxic encephalopathy**, infections such as **encephalitis** or **meningitis**, **brain tumors**, or **aneurysms**, **vascular malformations** or **stroke**.

- **Encephalitis:** potentially life-threatening infection/ inflammation of the brain
- **Meningitis:** an infection and inflammation of the central nervous system that affects the membranes and cerebrospinal fluid surrounding the brain and spinal cord
- **Metabolic/toxic encephalopathy:** encephalopathy, or abnormal brain function, is caused by abnormalities of the water, electrolytes and other chemicals that adversely affect brain function. For example, in addition to liver and kidney waste products, it may be because of abnormally high or low blood sugar levels. Toxic changes caused by poisons such as carbon monoxide, alcohol or drugs can also cause brain injury.

Just like if you hit your thumb with a hammer, it will swell up, swelling in your brain can happen as a normal response to an injury (trauma) or irritation (non-trauma). This is called **cerebral edema**.

There is a balance of brain, cerebrospinal fluid and blood within the vessels of the brain. The skull is a fixed compartment, so any increase in either brain size, or the amount of blood or CSF puts pressure inside the skull which can be dangerous. Pressure on the brain tissue reduces blood supply, and therefore oxygen and causes damage to the cells.

A brain **tumor**, an abnormal growth of cells within the brain tissue can be either low-grade, meaning slow growing, or high-grade, or fast growing. These abnormal cells can originate in the brain (primary) or come from other areas of the body (metastasis). As this growth gets larger, it occupies space in the skull, pushes on the brain, causes swelling and interferes with blood and oxygen supply to healthy brain tissue.

Anything that hampers blood and oxygen from reaching the brain for over 2 to 4 minutes can cause brain damage. For example, drowning, choking, cardiac arrest and hanging can restrict blood and oxygen from travelling to the brain. This is referred to as **anoxia**, or the state where brain cells are deprived of oxygen.

Strokes are the best known results of circulation problems and strokes can cause brain damage. Strokes are caused by an interruption of the blood supply to part of the brain. For example, an artery may be blocked by a floating blood clot (**embolism**), or may become too narrow for blood to flow through it (**thrombosis**, or hardening of the arteries).

Occasionally an artery wall has a weak section (**aneurysm**) which balloons out under the pressure of blood flow. This weak section may burst or leak, causing bleeding inside the brain (**intracerebral hemorrhage**). Surgery is often needed to clip off the aneurysm and remove the blood. An abnormal tangle of blood vessels (**arterio-venous malformation**) can cause damage similar to an aneurysm.

**Traumatic brain injuries** that affect the brain but don't penetrate the skull are called **closed head injuries**. The skull may not seem damaged even when there is considerable damage to the brain. This is usually the result of the head hitting an object, or vice versa. The brain may hit the skull at the point of impact, then bounce against the other side of the skull, and rotate at a high speed.

Whenever the brain is violently shaken or rotated there is a shearing or tearing of tissue. If blood vessels are broken, bleeding may continue until a pool of blood (**hematoma**) builds up, causing pressure on the brain. An **epidural hematoma** is blood between the dura and the skull. A **subdural hematoma** is bleeding below the dura layer. A **subarachnoid hematoma** refers to bleeding under the arachnoid layer of the brain. An

**intracerebral hemorrhage** refers to bleeding inside the brain. An **intraventricular hemorrhage** is bleeding within the ventricles.

When the brain moves around the skull, it can also cause the connections between the brain cells, called axons, to stretch and snap. This is called **diffuse axonal injury** (DAI). Injury to the axons, or the connections in the brain, can lead to a large decrease in how quickly messages get sent from one part of the brain to the other. For example, if the main road through a city is closed, you can still drive across the city but it takes much longer because you have to travel on smaller, slower routes. (You also need to learn the new route!) This is the same effect as DAI.

## 4. Physical Problems

### Visual Problems

Visual problems of any kind are frightening, and make life more difficult for the injured person. Because it can take several months for the nervous system to stabilize, it may be a while before anyone can judge how much visual difficulty is likely to persist. An ophthalmologist will decide on treatment, such as surgery, or a prescription for glasses. Often the injured person must learn new skills to adjust to visual losses.

Normal vision depends upon the following functions working together. All of these functions are controlled by the brain.

- The eyes must move together and focus on something.
- Nerve receptors at the back of the eye (retina) then send messages back along the optic nerve.
- These messages are interpreted by the occipital lobe at the rear of the brain.

If something goes wrong at any point in this chain of events, vision will be affected. The following are some visual problems that can happen after brain injury.

### Drooping eyelid (ptosis)

A drooping eyelid will block vision in the affected eye. It's hard to judge distances using only one eye. The injured person may feel dizzy and not see where steps are, be unsure of how fast things and people are moving towards him, or have trouble pouring liquids from one container to another. It may take awhile for vision to adjust even if the eyelid function gradually resolves.

### Double vision (diplopia)

This happens when the eyes do not move exactly together, and the injured person literally sees two of everything. This makes it hard to decide exactly where objects are. Someone with double vision is likely to bump into furniture, and to drop or spill things. Sometimes an eye patch or glasses with prism lenses are prescribed.

### Blurred vision

This can be like being near-sighted. Close-up vision may be clear, but more distant objects tend to blur into the background. To help someone with this problem, things, such as furniture, need to stay in place and should not be moved without telling the injured person.

### Loss of vision

Damage to some part of the nervous system that sends messages from the eye to the brain may cause vision loss. This loss can be complete or partial. Often some part of the visual field may be missing. For example, the injured person can fail to see things to his left, but be able to see on the right.

A person experiencing a visual field cut may:

- suddenly notice objects that seem to appear or disappear
- bump into objects on the affected side
- turn the head toward the unaffected side
- not see food on the side of the plate on the affected side
- lose track of the last location on a page where the person was reading or writing
- cut words in half when reading and not understand

### To help someone with visual problems

- Remind the person to look around the environment, especially on the affected side.
- Mark “on” and “off” switches of frequently used items, such as televisions and kitchen appliances, with bright pieces of tape so the person can easily know when equipment is on or off.
- Position bright objects or favorite things to the affected side and ask the person to turn his or her head until they spot the objects.
- Draw a straight, brightly colored line down one side of a book or notebook as a cue indicating the edge of the page. Do this on the right side of the page if the right side is affected and on the left side if the left side is affected.

### **Hearing Difficulties**

A blow to the outer ear can cause injury to the eardrum, or a fracture or dislocation of the small bones (**ossicles**) in the middle ear. Injury can also happen in the inner ear, damaging the nerves which allow us to hear. Damage to the part of the brain that controls hearing can cause problems with the process of changing sounds into meaningful messages.

Damage to the outer and middle ear can usually be repaired. However, damage to the nerves of the inner ear and to the part of the brain that controls hearing can't be repaired. Damage to these areas is permanent and will not improve with time.

An **audiologist** (a hearing specialist) will test the injured person's hearing to find the type and severity of damage. If a large loss is found, the audiologist may make a referral to the appropriate specialist, or prescribe a hearing aid.

### **Loss of Sensation**

This may involve the ability to detect movement or position, to feel changes in temperature, or to feel touch to the affected part of the body.

This loss of sensation is very serious when considering personal safety, because the person can't feel an injury. It also makes it harder to relearn movement, since the feeling of moving is missing. At first, movement information must be sensed by thinking about the movement. Rubbing, massaging, and touching different types of cloth can speed the return of the senses by stimulating the nerve endings.

### **Bladder and Bowel Changes**

Brain injury may affect bowel and/or bladder function. The injured person may need help re-establishing and maintaining a pattern of regular bowel and/or bladder emptying.

#### Bowel management

The goals of bowel management include establishing a regular emptying pattern, maintaining dry, healthy skin, and avoiding incontinence, diarrhea, and constipation. Constipation can be caused by reduced physical activity, inadequate nutritional or fluid intake, and confused nerve messages to and from the bowel. Each person is assessed by a physician and recommendations are made as needed.

Bowel problems can occur if the person with brain injury cannot:

- Control bowel emptying voluntarily
- Recognize bowel fullness and the need to have a bowel movement
- Ask for help to the bathroom

- Walk to the bathroom
- Eat enough food with fiber and drink enough fluids
- Plan ahead and allow enough time to get to the bathroom

To maintain optimal bowel function, a person with brain injury should eat at regular times, focus on eating foods with fiber, drink the amount of fluids recommended by the dietitian or physician, and be as active as possible. Meeting with a dietitian to discuss a diet plan may be helpful. The person also may be asked to follow a bowel care schedule, which includes attempting to schedule a bowel movement at the same time daily and establishing regular times for meals.

At certain stages of recovery, your loved one may need to use other methods for bowel emptying (fiber supplements, stool softeners, suppositories, and/or laxatives). These methods typically are not used regularly because they decrease the colon's natural abilities, and these methods may be habit forming. Most individuals with brain injury regain the ability to regularly and effectively empty their bowels.

### Bladder management

People with brain injury also may have a problem with urination (bladder emptying) during the post-injury period. Difficulties with urination that were present prior to the injury (an enlarged prostate in men or a pattern of infrequent urination in men or women) may add to bladder problems after brain injury.

The goals of bladder management include preserving kidney function, preventing incontinence (accidental urination), preventing bladder overfilling and bladder infections, establishing a regular pattern of urination with complete bladder emptying, and maintaining dry, healthy skin in the genital area.

Problems with bladder management may include:

- Urinary retention (an inability to void or pass urine)
- Urinary incontinence
- Increased urgency to urinate
- Increased frequency of urination
- Incomplete emptying of the bladder
- Bladder infections
- Skin problems because of incontinence

The most common reason for bladder problems after brain injury is damage to the frontal lobe of the brain. A less common cause is direct damage to the part of the brain that controls behaviors and memory.

Damage to these areas may result in the inability to:

- Ask for help
- Control urination
- Recall when last urination occurred
- Plan ahead to get to the bathroom
- Walk to the bathroom in time
- Recognize the sensation of bladder fullness or the need to urinate

Early in the care of someone with brain injury, the bladder may be drained continuously through an indwelling catheter (a tube that is inserted and left in the bladder). The urine empties through the catheter into a drainage bag, which also allows for accurate recording of urine output. As the patient improves, the catheter usually is removed.

If the person cannot sense the need to urinate, other approaches to bladder management are considered, including:

- Keeping the indwelling catheter in the bladder
- Intermittent catheterization (inserting and removing a catheter several times a day to regularly empty the bladder)

- Scheduling attempts at urination
- Using an external condom catheter for men
- Using an adult diaper
- Other methods of bladder retraining to control urination may be recommended

To maintain optimal bladder function, a person with brain injury should drink fluids as recommended by the dietitian or physician. It may be helpful to meet with a bladder therapist to develop an individual plan. The majority of individuals with brain injury regain the ability to regularly and effectively empty their bladder.

### Weight Changes

Shortly after a brain injury there may be loss of appetite and subsequent loss of weight. Small, frequent meals, high in calories and protein, are planned if weight loss is a problem. Serving food in small portions will keep the injured person from feeling overwhelmed and stop further loss of appetite. Later there may be problems with too much weight gain, and a lower calorie diet may be needed.

Once his appetite returns, the injured person may go through a period when he eats continually. Sometimes there is a disturbance to the brain injured person's short term memory, as well as a loss of sensation. He may forget that he's just eaten and may not have a sensation of "fullness". He may even have a feeling of hunger just after eating. Or, there may be a disturbance to the "control centre" (**hypothalamus**) leading to less control over actions and emotions. As with some of the other problems, this often gets better over time.

### Swallowing Difficulties

Difficulty with swallowing or moving food from the mouth to stomach is called **dysphagia**. Dysphagia can put the injured

person at risk of having food go into his lungs (**aspiration**) instead of his stomach. Besides being extremely uncomfortable, aspiration can cause pneumonia and can be life threatening.

Symptoms of dysphagia may include:

- Choking
- Coughing
- trouble chewing
- gagging
- food spilling out of the mouth
- a lot of sneezing while eating
- food coming up through the nose
- gurgly, strained voice after swallowing
- a feeling that food is stuck in the throat after swallowing
- congested chest, a lot of phlegm
- continuing tiredness
- sudden weight loss

Problems that affect swallowing may occur after brain injury. Swallowing is coordinated by the brainstem and the brain's frontal lobes. The brainstem, which connects the brain to the spinal cord, relays messages to and from the swallowing structures (mouth, tongue, throat). The brain's frontal lobes control the muscle action of the swallowing structures.

Problems that affect swallowing after brain injury can vary widely and may include one or more of the following:

- Poor head or upper body control
- Decreased lip and tongue strength, range of motion and coordination
- Impaired memory or concentration

If a person seems to have trouble swallowing, a clinical swallowing evaluation and modified barium swallow (a

videotaped X-ray of the swallowing process) may be done. With test results, decisions can be made about treating any swallowing problems.

A person who has trouble swallowing may need nutrition through a nasogastric or gastrostomy tube (feeding tube in the nose or stomach). Having either tube does not rule out the possibility of eating by mouth, but ensures proper nutrition and hydration (fluid intake). How long the tube is in place depends on the person's progress.

Exercises, treatment techniques and positioning may help improve a person's ability to chew and swallow. A speech therapist will teach the person with brain injury and caregivers how to perform these exercises and techniques. As a caregiver, your encouragement and help with the swallowing program are essential. Most people regain the ability to swallow after brain injury, though it may take longer for some than others

### **Changes to Skin**

A brain injury can cause the oil glands in the skin to overwork. This may cause acne on the face, back, and chest. Careful washing with a mild soap and water is important. If needed, antibiotics or skin lotions may be prescribed. Oily hair may also develop. Daily washing with a medicated shampoo is helpful.

Because of the loss of sensation that often happens with a brain injury, the injured person's skin needs to be checked regularly for scrapes, reddened areas, and sores. It is especially important to check the tail bone, knees, elbows and anywhere there is a bone that doesn't have a pad of muscle or fat to protect it. The nursing staff can give you more information on skin problems and skin care.

### **Fatigue**

Fatigue is very common during brain injury recovery. Fatigue may result from the injury (and other injuries in cases of trauma) or from additional physical and mental effort required to do tasks that once were performed with little or no effort. Physical functioning, attention and concentration, memory and communication can be adversely affected by fatigue.

The injured person will need more sleep at night and may have to take mid-day naps. He will tire easily because even simple self-care actions and movements require deliberate thinking. Too much activity or the loss of ability to block out sights, sounds, or movements can also cause fatigue.

Often, the injured person is embarrassed about his fatigue and denies that he is tired. The trouble is that he may then push himself to exhaustion and possible physical set-backs. To avoid strain, it is important to encourage the injured person to rest in a quiet, non-distracting room, and go to bed early at night. Important activities should be done when he is feeling best, often in the morning. If an activity is planned for later in the day, a rest may need to be taken first.

When a person with a brain injury first returns home, knowing how much that person can or should do can be difficult. Often during this transition, the person and family members become discouraged with the slow pace of recovery, changes in responsibilities, or they may try to do or expect too much. This is just one step in the recovery process. In time, the person's stamina and energy level likely will improve, and the ability to engage in activities may be increased.

### To help someone with fatigue

- Encourage use of a calendar or planner to help manage mental fatigue.
- Set a schedule that includes regular rest breaks or naps (for example, one nap in the morning and one in the afternoon after some activity, physical or mental). Rest breaks or naps should not exceed 30 minutes.
- Avoid evening naps.
- Gradually decrease the length and number of breaks as the person's ability to tolerate activities with less fatigue improves.
- Resume activities gradually, over weeks or even months.
- Start with familiar tasks the person can complete without fatigue.
- Encourage breaks, every five minutes, during tasks, before or as soon as signs of fatigue appear.
- Gradually increase the complexity of the task, encouraging breaks as needed, to slowly increase the length of time.
- Watch for signs of fatigue, such as increased inattention or distractibility, repetition of tasks or comments, irritability or increased errors.
- If the health care team recommends, use assistive aids (for example, a cane for walking) to conserve energy or a wheelchair for long distances.
- Plan ahead for fatiguing activities, such as visitors, trips, going out.
- Schedule a nap before visitors come or before going out.
- Consider limiting the person's time with visitors or a rest break during visits.

### **Dizziness and headaches**

The injured person may talk of feelings of lightheadedness or dizziness because of an upset in his sense of balance or an upset in his circulatory system. These symptoms are often related to the way he moves. A change from lying flat to walking should be done gradually. **Vertigo** (a feeling of moving in space or of things moving around you) can also happen. Moving slowly can help to reduce the sense of vertigo.

A feeling of faintness is less common. It may be due to an upset of the circulatory system which can cause a drop in blood pressure. Some people have headaches because of scalp bruising, head trauma, sinus injury, eye strain, or tension. It is important to find out the type of headache pain, its site and frequency before treating it. Headaches, fatigue, vertigo, dizziness, and faintness should all be reported to the injured person's nurse and doctor.

### **Difficulties with movement**

Our highly complex nervous system allows us to move normally. A brain injury causes changes in this complex system, interfering with its operation. Messages from our senses travel up nerve pathways to the brain to provide information about what is happening outside or inside the body. The messages are processed in the brain. The brain then sends return messages down the pathways to muscles. A brain injury may damage part of the nervous system, causing an interruption in these pathways which in turn causes a change in the quality of movement.

Physical therapy begins with an assessment of the injured person's physical status and abilities. After the assessment, therapists will plan a treatment program to help the person reach their highest possible level of motor function. For one person this may mean walking; for another it may mean sitting

upright; for another it may mean doing complex activities such as running or playing sports.

The following key areas are assessed:

- Sensation
- Vestibular function
- Muscle tone
- Muscle strength and motor control
- Coordination
- Posture
- Balance
- Endurance
- Range of motion
- Functional mobility – bed mobility, transfers, walking, stair climbing

### Sensation

Sensation gives us feedback about how we are moving, what we are feeling and what is going on around us. Forms of sensation include light touch, pain, temperature, the movement of joints and muscles and vision.

### Vestibular function

Vestibular function depends on a complex system of sensory receptors located in the inner ear. The vestibular system tells us how we are moving relative to the environment and gravity.

After a brain injury or stroke, a person may experience dizziness. Possible causes include bleeding in certain parts of the brain, trauma to the balance organ in the inner ear or as a side effect of medication. Debris displaced in part of the inner ear may cause dizziness brought on by position changes.

When indicated, referral to a physical therapist specialized in the assessment and treatment of vestibular disorders will be made.

### Muscle tone

Muscle tone is the amount of tension in a muscle when it is at rest. When muscle tone is normal, a person's limbs and body feel easy to move. Brain injury may damage the normal control of muscle tone. This may cause **hypotonicity** (less than normal muscle tone; limbs feel floppy and heavy) or **hypertonicity** (more than normal muscle tone; limbs feel stiff and tight). Both of these states will affect the injured person's ability to control movement.

### Muscle strength and coordination

After a brain injury, muscles may show variable degrees of weakness. Within one limb some muscles may be stronger than others. It is helpful to assess how smoothly, accurately and quickly muscles can be used (**coordination**). Damage to certain parts of the brain may result in slow, jerky, or uncontrolled movements.

### Posture

The head and neck provide a stable base for normal use of the eyes, mouth and tongue. The trunk, i.e. the body between the shoulders and hips, provides a stable base for the use of the arms and legs. The head, neck, and trunk need to be properly positioned when the person is standing and sitting for normal movement to occur.

Brain injury can affect the muscles that control head, neck and trunk positions and can, also, distort the sense of what is midline or upright. This may be caused by faulty information coming from the senses about position, limited range of motion, abnormal muscle tone, pain or weakness. It may, also, be

caused by the fact that poor posture has become a habit over the individual's lifetime.

If posture is abnormal or poor, help may be given by asking the individual to concentrate on what he/she feels, reminding him/her to visually check how he is sitting or standing or by physically assisting the individual to achieve an erect and midline posture

### **Balance**

All of us make continual adjustments to ensure that we maintain our balance. After a brain injury, the injured person may react too quickly, too slowly, or not at all, when faced with challenges to their balance system. To improve balance, therapy may involve practicing activities in variable situations, for example, walking on different surfaces such as carpets, tile, rough concrete and snow.

### **Endurance**

Endurance refers to strength over time and can be measured by a person's tolerance for treatment, tolerance for increased intensity of treatment, or, for example, by the distance a person can walk and the speed that a person can achieve when walking.

Fatigue is the most common physical complaint (and the most long-lasting one) reported by brain injury survivors. Fatigue may be due to several factors, including:

- Increased energy demands of the healing brain
- Deconditioning (due to inactivity from spending weeks in bed)
- Pain
- Sleep disturbances

- Infections
- Complications affecting brain recovery, e.g. increased swelling around the brain
- Other medical conditions, e.g. anemia, respiratory conditions, diabetes

## 5. Seizures

Electrical activity in the brain is normal but if a person has sudden, excessive, and disorderly electrical activity, a seizure occurs. The actions or behaviors you see when a person has a seizure are responses of the body to electrical messages sent out by the brain.

After a brain injury, there may be a scar tissue in the brain. This scarring can make the person more likely to have seizures. This is often called a seizure disorder or **post-traumatic epilepsy**.

Seizures are most common in the first year after injury, but the first one can occur anytime up to five years after the injury.

### About seizures

- A person having a seizure cannot swallow his tongue.
- A person having a seizure will rarely die.

### Types of seizures

There are different types of seizures. Seizures are generally categorized into two types, generalized (grand mal, tonic/clonic, absence) and partial (complex partial and simple partial) seizures. Look and watch for these actions and behaviors.

#### Grand mal seizures (tonic clonic seizures)

- Usually lasts 2 to 5 minutes but may last longer.
- The person may cry out, become unconscious and fall.
- It affects the entire body.
- Muscles of the arms and legs stiffen and then have jerky movements.
- He may bite his tongue (he cannot swallow his tongue).
- Foamy saliva (spit) may come from his mouth.

- The person may stop breathing for a few seconds only (his face may turn blue).
- Jaws are clenched.
- Hands are clenched.
- Eyes may be open.
- He may lose control of his bladder or bowel.
- Breathing sounds like snores (this snoring means that the seizure is almost over).
- After the seizure the person may be confused, his speech may be slurred, he may be depressed, he may complain of a headache.

#### Absence Seizures

- Lasts for only a few seconds.
- The person suddenly stops talking.
- He will have a brief lapse in awareness of what is happening around him.
- He may stare, blink, or have eyelid flutters.

#### Complex partial seizures

- Usually lasts a few minutes.
- The person may smell a funny or odd smell.
- He may have a funny taste in his mouth.
- He may have a sense of déjà vu.
- He may smack his lips or make chewing motions.
- He may pat a part of his body or pick at his clothes while in a dreamy state.
- He may have difficulty talking or not be able to talk at all.
- He will usually be unaware of any activity during this type of seizure.
- He may be confused or drowsy after the seizure.

#### Simple partial seizures

- Usually lasts a few minutes.
- The person does not lose consciousness.
- He may have a sense of déjà vu.

- He may jerk involuntarily or shake one of his body parts.
- These may spread to other body parts and become generalized.

### **First aid for seizures**

- Protect the person from injury.
- Put something soft under his head, move objects away, help him to the ground.
- Loosen tight clothing such as a necktie or belt and remove eyeglasses.
- Position the person lying on his or her side. This will allow saliva to drain from the mouth and prevent the person from choking.
- Do not restrain (hold) the person down.
- Do not put anything in his mouth.
- Clear away hazardous objects that may be nearby.
- After the seizure, the person will usually be temporarily confused and drowsy. Some people need to sleep after a seizure. Do not offer food, drink, or medication until the person is fully awake.
- Call 911 for an ambulance, if breathing does not resume after the seizure, another seizure begins before the person recovers from the first seizure, the person has been injured during the seizure, or the seizure lasts longer than 5 minutes.
- Keep a diary of all seizures. Record the date, time of day, what the person was doing before, during, and after the seizure, and how long the seizure lasted.

### **Drugs to control seizures (anticonvulsants)**

Controlling seizures is very important. Drugs are the primary treatment for seizures. It will take about 2 weeks to adjust to a new medication or dosage change.

Drugs do have side effects. It is important to talk to the doctor about the side effects of the drugs.

### **Important points about anticonvulsant drugs**

- The drug should be taken at the same time every day.
- Know the name of the drug and the exact dosage.
- Do not suddenly stop taking the medicine.
- The injured person should not drink alcohol. Alcohol may change the way the medication works, and, also increase the risk of seizures.
- Check with the doctor or pharmacist before new drugs are used, even over the counter drugs like cold medicines or headache tablets.
- Have the doctor take regular blood tests to check drug levels in the injured person's blood.

### **Causes of seizures**

Seizures may happen even when the injured person is taking anti-convulsant drugs. Things that can cause seizures include:

- Fever
- drinking alcohol
- sick with flu, or colds
- emotional upsets
- fatigue
- low blood sugar
- poor nutrition
- flashing lights such as video games
- loud noises
- constipation
- menstruation
- reduced oxygen supply

## 6. Cognitive Difficulties

The kind of changes in cognition, or cognitive disabilities, that a brain injured person will have depends on a number of factors:

- the part of the brain that was damaged
- the severity of the damage
- the stage of recovery
- pre-injury factors such as personality, age, intelligence, education and work background.

It's hard to predict just how a person's thinking will be affected by a brain injury. We do, however, know that there is a generally predictable pattern of recovery soon after a serious brain injury. One scale that is often used to describe cognitive disability and recovery is the **Rancho Los Amigo Scale**.

### Levels of cognitive functioning

The **Rancho Los Amigo Scale** is a ten level scale that describes the general pattern of recovery after most brain injuries. People with brain injuries don't usually move quickly or clearly from one level to another. In fact, they often show characteristics of more than one level at the same time. The following section describes what you can see at each level and some of the things you can do.

#### Level 1: no response (total assistance)

At this early stage, the injured person appears to be asleep. He doesn't respond to sound or touch, or see things. He is not suffering, physically or emotionally at this stage. They will likely be in the ICU as they are not able to protect their airway and breathe on their own.

#### Level 2: generalized response (total assistance)

At this level, the injured person still appears to be asleep most of the time, but does respond inconsistently and without purpose to some stimulation, such as sound or touch. His responses are limited, and are often the same, even to very different stimulation. Pain will likely cause the first response. At this stage he does not have well developed thoughts or feelings.

#### Level 3: localized response (total assistance)

At this level the injured person will seem more alert for short periods of time. He will begin to respond in a more consistent way to general stimulation. He may follow simple commands, such as closing his eyes or squeezing your hand. At this level the injured person will begin to respond to discomfort by turning away when being suctioned or by pulling at the catheter or feeding tubes.

#### Suggestions for the family for level 1, 2, and 3

In general, Levels 1, 2 and 3 are a time of low activity or underactivity. The goal is to first begin to develop responses to sensory information (touch, sound, smell, sight) and then to slowly increase the frequency, rate, duration, variety and quality of responses. Go slowly. Over stimulating will not make the brain heal any faster.

- Talk to the injured person in a calm, slow, normal voice. Say the things that are important to you and the injured person. Do not expect him to remember the things you said.
- Each time you see him, say who you are. Tell him the day and the date and that he is in the hospital. Tell him how he was hurt and that now he is getting better.
- Explain to the person what you are about to do, for example "I am going to move your leg".

- Speak in reassuring tones. The ability to hear often comes back before the ability to understand what is being said. The tone of voice is more important than what is being said. Even though it may be hard to have a relaxed tone of voice in these early stages, it is far more meaningful to the injured person than the actual message.
- Even though the injured person, at this stage, can't understand everything that is being said, don't talk about his condition as if he wasn't there. It's a bad habit to develop, and can lead to talking about him later on, when he is aware of being treated like a non-entity.
- Continue to calmly show affection in whatever way you can.
- Talk to him about familiar people and things, names of family members and close friends, school and jobs, holidays, hobbies, etc.
- Now and then play the radio or tapes of music that the injured person would enjoy. Don't leave it on all the time or it will become background noise.
- Keep a journal in which a daily record of the injured person's progress can be recorded. This can also serve as a means of communication between family members and members of the health care team.

Take care of yourself. Especially in the very early stages of the injured person's recovery, you may be afraid to leave the hospital because you are worried and you want to help or you may be afraid that the injured person won't survive. In the later stages there's more that you can do that will help. It is important to learn to pace yourself early. Get enough sleep. Build in some things that you find relaxing, and get some exercise. Eat at least one, preferably three, nutritious meals every day. Work out rotating visiting schedules with other family members. Let people help you with things that they can do, like meal preparation. Such favors will help to reduce your other worries and allow others to feel helpful.

#### **Level 4: confused – agitated (maximal assistance)**

This new stage is very different from Levels 1 - 3 and can be frightening for family members. The injured person shifts from being underactive to overactive. His behavior can be unpredictable and bizarre; he may scream or cry for no apparent reason, may be aggressive or agitated and his speech may be unclear and irrelevant. At this level of recovery, the injured person will have a poor memory for new information and may make up stories. In fact, the only memory he has is for things that happened before the brain injury. He may be very confused and frightened. For their own safety, restraints may be used. He is not able to pay attention for very long and will likely need a great deal of help with self care.

#### **Suggestions for the family for level 4**

- **Remember this is a stage, a sign of improvement; it is not a personality change.**
- Frequently remind the individual of the day, time, and place.
- Limit the number of visitors to one or two at a time.
- Reduce the number of things going on at any one time. For example, don't talk to the injured person, play the radio, feed him, stroke his arm, and visit with other visitors all at the same time. He needs structure and order. Too many things happening at one time will add to his confusion.
- Communication is important for recovery. If the person is not speaking, use another consistent way of communicating, such as head movement or finger tapping to show yes or no.
- When he becomes agitated, do not walk out on him or ignore him. Human contact and reassurance by family members usually have a soothing effect. Touch him, wash his face or body with warm water, or play soft music.

- It's very normal for family members to get impatient and frustrated. If the brain injured person swears at you, or you witness a tantrum, don't take it personally. Remember, it's the brain injury swearing at you, not your husband, wife, son, or daughter. Be patient, for he doesn't usually know what he's doing or saying.

By this stage of recovery, family members are often exhausted by the range and intensity of emotions they have experienced. Feeling low from the fear of losing someone you love, to feeling high from seeing the injured person stabilize and become more alert is part of the process. By this stage, family members are usually aware that some disability has resulted from the brain injury, and that rehabilitation is going to be a very long and slow process. This growing awareness may bring feelings of depression and fear. It is very normal to feel this way. You may feel better if you talk about your feelings with a member of the health care team.

#### **Level 5: confused – inappropriate (maximal assistance)**

The injured person is now alert and able to pay attention to activities around him, but will have difficulty focusing on the important, relevant parts of an event. Severe memory loss is evident and hinders new learning. He is highly distractible and not able to focus his attention. Wandering may be a problem. Conversation may consist of everyday phrases such as "I'm fine, how are you?", but break down with more complex topics. Verbalization is often inappropriate. He will show little initiative and depend on others to direct or cue him. He may now be able to perform simple self-care activities, but will still need some help. The past and present are confused and the person may appear to forget how to use familiar objects.

#### **Level 6: confused – appropriate (moderate assistance)**

The person now displays purposeful behavior. He can follow simple directions, and is able to do previously learned tasks, such as self-care. A schedule can be followed with some assistance but any changes in the routine can be confusing for him. Memory problems still lead to poor judgment and errors, but recall of past memories (before injury) are generally accurate. The ability to pay attention and concentrate has improved. Orientation to time and place is occasionally correct. He may now recognize staff and become very attached to family members (often phoning home frequently). He will be easily overwhelmed with excess information and not yet able to plan or anticipate events. Direction is still needed.

#### **Suggestions for the family for level 5 and 6**

- Be patient and repeat information as necessary. Help the person to develop memory aids.
- Go over information about family and friends. Use the photo albums you've put together as a way of stimulating memories.
- He may laugh or cry easily and not always appropriately. Usually the best thing to do is to ignore this response or suggest another activity, or change the topic until he calms down.
- Help him with homework or assignments that he is given by the therapists. Encourage him to make his own entries in the journal.
- For basic tasks, provide structure by giving step-by-step instructions.
- Slowly increase his independence by gradually decreasing the amount of help you give for specific activities.
- Within his tolerance, use every situation as a learning experience. Everyday tasks will still be hard for him. Help him count money and make change. Ask him about the

steps involved in making coffee or doing the laundry, and then have him do the task he has just described.

### **Level 7: automatic – appropriate (minimal assistance)**

By this time the injured person appears normal on the surface. He is now able to go through daily routines with little or no confusion. He is very aware of staff, family, and his surroundings; has a superficial awareness of his condition; and is able to learn, but at a decreased rate. Judgment, problem solving, and planning remain poor, thus, some supervision is needed. While his memory has improved there are still gaps. There is independence in self-care and activities of interest are initiated. But he has poor judgment, reduced problem solving ability and cannot plan realistically for the future. He has very limited insight into these problems.

### **Suggestions for the family for level 7**

- Talk about situations within the home that could be dangerous for the injured person and have him tell you what he would do to avoid them.
- Encourage him to write in his journal daily.
- Make sure that your words and body language convey the same message.
- Provide support to the individual with decision-making as necessary.
- He may still be slow in answering questions or hesitant in beginning conversations or activities. Be patient and be creative. He may appear unmotivated or lethargic because he can't think of anything to do but watch television. Help him to think of other things.
- Encourage him to continue with therapy or seek counseling if needed.

### **Level 8: purposeful – appropriate (stand-by assistance)**

At this level of recovery, the injured person's memory for past information is good, while memory for recent events and new learning may still seem foggy or fuzzy. He is able to learn new information, although not as much or as quickly as before the accident. He is able to follow routines with stand by assistance and make changes with minimal assistance. After a severe brain injury, it is common for the injured person to continue to show decreased ability to reason, tolerate stress, or use good judgment in emergencies or unusual situations. Often social, emotional, and intellectual abilities continue to be less than before the injury, but are good enough for the person to function in most social situations. Unless previously acquainted, others often cannot notice any existing physical, language, or cognitive problems.

### **Suggestions for the family for level 8**

- Encourage involvement in the home, school or job within the person's intellectual and physical limits. Help him pace himself.
- Managing medication should be the injured person's responsibility. The goal is to help him achieve maximum independence in all areas without compromising safety.

Try to measure improvement from the time of the accident and avoid comparing him to how he used to be. As well, learn to appreciate the new person; one who is likely different in many ways since the injury. There may be personality and behavior changes as well as differences in his pattern of likes and dislikes and some ongoing problems with memory and judgment. However, he is still a person who needs your support, affection, and companionship.

### **Level 9: purposeful – appropriate (stand-by assistance on request)**

By now, the injured person should be able to recall and integrate past and recent events. He can relearn higher level tasks such as driving and job training. He can carry out routines independently but may request for assistance with unfamiliar tasks.

### **Level 10: purposeful – appropriate (modified assistance)**

At this stage, the injured person should be able to complete activities independently, yet may require more time than usual. He can also set his own personal and work goals. He is able to monitor himself in terms of appropriateness of social interactions and can acknowledge other's needs and feelings. Although this person may seem "normal", take note of possible periodic episodes of depression. Living with a brain injury is a life-long process and the person still needs support from his friends or family just like anyone else.

### **Suggestions for the family for level 9 or 10**

- Continue to provide emotional support and encouragement.
- Give him the freedom to make his own choices; however, be prepared to give assistance when requested. Encourage him to ask for help when needed.
- You need to be patient and tactful.

You have to walk a fine line between encouraging independence and still providing the necessary background support and interpretation needed for the injured person to deal with the world. It's a delicate balance and hard to do. Congratulate yourself whenever you're successful

### **Difficulties with attention and concentration**

In the early stages of recovery, the injured person may not be alert enough to communicate. He may not be fully aware of his environment. His attention may wander. He may be restless. At times, he may get distracted by one small detail or focus on the wrong information. For example, during a conversation with you, his attention may be on your tone of voice or your earlobe, rather than what you are saying. Or, he may be trying to pay attention to your words, your appearance, noise from the street, and other activity in his room, all at the same time.

If you can't concentrate, it's hard to complete a task. We all have problems concentrating, especially when we are tired and feeling unwell. For the brain injured person, lack of concentration can be so severe that the simplest task, such as washing his hands or dressing, cannot be completed

#### To aid concentration and decrease attention deficits

- Reduce distractions; have only one person in the room, turn off the TV or radio.
- Simplify tasks, break them into small steps.
- Remove any time pressures or stress of any sort. Don't rush through a task or expect a perfect performance.
- Be sure you have his attention before beginning a discussion or task.
- If the person's mind is wandering, try to keep his attention through voice quality. Show excitement in your voice and use gestures to bring his attention back to the task. If he seems to be withdrawing from you, try a quiet, soft-spoken approach.
- Give new information in small bits and repeat it often. Have the injured person repeat back the information to be sure he understands.

- Encourage hobbies or enjoyable activities that are within the person's capability. Card games, puzzles, knitting, and reading will help the injured person strengthen his concentration.
- Praise any improvement in length of attention to activity.
- Watch closely for tiredness. The person who has difficulty focusing may tire quickly with any activity— mental or physical. Encourage frequent rest breaks.

### Memory difficulties

Loss of the ability to make new memories can be the most disabling deficit. Memory deficits range from mild problems, such as occasional difficulties remembering names, to severe post-injury amnesia where events happening just a few seconds ago are not remembered. The person may make up convincing stories to fill memory gaps; this is not intentional lying.

A memory deficit can affect the injured person's progress in all areas. If memories are lost quickly, he will not be able to learn from new experiences. The consequences for rehabilitation are great. In therapy, the person is learning ways to walk, to use assistive devices, communicate and think effectively. If recall from one day to the next is poor, the benefits from treatment may be small.

During the assessment stage of therapy, different types of memory will be looked at. Therapists test memory for events that happened before the accident (known as remote memory); memory for events in the past few seconds (immediate memory); and memory for events that took place a few minutes, hours, or days ago (recent memory). Immediate and especially recent memory tend to be more severely disabled than remote memory. Recovery of memory is often

slow and incomplete, but there are ways to help overcome or compensate for this.

### To aid memory and minimize confusion

- Have clocks and calendars around the house and in the person's room.
- Encourage the use of a journal or notebook to write down important information. When family or friends visit, enter the date and activities in the notebook.
- Provide a radio, so the person can listen to his favorite station and hear the news and time.
- Develop a routine or schedule at home. Post this in a highly visible spot like the fridge.
- Remind the person of the time, names, appointments, and so on. Try to incorporate this information into your social conversation.
- Gently remind the person of correct details of past and present events. Confirm accurate information with other people.
- Use short sentences and simple words when talking to him.
- When giving new information, repeat it frequently and write it down for later reference. Have the person repeat new information back to you to be sure he has understood and remembered.
- Have the injured person use a tape recorder to tape conversations, so they can go back and listen to them again later.
- Whenever possible, do activities that he is familiar with and capable of— like playing cards.
- People with memory problems cope best in familiar and routine situations that don't require them to adapt to changing circumstances.
- In extreme cases, devices can be purchased that will shut off stoves and other appliances automatically. This can help to prevent safety hazards.

## Difficulties with judgment

Problem solving and judgment may be impaired after a brain injury. The injured person may have difficulty sizing up a situation and figuring out what response is appropriate and relevant. He may be unable to delay his first impulses. His thinking style may be inflexible. Once he has an idea or solution, it may be hard for him to consider alternatives. Because of poor judgement, a frequent outcome of brain injury, he may not make decisions in his best interest.

### To aid judgment and problem solving

- Involve the injured person in decision-making whenever possible.
- Encourage him to plan and reason out loud so you can help with his decisions and gently correct his thinking errors.
- Provide him with choices instead of asking for a suggestion or opinion. For instance, ask if he wants to go for a walk, practice his exercises, or watch TV, instead of asking him what he wants to do.
- Point out important things to consider when making a decision. Encourage him to write these down.
- Give him feedback on his behavior; on both the correctness and errors of his responses. Let him know if his behavior or ideas are right or wrong, appropriate or realistic.
- Help him remember similar problems or situations from the past and what behavior was appropriate then.
- Reduce distractions, reduce the demands, and allow extra time in problem-solving.

## Difficulties in planning

After brain injury, many people find it difficult to plan, begin, and complete an activity. The person may appear disinterested or

unmotivated; this is typically not intentional. He may not be able to think ahead and lack follow-through for a completion of a task. His thinking may be fragmented, disorganized, and incomplete. As a result, he may not be able to evaluate his own behavior. This may show up as repetitive movements or speech. He may be impulsive and act quickly without thought. He may also need a lot of time to understand information and respond appropriately.

### To aid planning

- When possible, encourage participation in household chores (within capabilities). Things like setting the table, washing the dishes, or preparing a salad, require planning but may be familiar to the injured person. Help only when it is necessary.
- Use a checklist so that the injured person can check off each step of a task as it is completed.
- Break down the task into small steps and give guidance at each step. For example, when making a salad, give instruction on preparing the lettuce. When this is done, provide instructions on making the dressing, and so on.
- Reduce distractions, reduce the demands, and allow extra time in problem-solving.
- The injured person might be able to complete a task if you provide a prompt to begin it. Provide a clear explanation of an activity before starting.
- Limit distractions, such as noise or too much equipment on the table.
- Give instructions or directions slowly to allow the person time to understand and respond.
- Routines and schedules outlining future events promote better organization. Establish a time frame for accomplishing tasks.
- Use a calendar so that the injured person can see what is upcoming, and that they may prepare for it.

## Impaired self awareness

As a result of the brain injury, self-awareness may be impaired. The person may lack awareness of deficits and limitations. This is not typically intentional, rather, it is a common phenomenon following traumatic brain injury in particular. He may have an inaccurate self-image or self-perception, which may lead him to overestimate his abilities and underestimate his problems.

### To help someone with impaired self awareness

- Prompt accurate self-statements.
- Anticipate lack of insight and use feedback generously and supportively.

## Apraxia

**Apraxia** is the inability to perform skilled movements when muscle strength, coordination and sensation are normal. The person knows and understands what he wants to do but can't organize the movements to do it. He often uses objects incorrectly. A person with apraxia may have difficulty with a number of things, such as:

- Writing
- folding towels
- putting a letter into an envelope
- putting clothes on in the correct order and on the right body part
- recognizing the front and back of clothing
- organizing movements to stand up from the bed
- using eating utensils
- being able to tell the difference between a toothbrush and a hair brush

- putting a belt through the belt loops

### To help someone with apraxia

- Encourage him to practice writing something that is familiar to him, like his name.
- Encourage him to practice using clothing labels to tell the back from the front.
- Place your hand over the person's hand and move it through the correct motions to perform a task.
- Keep things in the same place in the bathroom at all times.
- Put the belt through the loops before the injured person dresses.
- Be supportive. Explain the problem to the injured person and let him know you understand how difficult it is for him.

## 7. Problems with Perception

Accurate perception depends on our knowledge of our own body and how it moves, and our ability to take in information from our senses (what we see, hear and feel). It also depends on our ability to compare new sensory information to information stored in our memory from past perceptual experiences. We can then use the combined information to make decisions about how to respond to new situations. This processed information builds over a lifetime and allows us to perform the highly complicated tasks we do everyday like: getting dressed, cooking, driving a car, and reading.

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

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

### Unilateral Neglect

Unilateral Neglect is ignoring body parts or objects on either the right or left side. A person with unilateral neglect may only dress one side of the body or shave one side of the face. He may bump into things on the neglected side. He may have a tendency to turn his head toward the unaffected side.

To help increase awareness of the neglected side

- Sit on the neglected side when talking to the injured person.
- Touch or hold the neglected hand.
- Remind the injured person to watch his neglected side as he goes through doorways or around furniture.
- Place objects that he wants or needs on his neglected side.
- When dressing, have him dress the neglected side first.

### Spatial relations syndrome

This is a type of perceptual problem that includes difficulties such as understanding the relationship to objects in space. An example of this is confusion about up/down, in/out and front/back. It also includes difficulties judging distance between two or more objects. This type of problem is sometimes also associated with apraxia.

People with a **spatial relations syndrome** may have difficulty:

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

To help someone with a spatial relations syndrome

- Organize drawers and cupboards and keep everything in the same place.

- Encourage the person to slow down and examine areas carefully by looking and feeling. Have him practice locking and unlocking the brakes on the wheelchair when transferring.
  - Remove all extra cutlery from the sides of the plate. Present the correct utensil to use with the type of food.
  - Leave a light on in the bedroom or bathroom and remind the injured person to look for the light. Labeling rooms with a sign or colored arrow may also be helpful. Practice moving from one room to another with the person.
  - Encourage using both hands to feel for objects.
  - Have the injured person move slowly, feeling for the edges of steps with his toes when going up and down stairs. Brightly-colored tape across the edges of each step on the stairways can also be placed.
  - Provide gentle reminders and ask the person to move when standing too close or too far away.
- Encourage him to use whatever sense is working. For example, if he can't recognize things by sight, have him feel things to identify them. If he can't identify things by touch, have him use his vision as much as possible.

## **Agnosia**

**Agnosia** is the inability to recognize familiar things through the senses of seeing, hearing or touching. A person with agnosia may have one or more of the following problems:

- can recognize letters, but can't recognize words
- difficulty recognizing familiar faces
- unable to pick out a color by name, although able to tell if two colors are the same or different.

### To help a person with agnosia

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

## 8. Communication Difficulties

People learn to do this in childhood, and come to take the ability for granted. But communication is not a magical gift, it depends on the brain. If a person's brain is damaged, he may find it harder to use speech and language. Such a loss is frustrating for the person with the injury. It also makes it difficult for others who are trying to help.

**The Brain** section described how more than one area of the brain can be affected following a head injury. This means that there could be several things working at once to affect communication. For example, a person might have some specific damage to the language areas of the brain, causing the comprehension and expression difficulties we call **aphasia**.

There might also be some damage to the areas controlling speech pronunciation (**dysarthria** or apraxia of speech), or voice production (**dysphonia**). Damage to other brain areas may make the person confused, disoriented, impulsive, or withdrawn and silent. These cognitive and behavioral features can make conversation sound inappropriate. When communication difficulties are due to underlying cognitive impairments, this is called a **cognitive-communication disorder**.

Of course, not many people will have all of these difficulties at once, but it is possible for several to be combined, especially in the early stages of recovery.

### Normal communication

Before going any further, let's look at some of the things the brain normally does when we communicate. What must happen if, for example, someone asks a question, and you reply?

- You hear the speaker's voice and focus on it.
- You derive meaning from the speech sounds.
- You match the meaning of what you've heard with information you've stored in your brain.
- You form a mental image of your reply.
- In your mind, you put your response into words.
- You activate the muscles controlling voice and speech.

This is a simple summary of some quite complex activities. Usually the brain performs these functions quickly and efficiently. If injury affects parts of the brain controlling language or speech, these activities may break down at some point.

### Comprehension difficulties

It will be very hard for a person to understand (comprehend) what is being said if, as a result of brain injury, he can't:

- hear the speaker's voice and focus on it
- get meaning from words or use speech sounds to make words
- match the meaning of that being heard with information stored in the brain

This comprehension difficulty may be severe, or it may only affect the person at certain times, such as when he's very tired. Usually, if a person has language comprehension problems, he will also have trouble reading.

## Expressive language difficulties

In order to communicate with others we need to be able to:

- come up with what we want to say
- put our response into words in our mind
- activate the muscles controlling voice and speech

The ability to form words to share thoughts is particularly important. If this function is disturbed, the injured person will have difficulty making sentences or finding the right words.

## Speech and voice difficulties

Sometimes all stages of communication work quite well except the process of making the sounds of speech. Damage to certain areas of the brain can interfere with messages to the muscles of the tongue, lips, jaw, larynx (voice box) and other areas. The result may be a weak, breathy voice, or slurred speech sounds.

## Helping those who have communication problems

The **speech-language pathologist** (speech therapist) working with the injured person will be able to guide you in ways that you can help. There is no “recipe” for treatment that fits all individuals, but a few guidelines are listed below. Perhaps the most important thing is to retain your natural relationship with the injured person, without becoming too much of a “teacher”.

## To help communicate

- Establish an easy, non-demanding atmosphere, where the injured person feels free to communicate without feeling he is under pressure to perform.
- Reduce background noise and other distractions when talking with the injured person. Get the person’s attention before speaking. Limit the number of people in the room, especially if there is a comprehension problem.
- Stay near the injured person and speak in direct, clear, short sentences. Keep an adult tone of voice and vocabulary.
- Ask open-ended questions.
- Emphasize important information.
- Use gestures and demonstration if your message does not seem to be getting through.
- If the injured person has trouble expressing himself, give him time to communicate in the best way he can. Give the individual your full attention until the thought is completed. Don’t complete sentences for him, although you may repeat or paraphrase his message to confirm your understanding of it.
- When necessary, give cues to help the injured person find or express the words he wants.
- The injured person may talk non-stop and not give the listener a turn to speak. If this occurs, politely interrupt and announce that you would like to speak.
- If all else fails, admit honestly that you’ve not understood and ask him if it’s really important or suggest he tell you later (often he will).

## 9. Social and Emotional Issues

### Behavior and personality

Sometimes, personality traits may become exaggerated or more extreme after a brain injury. For example, the reserved, quiet person may become even more withdrawn and quiet; the assertive, active person may become aggressive and even more outspoken.

A person with a brain injury may have poor emotional control resulting in mood swings that often seem unrelated to what is happening. There may be strong emotional outbursts triggered by minor frustrations. Or he may seem demanding, self-centered, irritable, or impatient. Even with a minor brain injury, irritability and impatience can be present in the short term. Finally, a person with a brain injury may lose interest and motivation to take part in former hobbies.

### Mood swings and anger management

Some of the most common personality changes seen after a brain injury are increased irritability and problems with controlling anger. There are several reasons for this. Damage to several areas of the brain can lead to difficulty controlling one's behavior, including control of temper. The injured person will often have a lower tolerance for frustrating situations. Where a person may have been able to keep quiet in a difficult situation prior to the injury, he may now have trouble doing so. He may blurt out angry words before he knows it or before he is able to stop himself from saying hurtful things.

Irritability after brain injury sometimes relates to difficulties and frustration in doing things that the person was able to easily do

before. As a result, he may become angry over seemingly small matters. Like the rest of us, the brain injured person may direct the anger he feels towards himself or those who are closest to him. The recipients of the anger may well end up feeling angry and hurt.

It usually doesn't help to blame the brain injury survivor for his short temper or to tell him that if he only tried harder he could control his temper. But there are some specific strategies that can help to control anger.

- Remain a model of calm assurance and confidence if an emotional outburst occurs.
- After calming down, encourage him to write down what happened to cause the anger, what he thought and did when he was angry, and what happened after he was angry. In this way he will have a written record of what happened. He can then look back at his written notes, alone or with another person and see more clearly what is happening and what can be done about it.
- Respond immediately to inappropriate ideas but maintain the original focus of the discussion.
- Suggest alternatives for behavior. Praise and reward desired behavior.
- Encourage the injured person to take a "time-out" when anger starts to build. When he starts to feel like he might be getting angry, he can say "I am beginning to feel angry and I would like to take a time-out". He can then leave the situation before it "explodes". He can then go for a walk or sit in a quiet room until he cools off.
- Listen to and express desire to understand the person's feelings.

Family and friends need to be told ahead of time that the person may need to take a time-out to help prevent anger outbursts. Time-out is not a sign of weakness, nor is the person

trying to run away from his problems. Time-out is a useful way of preventing angry outbursts. When he is calm, the problem that led to the anger can then be dealt with more reasonably.

Other ways of reducing chances of anger outbursts include:

- getting enough sleep so that the person is well rested
- avoiding drinks containing caffeine or alcohol
- telling oneself that “this is not the end of the world” or “this is not worth fighting about”
- identifying situations that seem to lead to anger and calmly change them or avoid

## Depression

Feelings of sadness, frustration and loss are common after a brain injury. Such feelings often appear during the later stages of recovery, when confusion decreases and self-awareness improves. However, if these feelings become overwhelming or interfere with recovery, the person may be suffering from depression.

Depression can arise as the person struggles to adjust to temporary or lasting disability caused by a brain injury. Depression also may occur if the injury has affected areas of the brain that control emotions.

Being depressed is not a sign of weakness, nor is it anyone’s fault. Depression is an illness. A person cannot get over depression by simply wishing it away, using more willpower or “toughening up.” Depression after brain injury may result from biochemical and structural changes in the brain. Fortunately, medication and other therapies can help most people who have depression.

These are symptoms of depression:

- Persistent sadness
- Irritability, moodiness
- Anxiety
- Loss of interest or pleasure in life
- Neglect of personal responsibilities or personal care
- Changes in eating habits or sleeping patterns
- Fatigue, loss of energy, lack of motivation
- Extreme mood changes
- Feeling helpless, worthless or hopeless
- Physical symptoms such as headaches or chronic pain that do not improve
- Withdrawal from others
- Thoughts of death or suicide

If the person with brain injury has symptoms of depression, his or her health care provider should be consulted. Effective treatments are available, including individual and group therapy, medication or a combination. Early treatment can help prevent needless suffering. Mental health professionals, including rehabilitation psychologists and social workers, are available to assist.

If your loved one expresses suicidal thoughts or threatens self-harm, immediately call 911 or your local emergency services provider.

## Lowered self esteem

Self-esteem is a person’s assessment of self-worth and is often adversely affected by brain injury. A problem may be more significant if the person with brain injury has had a mild to moderate injury or a severe injury with good self-awareness. The more aware the person with brain injury is, the more likely are changes in self-esteem.

Challenges vary among people with brain injury. Be aware of how you reference the person with brain injury. Avoid labeling, categorizing or stereotyping a behavior or communication skill that was altered by the injury. Learning as much as possible about brain injury and exercising patience and compassion are good steps toward understanding and nurturing the self-esteem of the person who has brain injury.

#### How families can help

- Focus on the positives.
- Allow the person to express feelings.
- When necessary, redirect conversation to positive or neutral thoughts.
- Express your concern and desire to understand the person's feelings.
- Point out the person's successes, even partial successes.
- Encourage as much independence as possible.
- Do not criticize.
- Give caring, realistic feedback.
- Help the person plan ahead to maximize opportunities for success.
- Choose activities and tasks that the person can successfully complete

#### **Socializing difficulties**

After a brain injury, the injured person may find it difficult to participate in or be part of social situations. He may act impulsively, such as speaking out without considering the consequences. He may not always be sensitive to social boundaries or exhibit socially inappropriate behavior. The injured person may act out of place in unfamiliar social or public settings.

#### What to do prior to the event

- Provide clear expectations for desirable behavior in social settings or in special circumstances such as job interviews, attending a funeral, or going to church.
- Plan and rehearse social interactions so that he will be familiar, predictable, and consistent.
- Establish verbal and non-verbal cues to signal the person to stop and think.

#### What to do during the event

- Encourage the person to slow down and think through responses.
- Prompt the individual to consider consequences of behavior.
- Provide positive feedback for appropriate behavior.
- Encourage a break in activity when frustration or fatigue is evident.
- If undesired behavior occurs, calmly and confidently address the behavior in private. Be objective and explain that the behavior, not the person is inappropriate.
- Reassure and be fair in your expectations.

#### What to do after the event

- Review the behavior, the effectiveness of verbal and nonverbal uses, and the overall success of the outing.
- Praise appropriate behavior and responses to cues and redirection.

## Effects due to stress

The stress caused by the physical and cognitive changes after a brain injury can often lead to emotional disturbances. The person with memory problems or poor emotional control may feel that he is losing his mind, instead of experiencing the results of the injury. He may react to the disability and losses with depression, anxiety, disappointment or frustration. Out of fear or confusion, he may deny the problems and their implications.

Some people feel angry about their condition and take their anger out on family members. Others may give up hope and appear depressed and withdrawn. The way a person adapts to his disabilities depends on the extent of the injury, the pre-injury personality, and the attitude of family and friends. Adjusting to the changes created by a serious brain injury can take many years.

## How families can help

- Encourage talk about fears and concerns with the injured person and with other family members and close friends.
- Help the injured person set realistic goals.
- Keep up hope for continued recovery.
- Seek professional help in the community to help you develop new resources, and make sense of what is happening to you and your family.

# 10. Life Following a Brain Injury

## Going home

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

Outpatient therapy usually lasts considerably longer than inpatient therapy. Members of the health care team will develop rehabilitation goals that optimize the abilities of the person with brain injury. Having realistic goals and expectations for yourself as a caregiver is important throughout the recovery process. Remember that the rehabilitation team is available to answer your questions and to encourage you during the adjustment to life at home with a loved one who has a brain injury.

## Relationships

Providing companionship and emotional support for the person with a brain injury may be necessary, in addition to physical care. Caregivers also may have many other responsibilities, including employment outside the home and caring for the home and children. Being a caregiver can be overwhelming, and adapting to these changes is challenging.

Seeking appropriate community-based social support can help lessen stress and loneliness. Many communities have brain injury support groups and centers for independent living that can help make connections with other people who have similar concerns and needs.

## Suggestions for the caregiver

- **Ask for help when you need it.** Caregivers frequently try to handle everything alone. Expecting too much of

yourself may add to the stress. Do not be afraid to ask for help. Find options for assistance such as home health care or respite care.

- **Set limits.** There are only so many hours in the day and only so many things you can do. Some things can wait.
- **Take time away from the person you are caring for.** Taking an hour, a day, a weekend or a week away can do wonders to restore your emotional well being.
- **Maintain contact with friends and family** to discuss your concerns or have fun.
- **Learn relaxation techniques** such as breathing exercises, meditation or progressive muscle relaxation.
- **Take care of yourself.** Caregivers are vulnerable to stress-related illnesses. If you are concerned about your health, make an appointment with your physician. Inform the physician about your situation.
- **Take time for exercise.** Exercise increases stamina, lessens anxiety and depression, improves or maintains muscle tone and strength, and increases self confidence. These benefits make exercise a worthwhile use of your limited time.
- **Join a support group.** Support groups are an outlet for sharing problems and concerns. People with similar issues understand what you are feeling.
- **Keep your sense of humor.** Laughter is a great stress reducer because, for a moment, you are not focusing on problems.

## Intimacy and sexuality

Love, affection and sexual feelings are healthy human desires. If these desires are not understood or expressed, confusion, distress and feelings of inadequacy may result. Sexuality involves the expression of male or female identities through sexual actions, attitudes and behavior in relationships. From

childhood on, we become aware of sexual differences. We are taught directly and indirectly how to behave with the opposite sex.

The ability to appropriately express these learned behaviors may be lost after a brain injury. The adult with brain injury may not understand when it is appropriate to kiss, hug and touch you or other people.

Addressing your relationship with your family member should be done early in the rehabilitation process. You may find yourself in a parent role with an adult person or spouse. You may be perplexed by changes in your partner, who may act differently after the injury. Feelings of confusion, anger, fear, frustration and helplessness are understandable.

Talking about your feelings with a member of the rehabilitation team or someone you trust may help. Although at first you may feel uncomfortable discussing sexual matters, rehabilitation team members understand your feelings. The goals of rehabilitation for the person with brain injury include independence, self-reliance and healthy personal relationships. The ability to develop and maintain social relationships may be the most important measure of successful rehabilitation. Therefore, recognizing and discussing concerns about love and sex are important.

Most people have difficulty talking about sex. The closest family member of a person with brain injury is usually the most effective person to help the injured person relearn how to express sexual feelings appropriately. This family member may benefit from professional support and guidance in addressing sexual issues.

A person with brain injury who cannot recognize sexual cues, may not respond to a partner. Many people who have suffered a brain injury have cognitive and psychological changes that can cause problems in their sexual relationships. The most

common problems are loss of interest in sex, less ability to fantasize, and a lack of sensitivity to their partner's needs. It is unusual for there to be a purely physical reason for sexual problems, such as the inability to get an erection or to achieve orgasm.

The psychological changes in the injured person may require adjustments in the roles of other family members. If the individual is left with a disability that results in some degree of dependence, his partner may have to assume most of the initiative in the sexual relationship. Providing directions and cues are ways to reach your partner

During the rehabilitation period, physical closeness can be restored by touching, caressing, cuddling and resting together. Physical contact will not only provide the nurturing and reassurance needed by every person who is injured or sick, but will also help partners to begin to get used to the changes that have occurred. Hospitals don't offer much privacy, but you can ask for times of privacy in the person's hospital room, and use weekend passes for these opportunities.

Acceptance and trust are especially important for intimacy and in a sexual relationship. If there are personality changes in the injured person, normal sexual activity may be slow to return. It may take a period of "getting to know" your partner again. As well, if there are also physical changes, these will also require some adjustments by both partners.

It may be helpful to talk about these issues with friends, other family members, hospital professional staff or others in the community. Social workers, rehabilitation nurses and rehabilitation psychologists are resources for support in addressing sexual issues and concerns. Your intimacy and sexual relationship with your partner are extremely important to address, so don't feel intimidated or embarrassed about reaching out for help.

## Driving

Driving can be affected by a brain injury in a number of ways. A person with a brain injury may have physical, thinking, perceptual or vision impairments, or seizures that make driving unsafe, such as problems with attention, concentration, visual scanning, rapid decision making and/or reaction times.

**It is a legal requirement that you have medical approval before someone starts driving again following a brain injury.**

The Alberta Solicitor General Department requires that, by law, all drivers must report any disease or disability that can affect their driving ability. A change in health must be reported to the Alberta Solicitor General Department through the closest branch of the Alberta Motor Vehicles Division or a registry office. This is usually the responsibility of the injured person or his family. If the healthcare team chooses, they can submit a report. The team will let you know if that has been done.

When reporting a disability, the injured person must provide a medical report. The Alberta Registry may suspend your license but this can be reinstated when your doctor states you are ready to return to driving.

In order for your doctor to make this decision they may refer you for a pre-driving assessment through an occupational therapist. If you are referred, you will be asked to have your vision assessed to ensure that you meet the visual standards for driving in Alberta. Assuming that you do, you will take the actual pre-driving assessment, which includes:

- A brief physical review to ensure you are physically, or functionally able to drive

- An adapted equipment review to see if you need any modifications to your car in order to drive, for example a left sided gas foot pedal
- Perceptual/cognitive testing to ensure that you have the basic requisite skills to drive
- Reaction time testing

Based on the results of all parts of the testing suggestions will be made to your physician. Your doctor will decide whether you are to return to driving and whether you need a road test by Alberta Registry.

You will provide the medical report to Alberta Registry and may take a road test to establish the ability to drive in a safe, responsible manner. This may be done with the help of physical aids or devices that adapt the vehicle to the injured person's needs. Talk with your loved one's health care provider if you have questions or concerns about his or her driving ability.

## Returning to work

Can a person return to work after a brain injury? The answer depends on the person and the extent of the injury. A brain injury can cause many changes in behavior, emotions, communication, and thinking skills. Keeping a job may be difficult, even the same job held prior to the injury. Regardless of whether the person with a brain injury returns to work, discovering how best to use talents will make life more rewarding. Paid employment or volunteer or leisure activities may be options.

Work (defined as productive activity) plays a major role in most people's lives. Work provides a sense of achievement, recognition, responsibility, financial independence, social interaction and structure. Those who return to work after brain

injury become generally healthier and have a higher self-esteem than those who do not.

Returning to work after a brain injury depends on:

- Availability of jobs
- Health
- Desire to work
- Physical abilities
- Ability to adjust to changes
- Social and behavioral abilities (for example, control of behaviors and getting along with co-workers)
- Thinking and problem-solving abilities
- Self-awareness of deficits and limitations
- Vocational interests and capabilities
- Willingness to receive further training
- The willingness of an employer to adapt the job or workplace to the injured person

Some agencies can help people with disabilities reach their vocational goals. The agencies' services may include physical and vocational evaluations, training, help with assistive devices, transportation and finding jobs. They work with the rehabilitation team to determine what employment is the best fit for the person.

Returning to work after a brain injury can be challenging and rewarding. Interests, aptitudes and financial options must be considered. The rehabilitation team will make every effort to help the injured person regain or develop job skills.

### **Returning to school**

For children and teenagers, returning to school is important for social and educational growth. At school, in addition to learning, young people find friends and peer support and develop social skills. School also provides a place to monitor

children's intellectual and social growth. Sometimes the effects of a brain injury are not initially apparent in young children but become more noticeable later when thinking and social demands increase at school.

School systems have special programs to help students with disabilities return to school. Most schools have trained special educators. However, not all special educators are familiar with the needs of people with brain injury. If someone who specializes in education after brain injury is not available through the school system, members of the rehabilitation team often consult with schools and help local educators develop an educational plan to meet the injured student's academic needs.

For those returning to high school and college, developing specific accommodations can help the person with brain injury be successful in school. In most colleges, an office for students with disabilities assists in assuring that teachers provide such accommodations.

Some common accommodations to assist with learning are:

- Extra time for tests to compensate for slowed thinking or information processing
- Tests given privately in a distraction-free environment to accommodate for difficulties with attention, concentration and increased distractibility
- Placement in classrooms with less noise and distractions
- Tape recording lectures to compensate for attention, concentration and memory problems
- Access to teachers' or peers' class notes to compensate for difficulty in dividing attention between listening to a lecture and taking notes
- Assignments provided in writing to compensate for memory and concentration problems

- Providing a place to rest or take breaks to compensate for fatigue and increasing frustration
- Tutoring with a peer or professional

In many cases, parents and family members become advocates who assure that the student with brain injury receives the necessary services to successfully return to school. Parents and family members also serve as go-betweens to make sure that rehabilitation professionals and school personnel meet to develop a plan for successful return to school. Members of the brain rehabilitation team are prepared to assist parents and families in these efforts and to acquaint them with resources available through the school system and government.

### **Recreation and leisure**

Participation in meaningful leisure experiences is essential to the recovery of the person with a brain injury. Leisure activities are excellent ways of releasing stress, gaining skills, increasing enjoyment of life, and experiencing satisfaction. Leisure pursuits can range from light fun to more serious activities that add meaning and quality to life.

A brain injury may result in some lifestyle changes for the injured person. Some of these changes usually occur in a person's leisure and recreational pursuits.

Some of the issues that may arise are:

- The brain injured person may have a dramatic increase in free time; especially if it is not immediately possible for him to return to work or become involved in past leisure activities.

- A lack of interest, motivation, or ability to generate ideas for leisure activities. Some may not realize the importance of leisure activities.
- A decrease in social skills and opportunities for leisure activities because of physical problems or poor communication skills may overwhelm the brain injured person.
- A lack of cognitive skills needed to participate in some activities, such as attention, concentration, initiation, planning, and problem-solving.
- A lack of adequate recreational resources (e.g. facilities, programs, adapted equipment) in the injured person's community.

Rehabilitation is not only for physical and cognitive problems. If the injured person is to recover from brain injury, it is important that all aspects of his life be attended to, including recreation and leisure. The focus of recreation therapy is to promote a maximum level of independence in leisure experiences and to ease reintegration of the injured person into his community.

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

### Increasing leisure activities

- Encourage the injured person to take part in hospital and out-of-hospital recreational activities (families and friends are welcome to attend).
- Allow the injured person to try new interests and make decisions about what he would like to do. Try not to bombard him with too many ideas at once, as this may be confusing and frustrating. (The recreation therapist

can give ideas and provide information on recreation activities.) When assisting the injured person with making decisions on an activity, provide two or three options.

- Work with the injured person to help him to plan recreational activities on weekends and passes. If necessary, break down the steps involved so that they are easier to understand. Try to get him to do as many of the steps as he can.
- Be patient and understanding. A person who suddenly loses the ability to do familiar activities may find it hard to start them up again, or to try new ones.
- Provide puzzles, books, pictures, and a radio/music player, both in the hospital and at home.
- Model the importance of leisure and recreation by taking part in activities yourself.

### Use of alcohol and drugs

A brain injury can affect how people think and manage emotions. If a person with brain injury drinks excessive alcohol, uses illicit drugs or prescription drugs in excess, those substances can further interfere with thought processes and can result in serious damage to the cells and nerves in the brain. Consequently, the effects of brain injury become worse. Family members play an important role in helping the person with a brain injury comply with physician recommendations about using alcohol and drugs.

To provide support, family members must:

- Take substance abuse seriously and avoid thinking of it as being a “phase”
- Help motivate the person to lead an alcohol-free and drug-free lifestyle

- Assist the person in developing plans to cope with situations that have resulted in alcohol and illicit drug use in the past
- Rehearse ways to avoid or react differently to such situations so that future abuse can be prevented

Rehabilitation professionals strongly recommend that a person with brain injury avoid drugs or medications if recommended by a physician, including alcohol and cigarettes. A rehabilitation psychologist, social worker or chemical dependency specialist can help assess whether a drug or alcohol problem exists. Alcohol and other drug treatment programs are available to help a person with brain injury recover from chemical dependency. Talk to any rehabilitation team member or physician if you have concerns about your relative about the use of alcohol and drugs.

Alcohol and drugs can trigger seizures and disturb:

- Alertness and concentration
- Self-awareness
- Perception
- Memory and learning
- Reasoning, planning and problem-solving
- Judgment
- Speech and language
- Motor control
- Emotions
- Social interactions or social behavior
- Motivation

## Resources

In addition to the resources available through Alberta Health Services, including the Calgary Brain Injury Program, there are a number of community groups that provide support and advocate on behalf of people with brain injuries and their families.

These organizations have formed to provide ongoing support and information to brain injury survivors and their families. Our website has resources listed primarily within Alberta, but also has links to other resources across Canada. If you live in another community, contacting these organizations may help you to find out about resources in your own community.

Visit our website:

**The Calgary Brain Injury Program**

[www.albertahealthservices.ca/CBI-211.asp](http://www.albertahealthservices.ca/CBI-211.asp)

You can also call:

**HEALTHLink Alberta**, a 24 hours a day, seven days a week telephone health advice and health information service answered by registered nurses that anyone in Alberta can access.

Phone: 1-866-408-5465 (toll-free)  
or (403) 943-5465 (Calgary)  
or (780) 408-5465 (Edmonton)

Website: [www.albertahealthservices.ca/223.asp](http://www.albertahealthservices.ca/223.asp)

# Definitions

These include the definitions seen throughout this book, as well as other words/phrases you may hear.

## **ADL**

activities of daily living

## **affect**

emotional state.

## **agitation**

state of anxiety displayed in restlessness and poor emotional control

## **agnosia**

the ability to recognize familiar objects through the senses of vision, hearing and touch.

## **agnosia (types)**

### **visual agnosia**

inability to recognize things seen whether or not there is any loss of vision. This may result in being unable to recognize family or friends.

A chair may appear larger or smaller than it actually is.

The person may not recognize colors.

### **auditory agnosia**

difficulty recognizing differences in sounds. Such a person couldn't tell the difference between the sounds of a car engine running and a vacuum cleaner, or between the phone ringing and a fire alarm going off.

## **tactile agnosia (stereognosis)**

impaired ability to recognise objects by touch, even though the person can feel the object. This results in difficulty buttoning a shirt or putting a belt through belt loops.

## **agraphia**

decline or loss of ability to write.

## **alexia**

inability to read.

## **ambulate**

to walk

## **aneurysm**

a sac formed by the dilation of the wall of an artery or vein. The expansions are usually weak and prone to rupture.

## **angiomas**

congenital collection of abnormal vessels that result in abnormal blood flow.

## **anomia**

difficulty in naming objects.

## **anoxia**

absence, or lack of oxygen.

## **anterograde amnesia**

loss of memory for events occurring after the brain injury. Also referred to as **post traumatic amnesia** in head injury cases.

## **anticonvulsant**

medication to decrease possibility of seizures or to control seizures once they do occur

**aphasia (or dysphasia)**

a communication disorder caused by brain damage. The dysphasic person is likely to have difficulty understanding language and/or expressing his thoughts accurately in words.

**apraxia**

see dyspraxia.

**arteriovenous malformation (AVM)**

congenitally abnormal vessels often causing abnormal blood flow to the brain.

**ataxia**

unsteady and uncoordinated movement.

**attention**

ability to focus on what's important and not get distracted by what isn't important. Difficulties with attention after a brain injury can make it hard to follow a conversation, hard to work, or unsafe to cook a meal or drive.

**alternating attention**

allows you to switch from one task to another without losing track of what you are doing

**attentional capacity**

this is how much information you can take in your head at once without getting overloaded; for example the average adult can hear and repeat a 7-digit phone number but usually won't remember it 5 minutes later

**attention span**

length of time one can concentrate upon an activity or task. It varies depending on the task, level of fatigue and other factors

**complex attention**

or working memory; this can be the biggest problem following a brain injury. This includes divided, alternating and selective attention, Trouble with complex attention shows up in many different ways, for example, being overwhelmed by bright lights, noise and other distractions, forgetting what we were going to fetch from the bedroom, or difficulty preparing a three course meal.

**divided attention**

ability to keep track of several things at once

**selective attention**

being able to ignore distractions

**better**

a relative state. This is a word used often by all staff. It does not refer to a 'cure', but to a relative state of improvement in some area.

**body image**

the mental picture a person has of his body.

**burr holes**

holes drilled in the skull to remove a hemorrhage.

**cerebellum**

a structure of the brain sitting below and in back of the cerebrum. It is concerned with coordinating movements, balance and muscle tone.

**cerebral contusion**

bruising of the brain.

**cerebral hemorrhage**

bleeding into the substance of the brain damaging the tissues.

**cerebrum**

the main portion of the brain, consisting of two halves connected by a thick bundle of nerve fibers (the corpus callosum). Contains the frontal lobes in the forehead, the temporal lobes on the side, the parietal lobes at the crown, and the occipital lobes in the back.

**clonus**

rapid muscle spasms that occur in hypertonic muscles when stretched. For example, alternate contraction and relaxation of calf muscles will cause foot vibrating on wheelchair foot pedal. Control is obtained by prolonged pressure (15-30 seconds, if necessary) over the knee to achieve heel contact.

**closed head injury**

injury in which the skull remains intact without obvious external damage. An injury to the brain resulting from an external blow that does not cause an open wound

**cognition**

mental processes associated with attention, perception, thinking, learning and memory.

**coma**

unconsciousness with no detectable response to stimuli (sound, touch, light).

**community leisure awareness** is the process of making individuals aware of leisure opportunities within the community, in order to facilitate the transition from hospital to community.

**comprehension**

the ability to understand or draw meaning from what is seen (visual comprehension), heard (auditory comprehension), touched (tactile comprehension), smelled, or tasted.

**CT Scan or CAT Scan (computerized axial tomography)**

a technique using x-rays (in combination with computer technology) to distinguish between various tissue densities in the brain. Readings are fed into the computer which calculates values and integrates them into composite pictures illustrating brain, bone, and fluid. A doctor can check the readings for abnormalities; for example, structural deviations (e.g., ventricular enlargements), and lesions (e.g., subdural and intracerebral hematomas, tumors, infarctions and edema).

**concussion**

mild traumatic brain injury characterized by post traumatic amnesia or confusion of less than 24 hours, or coma of less than 30 minutes.

**confabulation**

providing misinformation or embellishing the facts because of memory problems

**contractures**

shortening of muscles from disuse which makes them resistant to stretching and leads to deformity.

**contusion**

a bruise: a brain contusion is a bruise to the brain tissue, usually caused by a blow to the head.

**convulsion**

spasms of involuntary contraction and relaxation of muscles; sometimes involving the whole body.

**cranial nerves**

these are twelve pairs of nerves contained in the skull as opposed to the spinal cord; they control the five senses (hearing, sight, smell, taste, touch), plus eye, mouth and facial movement and sensation, chewing and swallowing.

**craniotomy**

opening of the skull by an incision to allow the surgeon to work on the brain.

**cue**

verbal or nonverbal hint, suggestion or prompt.

**decerebrate**

an abnormal posture occurring in the unconscious patient in which all the limbs are rigidly extended.

**decorticate**

an abnormal posture occurring in the unconscious patient in which the arms are bent and tucked close into the body and the legs are extended.

**delusions**

beliefs not consistent with reality.

**depression**

mood state characterized by sadness, low self-esteem, fatigue, poor appetite, and loss of interest in activities

**diplopia**

double vision.

**disability**

being unable to execute some skill; usually arises from an impairment.

**disinhibition**

not inhibited, patient freely acts out his desires, expresses his thoughts contrary to social norms.

**disorientation**

not knowing who you are, where you are or the date/time. After waking from a coma, many patients are disoriented for a time.

**distractable**

unable to focus one's attention.

**dysarthria**

this term covers a collection of speech disorders resulting from damage to nerve pathways. The damage may be in the brain itself or at any point between the brain and the muscles. Dysarthria may affect the movements used for breathing, making a voice, resonating the voice, or producing speech sounds. The dysarthric person may also have difficulty with chewing or swallowing functions. Dysarthria is not a language disorder.

**Dyscalculia**

difficulty performing arithmetic because of brain injury or disease.

**dyslexia**

difficulty in reading.

**dysphagia**

difficulty in swallowing

**dysphasia**

see aphasia.

**dyspraxia**

a breakdown in a person's ability to carry out a purposeful movement or series of movements, even though these movements may occur involuntarily when the person is not deliberately trying to perform. For example, an individual might be able to whistle absent-mindedly, but be unable to do this on request. Dyspraxia of speech may be severe enough to make it difficult for the patient to get started on any voluntary speech acts. Milder forms of dyspraxia may result in scattered and inconsistent pronunciation slips, particularly on longer words.

**dyspraxia (types)****constructional dyspraxia**

inability to copy drawings or to manipulate objects to form patterns or designs.

**dressing dyspraxia**

examples are: putting a sock on a hand, putting clothes on backwards or donning shoes before socks.

**motor dyspraxia**

difficulty organizing movements. For example: to bring his legs over the side of the bed to stand up.

**ideomotor dyspraxia**

difficulty imitating gestures or performing a task on command, even though the person understands the command. When asked to sign his name, the person can describe what to do but is unable to pick up the pencil.

**ideational dyspraxia** unable to form a plan of movement and doesn't know proper use of an object because of a lack of perception of its purpose

**EEG (electroencephalogram)**

a test that reveals brain wave patterns. Can be used to detect epilepsy or other convulsive disorders; to help determine cause of stupor or coma; to help locate surface brain lesions; to monitor the course of neurologic injury; to monitor cerebral function. The recording of the electrical impulses coming from the brain.

**EMG (electromyograph)** machine that records the electrical activity of the muscles.

**edema**

the presence of abnormally large amount of fluid. In the brain, this is often caused by trauma, tumor or anoxia.

**egocentric**

self-centered, preoccupied with one's own needs, lacks interest in others.

**emotional lability**

uncontrolled emotional swings or instability.

**epilepsy**

a condition of the nervous system characterized by convulsions or seizures and possibly disturbance of consciousness.

**euphoria**

an exaggerated feeling of well-being or happiness that is inappropriate to the situation.

**flaccid**

loss of muscle tone resulting in limbs which feel floppy or heavy.

**functional**

ability to incorporate developing skills into meaningful activity in a reasonable amount of time.

**glasgow coma scale (GCS)**

examines a patient's ability to open their eyes, speak, and move. The GCS is used to assess and monitor a person's neurological status. It is also used to determine the severity of a brain injury. It is a total score of 15. A score of 8 or below indicates a severe brain injury. A score of 9 to 12 indicates a moderate brain injury. A score of 13 to 15 indicates a mild brain injury. This scale can help the team decide how much care may be needed.

**grand mal**

a type of epileptic seizure frequently preceded by an aura with generalized convulsions including the legs, arms, and facial muscles, and loss of consciousness.

**hematoma**

a localized collection of blood usually clotted, due to a break in the wall of a blood vessel.

**hematoma types:*****subdural hematoma***

a pocket of blood formed by a broken vein which forms under the dura mater (see meninges) Sub means under.

***epidural hematoma***

a pocket of blood formed by a broken artery above the dura mater. Usually occurs in the parietotemporal (on the side towards the crown area.)

***subarachnoid hematoma***

a pocket of blood formed below the arachnoid mater (see meninges).

**hemianopia**

blindness involving one-half of the visual field in both eyes.

**hemiparesis**

muscular weakness on one side of body only.

**hemiplegia**

muscular paralysis on one side of body only.

**hemorrhage**

see cerebral hemorrhage.

**hypertonic**

more tension than normal. One feels increased resistance when trying to move limb.

**hypotonic**

less tension than normal. The limb feels very heavy and is susceptible to joint damage as a result of reduced muscle tension

**impulsivity**

doing or saying things on impulse; not thinking ahead; not being able to 'inhibit' a statement or action.

**incontinence**

inability to control the bladder or bowel.

**independent**

ability to consistently perform an activity safely, in a practical amount of time, without supervision/assistance.

**infarct**

an area of tissue that is dead due to insufficient blood flow or oxygen. Often results from a blockage of an artery by a clot.

**insight**

awareness and understanding of one's behavior, personality and abilities.

**intelligence**

capacity for understanding, recalling and integrating what one has learned.

**intracranial pressure**

pressure within the skull due to a hemorrhage or swelling of the brain.

**judgment**

comparing or evaluating choices before making a decision.

**language of confusion**

this is not a specific speech or language disorder, although it affects the person's communication. The patient has difficulty keeping focused on an appropriate topic and his speech tends to ramble disconnectedly.

**leisure awareness**

is the process by which individuals develop a personal definition of leisure

**leisure component of a patient's lifestyle**

refers to free time a patient has at his disposal above and beyond the time necessary for existence (biologically) and subsistence (things he must do to survive: work, school, etc.).

**leisure counseling**

is a one-to-one, or small group process which assist individuals in determining their leisure needs and interests and how they can best meet these needs. It is a treatment technique which is used to facilitate a smooth transition through the stages of leisure education.

**leisure education**

is a process through which individuals develop an understanding of self, leisure, and the relationship of leisure to their own lifestyle.

**leisure skill development**

is the process of facilitating the development and/or upgrading of specific leisure skills for individual patients.

**memory**

the acquisition and retention of information. Following a brain injury, many patients have trouble learning and remembering new information but can recall things from the past (before the injury.)

**types of memory****immediate memory**

memory for a few seconds such as keeping a phone number in mind while you go to dial. Following a brain injury if this type of memory is affected it will show up as a problem with attention.

**recent memory**

memory for things that have happened more than a few minutes ago that your brain is starting to store away for later use. Following a brain injury, the ability to make new memories is commonly affected. It is affected by your learning ability and ability to find what you are looking for in your memory. This may be a result of reduced attention, the need to spend more effort to get information into memory, or difficulty finding information when we want it- like when you can't remember someone's name until the conversation is over.

**remote memory**

this is memory for things that happened many years ago and for events that happened before the brain injury. Although this may be a problem in the early stages of recovery while someone is in the hospital and confused, this sort of memory generally recovers.

**meninges**

membranes which cover the brain and spinal cord.

**dura mater**

the outermost, toughest, and most fibrous membrane.

**arachnoid mater**

the middle membrane.

**pia mater**

the innermost membrane. It contains blood vessels

**motivation**

a force that pushes a person to act. There is an incentive or desire to do something.

**motor status**

to do with movement, produced by muscles, nerves and neurological centers.

**magnetic resonance imaging (MRI)**

uses magnetic fields and radiowaves to scan your body. A computer processes the signal information and displays it as an image on a video screen. A contrast (dye) may be injected into your vein to make certain body structures more visible. It is painless and involves no exposure to radiation from the scanner.

**muscle tone**

resting tension in muscles.

**neglect**

the decreased ability to respond to stimuli presented on one side of the body, even if the sensation/vision is intact.

**neuropsychological assessment**

this is a series of tests by a psychologist. These look at memory, attention, thinking speed, and reasoning, to identify problems and recovery after an injury. This is usually done after you leave the hospital, to help plan for school, work, or further treatment.

**normal muscle tone**

limb feels easy to move.

**open head injury**

injury in which the scalp and skull are broken often with penetration of the brain.

**orientation**

awareness of oneself, other people, time and place.

**perception**

the ability to recognize objects in the environment.

**perseveration**

uncontrolled repetition of speech or activity.

**petit mal**

a mild, non-convulsive, epileptic attack with momentary loss of consciousness, sometimes characterized by staring, rolling of the eyes, or fluttering of the eyelids.

**post-traumatic amnesia (PTA)**

amnesia, or no memory of the time surrounding an injury of what happened. This lack of memory is caused by the brain physically unable to make new memories during this time.

**praxis**

ability to perform certain skilled, purposeful movements, regardless of strength, sensation or coordination.

**premorbid**

patient's condition before the injury

**prognosis**

prediction of the probable course of a disease or injury and the chances of recovery.

**proprioception**

tells us where a limb is in space. Critical feedback is provided by sensory nerve terminals giving information concerning movements and position of the body.

**psychotherapy**

a form of talk therapy for behavioral problems, mental illness or emotional distress.

**ptosis**

drooping of the upper eyelid.

**range of motion (ROM)**

refers to the normal amount of mobility for every joint which is usually maintained with everyday activity. If the limb is paralyzed, one needs to have this done passively by another person or by oneself using the other limb to assist.

**retrograde amnesia**

loss of memory for events occurring before the accident.

**righting and equilibrium reactions**

body's automatic mechanism for maintaining balance. It refers to movement or changes in body position to adjust to changes in centre of gravity.

**seizure**

a discrete clinical attack in which there is uncontrolled, excessive discharge of brain neurons.

**sensation**

specific senses that relate the environment to us; e.g. touch, temperature, sight, hearing, proprioception, smell and taste.

**skull fracture**

a break in the skull

**skull fracture (types)****linear fracture**

a simple break in the bone that doesn't cause any change in the shape.

**comminuted fracture**

several linear fractures that occur at the same time.

**depressed fracture**

a displacement of the fragments from the comminuted fracture which form an indentation of the skull (looks like a small bowl).

**compound fracture**

any of the above types of fractures combined with an external opening through the skin.

**basal skull fracture**

a break in any of the bones behind the eyes, nose, throat and inner ear, at the base of the skull.

**skull x-ray**

a picture of the skull which shows the patient's bony structures, so they can be checked for abnormalities such as fractures or cracks in the bone.

**spastic**

abnormally increased muscle tone.

**spasticity**

involuntary contraction of muscle that often can occur in specific patterns. One needs to restore balance of muscle tone to re-learn normal movement. Involuntary muscular contractions, shaking, jerking, which often follow injury to the central nervous system.

**spatial relations**

how one sees oneself or things in space.

**right/left discrimination**

the inability to tell left from right on self or in the environment

**position in space**

the relationship of objects in space, such as in/out, up/down, front/back.

**topographical orientation**

being able to find one's way in space.

**depth and distance judgement** ability to judge the height or distance of objects such as the height of steps or even where the first step starts.

**subluxation**

change in normal alignment of bones which may be due to hypotonic muscles. For example, the shoulder is a ball and socket joint and relies on support of muscles to maintain its alignment. So, if the tone is decreased, the weight of the limb will cause separation of the joint, leading to pain and damage of joint. Therefore, support of the arm by way of an arm tray, a table tray, or a sling, is critical.

**stroke**

the sudden onset of neurological dysfunction as a result of a problem with the blood vessels in the brain (e.g., a blockage or a rupture).

**tactile**

sense of touch, ability to feel.

**tonic**

prolonged muscular contraction or tension.

**unilateral neglect**

ignoring body parts or things on one side of his body or in the environment.

**ventricle**

a small cavity, such as one of the several cavities of the brain which are filled with cerebrospinal fluid