

# *Brain Injury* A Family Guide

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**1-800-992-3442**

# **BRAIN INJURY:**

## **A Family Guide**

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# **SECTION I**

## **THE CRITICAL PHASE**

## **WHAT IS TRAUMATIC BRAIN INJURY?**

A traumatic brain injury is an injury to the brain as a result of an external blow to the skull. A “closed brain injury” occurs when there is a blow to the brain as in a motor vehicle crash or a fall. When the skull hits a stationary object, the brain, which is inside the skull, turns and twists on its axis (the brain stem), causing localized or widespread damage. Also, the brain, a soft mass surrounded by fluid that allows it to “float,” may rebound against the skull, resulting in further damage. There may be a period of unconsciousness immediately following the trauma, which may last minutes, weeks or months. Due to the twisting and rebounding, the patient usually receives damage or bruising to many parts of the brain. This is called diffuse damage.

An “open brain injury” is a penetrating assault to the brain, such as from a gunshot wound, or an object going through the skull into the brain. This type of brain injury is more likely to damage a specific area of the brain.

Minor brain injury may occur with no loss of consciousness and possibly only a dazed feeling or confused state lasting a short time. Although medical care needed may be minimal, persons with minor brain injuries may still experience symptoms and impairments similar to those resulting from a moderate to severe brain injury, but of lesser intensity.

The official State of Florida definition for moderate to severe brain injury is: *An insult to the skull, brain, or its covering, resulting from external trauma, which produces an altered state of consciousness or anatomic, motor, sensory, or cognitive/behavioral deficits.*

## **HOW DOES THIS INJURY DIFFER FROM OTHER BRAIN INJURIES?**

The brain can also be damaged as a result of near drowning, heart attack, stroke and infections. This type of injury interrupts the flow of oxygen or blood supply to the brain. However, it is not categorized as a “traumatic brain injury” according to the definition above. This can be referred to as “anoxic or hypoxic brain injury.”

## **WHAT IS BRAIN SWELLING? BRAIN EDEMA?**

In response to the trauma, changes occur in the brain that require monitoring to prevent further damage. The brain's size frequently increases after a severe brain injury. This is called brain swelling and occurs when there is an increase in the amount of blood to the brain. Later in the illness water may collect in the brain, which is called brain edema. Both brain swelling and brain edema result in excessive pressure in the brain called intracranial pressure (ICP). Around the clock monitoring during this time is essential in order that intracranial pressure can be immediately treated. Treatment of brain swelling can be difficult. Very strong medications are administered and in some cases, removal of small amounts of fluid from the brain may be beneficial. Newly developed drugs and treatments aid in reducing secondary damage.

## **WHAT IS COMA?**

Coma is the prolonged period of unconsciousness in which an individual has no meaningful response to stimuli. In this sleep-like state, there is no speech, the eyes are usually closed, and there is no response to commands. However, a person in coma may have a simple reflex in response to touch or pain. The individual may react to pain by groaning or moving but will have no memory of the pain. However, it is suggested that people talk about or to the individual as if he/she could hear and understand what is being said.

There are several levels of coma. Professionals measure coma levels by the progression of responsiveness. In the acute phase of brain injury, the Glasgow Coma Scale is used. As the patient improves or stabilizes, the Ranchos Los Amigos Scale is used, which measures levels of cognitive (understanding and reasoning) thinking.

## **RANCHOS LOS AMIGOS SCALE**

The Ranchos Levels, as they are called, are an assessment tool or scale that does not require cooperation from the patient. Rather, they are based on observation of the patient as he/she responds to environmental stimuli. They provide a clear description of the various behavioral stages of a brain injury through which he/she begins to progress during the recovery process.

## THE CRITICAL PHASE

The Ranchos Levels are most useful in the first weeks or months following the injury. The speed at which progression from level to level will occur cannot be predicted. Many individuals may exhibit the characteristics of more than one Ranchos Level at any time.

An understanding of the characteristics of each of the ten Ranchos Levels is helpful when families and professionals deal with the behaviors demonstrated by patients following brain injury. The descriptions listed below provide insight into the expected progression during recovery and rehabilitation:

### **Level I - No Response: Total Assistance**

\*Complete absence of observable change in behavior when presented visual, auditory, tactile, proprioceptive, vestibular or painful stimuli.

### **Level II - Generalized Response: Total Assistance**

\*Demonstrates generalized reflex response to painful stimuli.

\*Responds to repeated auditory stimuli with increased or decreased activity.

\*Responds to external stimuli with physiological changes generalized, gross body movement and/or not purposeful vocalization.

\*Responses noted above may be same regardless of type and location of stimulation.

\*Responses may be significantly delayed.

### **Level III - Localized Response: Total Assistance**

\*Demonstrates withdrawal or vocalization to painful stimuli.

\*Turns toward or away from auditory stimuli.

\*Blinks when strong light crosses visual field.

\*Follows moving object passed within visual field.

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### **Level III (cont'd)**

- \*Responds to discomfort by pulling tubes or restraints.
- \*Responds inconsistently to simple commands.
- \*Responses directly related to type of stimulus.
- \*May respond to some persons (especially family and friends) but not to others.

### **Level IV - Confused/Agitated: Maximal Assistance**

- \*Alert and in heightened state of activity.
- \*Purposeful attempts to remove restraints or tubes or crawl out of bed.
- \*May perform motor activities such as sitting, reaching and walking but without any apparent purpose or upon another's request.
- \*Very brief and usually non-purposeful moments of sustained alternatives and divided attention.
- \*Absent short-term memory.
- \*May cry out or scream out of proportion to stimulus even after its removal.
- \*May exhibit aggressive or flight behavior.
- \*Mood may swing from euphoric to hostile with no apparent relationship to environmental events.
- \*Unable to cooperate with treatment efforts.
- \*Verbalizations are frequently incoherent and/or inappropriate to activity or environment.

**Level V - Confused, Inappropriate Non-Agitated: Maximal Assistance**

- \*Alert, not agitated but may wander randomly or with a vague intention of going home.
- \*May become agitated in response to external stimulation, and/or lack of environmental structure.
- \*Not oriented to person, place or time.
- \*Frequent brief periods, non-purposeful sustained attention.
- \*Severely impaired recent memory, with confusion of past and present in reaction to ongoing activity.
- \*Absent goal directed, problem solving, self-monitoring behavior.
- \*Often demonstrates inappropriate use of objects without external direction.
- \*May be able to perform previously learned tasks when structured and cues provided.
- \*Unable to learn new information.
- \*Able to respond appropriately to simple commands fairly consistently with external structures and cues.
- \*Responses to simple commands without external structure are random and non-purposeful in relation to command.
- \*Able to converse on a social, automatic level for brief periods of time when provided external structure and cues.
- \*Verbalizations about present events become inappropriate and confabulatory when external structure and cues are not provided.

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### **Level VI - Confused, Appropriate: Moderate Assistance**

- \*Inconsistently oriented to person, time and place.
- \*Able to attend to highly familiar tasks in non-distracting environment for 30 minutes with moderate redirection.
- \*Remote memory has more depth and detail than recent memory.
- \*Vague recognition of some staff.
- \*Able to use assistive memory aide with maximum assistance.
- \*Emerging awareness of appropriate response to self, family and basic needs.
- \*Moderate assist to problem solve barriers to task completion.
- \*Supervised for old learning (e.g. self care).
- \*Shows carry over for relearned familiar tasks (e.g. self care).
- \*Maximum assistance for new learning with little or no carry over.
- \*Unaware of impairments, disabilities and safety risks.
- \*Consistently follows simple directions.
- \*Verbal expressions are appropriate in highly familiar and structured situations.

### **Level VII - Automatic, Appropriate: Minimal Assistance for Daily Living Skills**

- \*Consistently oriented to person and place, within highly familiar environments. Moderate assistance for orientation to time.
- \*Able to attend to highly familiar tasks in a non-distraction environment for at least 30 minutes with minimal assist to complete tasks.
- \*Minimal supervision for new learning.

**Level VII cont'd**

- \*Demonstrates carry over of new learning.
- \*Initiates and carries out steps to complete familiar personal and household routine but has shallow recall of what he/she has been doing.
- \*Able to monitor accuracy and completeness of each step in routine personal and household ADLs and modify plan with minimal assistance.
- \*Superficial awareness of his/her condition but unaware of specific impairments and disabilities and the limits they place on his/her ability to safely, accurately and completely carry out his/her household, community, work and leisure ADLs.
- \*Minimal supervision for safety in routine home and community activities.
- \*Unrealistic planning for the future.
- \*Unable to think about consequences of a decision or action.
- \*Overestimates abilities.
- \*Unaware of others' needs and feelings.
- \*Oppositional/uncooperative.
- \*Unable to recognize inappropriate social interaction behavior.

**Level VIII - Purposeful, Appropriate: Stand-By Assistance**

- \*Consistently oriented to person, place and time.
- \*Independently attends to and completes familiar tasks for 1 hour in distracting environments.
- \*Able to recall and integrate past and recent events.
- \*Uses assistive memory devices to recall daily schedule, "to do" lists and record critical information for later use with stand-by

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### **Level VIII (cont'd)**

assistance.

\*Initiates and carries out steps to complete familiar personal, household, community, work and leisure routines with stand-by assistance and can modify the plan when needed with minimal assistance.

\*Requires no assistance once new tasks/activities are learned.

\*Aware of and acknowledges impairments and disabilities when they interfere with task completion but requires stand-by assistance to take appropriate corrective action.

\*Thinks about consequences of a decision or action with minimal assistance.

\*Overestimates or underestimates abilities.

\*Acknowledges others' needs and feelings and responds appropriately with minimal assistance.

\*Depressed.

\*Irritable.

\*Low frustration tolerance/easily angered.

\*Argumentative.

\*Self-centered.

\*Uncharacteristically dependent/independent.

\*Able to recognize and acknowledge inappropriate social interaction behavior while it is occurring and takes corrective action with minimal assistance.

**Level IX - Purposeful, Appropriate: Stand-By Assistance on Request**

\*Independently shifts back and forth between tasks and completes them accurately for at least two consecutive hours.

\*Uses assistive memory devices to recall daily schedule, “to do” lists and record critical information for later use with assistance when requested.

\*Initiates and carries out steps to complete familiar personal, household, work and leisure tasks independently and unfamiliar personal, household, work and leisure tasks with assistance when requested.

\*Aware of and acknowledges impairments and disabilities when they interfere with task completion and takes appropriate corrective action but requires stand-by assist to anticipate a problem before it occurs and take action to avoid it.

\*Able to think about consequences of decisions or actions with assistance when requested.

\*Accurately estimates abilities but requires stand-by assistance to adjust to task demands.

\*Acknowledges others’ needs and feelings and responds appropriately with stand-by assistance.

\*Depression may continue.

\*May be easily irritable.

\*May have low frustration tolerance.

\*Able to self-monitor appropriateness of social interaction with stand-by assistance.

**Level X - Purposeful, Appropriate: Modified Independent**

\*Able to handle multiple tasks simultaneously in all environments but may require periodic breaks.

\*Able to independently procure, create and maintain own assistive memory devices.

\*Independently initiates and carries out steps to complete familiar and unfamiliar personal, household, community, work and leisure tasks but may require more than usual amount of time and/or compensatory strategies to complete them.

\*Anticipates impact of impairments and disabilities on ability to complete daily living tasks and takes action to avoid problems before they occur but may require more than usual amount of time and/or compensatory strategies.

\*Able to independently think about consequences of decisions or actions but may require more than usual amount of time and/or compensatory strategies to select the appropriate decision or action.

\*Accurately estimates abilities and independently adjusts to task demands.

\*Able to recognize the needs and feelings of others and automatically respond in appropriate manner.

\*Periodic periods of depression may occur.

\*Irritability and low frustration tolerance when sick, fatigued and/or under emotional stress.

\*Social interaction behavior is consistently appropriate.

*Original Scale co-authored by Chris Hagen, Ph.D., Danese Malkmus, M.A., Patricia Durham, M.A. Communication Disorders Service, Rancho Los Amigos Hospital, 1972. Revised 11/15/74 by Danese Malkmus, M.A., and Kathryn Stenderup, O.T.R. Revised scale 1997 by Chris Hagen.*

## **WHEN WILL WE KNOW THE SEVERITY OF THE BRAIN INJURY?**

It is difficult to predict the outcome of a brain injury in the first hours or days after the incident. There are some general observations that tell us “on the average” outcome, but no one can specifically predict the effect of a brain injury. In general terms, the longer the coma lasts, the less likely the individual is to recover fully. The effect of a brain injury may be unknown for months or even years. The doctor may answer this question in terms of “wait and see.” This is a difficult answer to accept but is often the most accurate, since each brain injury is unique and doctors cannot be as precise as might be possible with other types of injuries.

## **WHAT IS THE BEST WAY TO OBTAIN INFORMATION FROM DOCTORS?**

Questions to doctors should be written down. This is a very stressful time for everyone and questions can be easily forgotten. It is advisable to be persistent with questions until they are answered. The family member who asks the questions may want to take notes on the answers. The family should be prepared for some unpleasant information and be aware that there may be no specific answers to some of these questions. It is also good to remember that the recovery process involves a number of specialists who work as a team and information should be sought from all team members in order to understand the patient’s situation.

## **THERE ARE MANY DIFFERENT PEOPLE CARING FOR THE PERSON WITH A BRAIN INJURY. WHO ARE THEY?**

Most hospitals use a team system approach in the care of patients with brain injuries. Family members may become disturbed because the lead doctor is not present at all times. However, each member of this specialized team has a specific and important job to do.

It may be difficult for family members to understand which team member does what, and to whom specific questions should be directed. The following is a list of professionals who may be part of the team during various stages of the recovery process:

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**Neurosurgeon** – Physician specialist trained to evaluate, treat and perform surgery for injuries and disease process affecting the brain, brain stem and/or spinal cord. The neurosurgeon is a primary care physician and may sign off the case once the crisis is past or upon completion of surgical follow-up.

**Neurologist** – Physician specialist concerned with treating disorders of the brain, nerves, and muscles.

**Rehabilitation Nurses** – Nurses with basic nursing skills and specialized training in rehabilitation techniques.

**Respiratory Therapist** – Concerned with helping the patient breathe adequately as a means of preventing further complications and/or infections. If the patient is on a respirator, the respiratory therapist is responsible for maintaining the equipment. If the patient is unable to cough up secretions, the respiratory therapist may assist by lowering the head, tapping the back, and suctioning the patient.

**Physiatrist** – Physician primarily concerned with evaluating the impact of the traumatic brain injury on the functioning of the patient's body (not just the brain) and helping the patient to overcome any disability that has occurred.

**Physical Therapist** – Concerned with helping the patient regain maximum functioning of body movement or preventing further deterioration of physical function in the unconscious patient. This is done initially by moving the arms and legs (called Range of Motion) and thereby exercising unused muscles.

**Occupational Therapist** – Concerned with helping patients with activities of daily living (ADL) and with recovering functions that help them return to gainful employment and maximum independence.

**Speech Therapist** – Concerned with helping the patient return to normal or alternative patterns of communication.

**Clinical Psychologist/Clinical Neuropsychologist** – Concerned with evaluating the mental functions of the patient's brain and planning training programs to help the patient's brain return to normal functioning as quickly as possible. He/She will assist with emotional and behavioral problems. Depending on the extent of injuries the patient has sustained, it is not uncommon for the admitting physician to consult with other physicians with special skills, such as infectious disease control; ear, nose and throat; orthopedic; ophthalmology; oral surgery; etc.

## WHAT IS ALL THE EQUIPMENT ATTACHED TO THE PATIENT?

The brain is the coordinator of the rest of the body's functions. Brain injury may result in the brain's not performing these functions as well as necessary. It is therefore essential that it be given as much help as possible from the medical staff and equipment in order that all bodily functions are maintained.

The section lists and describes, in alphabetical order, the equipment most commonly found surrounding a patient with a brain injury and how this equipment is used by the medical staff in helping the patient. Each patient may not have all of this equipment. A diagram follows showing the location of the equipment on the patient.

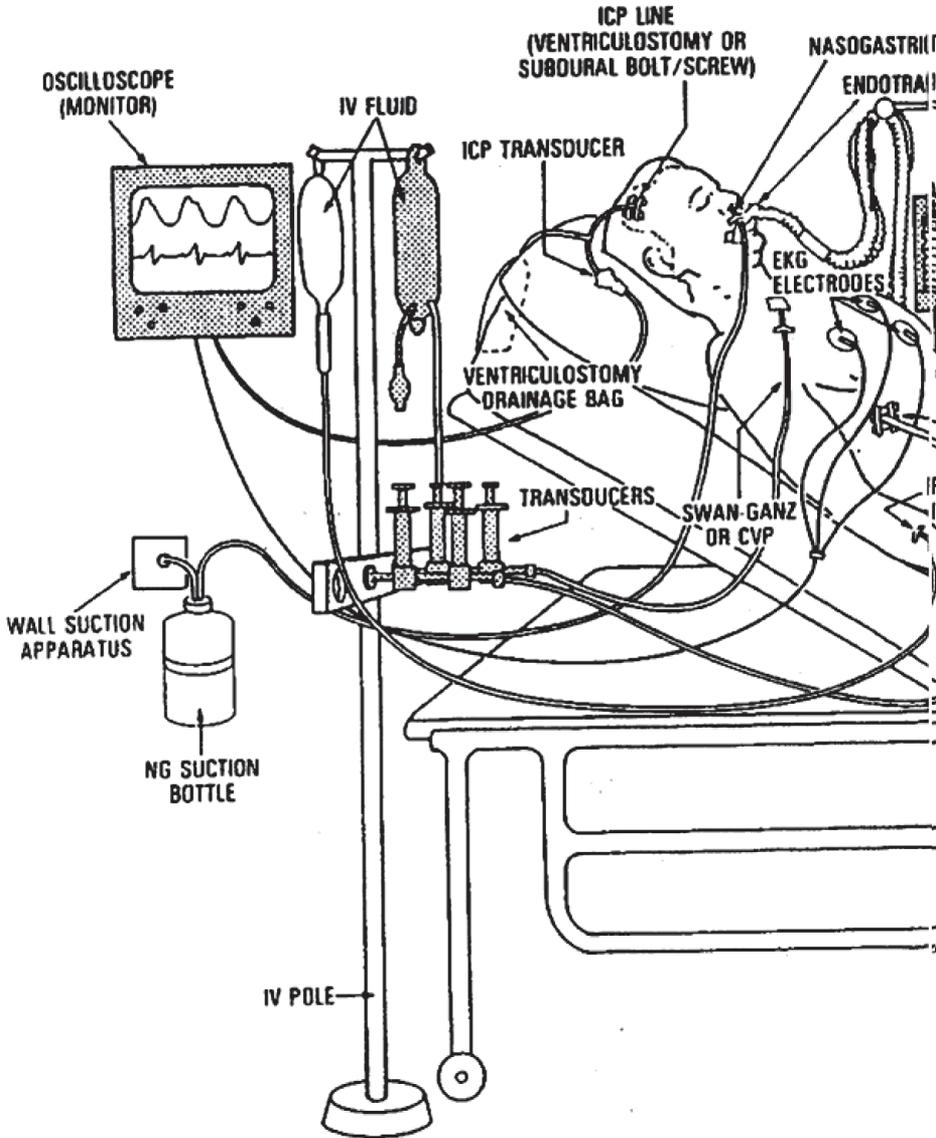
**Arterial line** – A very thin tube (catheter) is inserted into one of the patient's arteries (usually in the arm) to allow direct measurement of the blood pressure and to measure the concentration of oxygen and carbon dioxide in the blood. The arterial line is attached to a monitor.

**Brain stem evoked response (Evoked potentials)** – Auditory brain stem responses evoked by stimulating the brain stem with painless sound waves using headphones. These sound waves are received by the brain, and a machine is used to test whether the brain stem has received the signals. The quality of the brain stem's functioning in a comatose patient is thought to be an important indicator of the degree and site of brain injury. Since this test requires very specialized and expensive equipment, it is not available in all hospitals. A more common test is the EEG (Electroencephalogram).

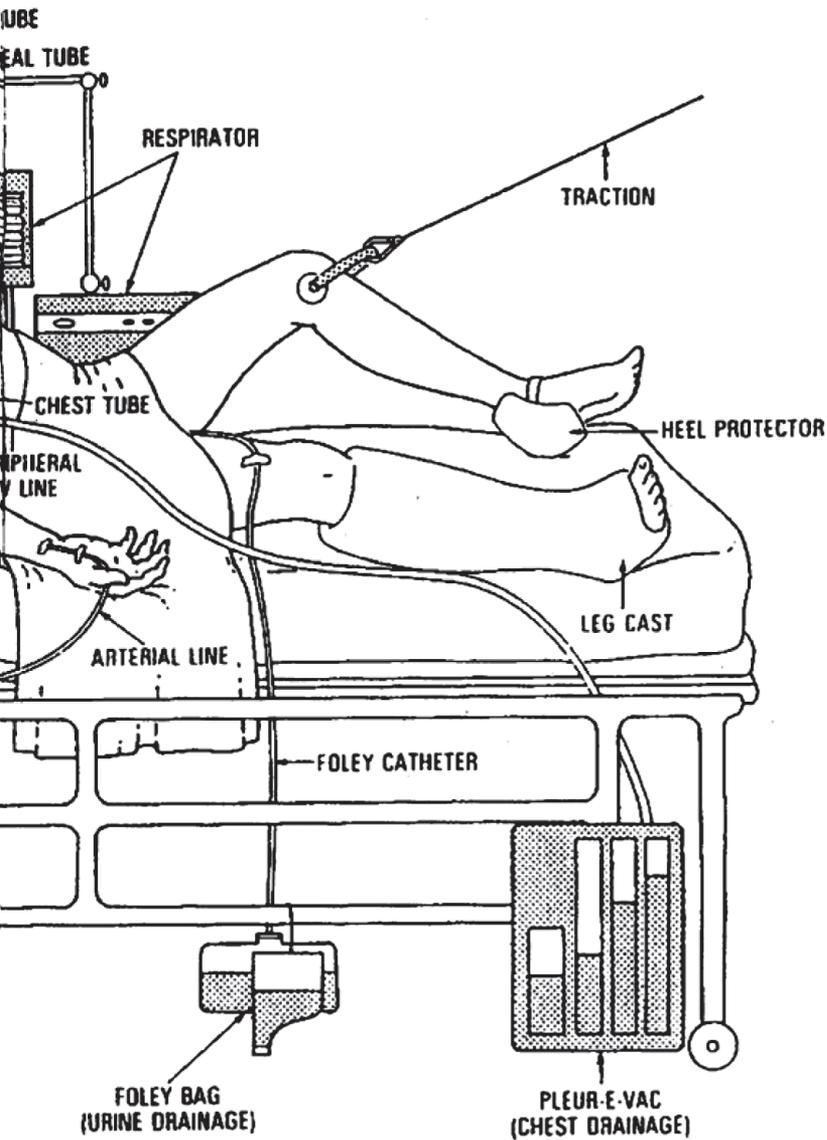
**Catheter (kath-a-ter)** – A flexible plastic tube of varying sizes with multiple uses.

**Central venous pressure (CVP) line** – A very thin tube (catheter) inserted into veins to allow direct measurement of the venous blood pressure (the pressure of the blood as it returns to the heart). CVP lines are inserted into veins in either the patient's arm or the chest just below the shoulder, or occasionally on the side of the neck. The CVP catheter is connected to a monitor.

**Chest tubes** – Tubes inserted into the patient's chest between lung and ribs to allow fluid and air to drain from the area surrounding the lungs. Removing this fluid and air from around the lungs allows them to more fully expand. An accumulation of fluid and air in the lung cavity can cause the lung to collapse. Chest tubes drain into a large plastic



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container near the foot of the patient's bed. The patient may have one or more of these tubes in place.

**Electrocardiogram (EKG)** – A set of electrodes placed in selected locations on the patient's chest to monitor heart rate and rhythm.

**Endotracheal tube (E.T. Tube)** – A tube that serves as an artificial airway inserted through the patient's mouth or nose. It passes through the throat and into the air passages to help breathing. To do this, it must also pass through the patient's vocal cords. The patient will be unable to speak as long as the endotracheal tube is in place. This tube is used to provide the patient with ventilator (respirator) support.

**Eye tape** - Tape used to close the patient's eyes. It is important that the eyes be kept moist. We do this naturally when we blink our eyes. This reflex is lost in the patient who is unresponsive but has open eyes. To protect the eyes and to prevent them from drying out, eye drops may be put into the eyes and eye tapes may be used to close them.

**Foley catheter** – This is a tube (catheter) inserted into the urinary bladder for drainage of urine. The urine drains through the tube into a plastic bag hanging low by the foot of the bed or attached to the patient's leg.

**Intracranial pressure (ICP) monitor** – A monitoring device to determine the pressure within the brain. It consists of a small tube (catheter) attached to the patient's skull by either a ventriculostomy, subarachnoid bolt or screw, and then connected to a transducer.

**Intravenous (IV) board** – A simple board usually attached with tape to the patient's forearm. It prevents bending and dislocation of the intravenous arterial or CVP lines.

## HOW LONG WILL IT TAKE TO RECOVER?

Due to the uncertainty accompanying brain injury, it is difficult to predict a level of recovery. However, to speak in general terms, the recovery from brain injury happens in stages. The first stage includes intensive, lifesaving medical and technical procedures, which occur in an acute care facility immediately following the trauma. After the acute care stage, the challenge of recovery then shifts to focus on the remaining stages of physical, occupational and neuropsychological restoration.

The rate of recovery is most rapid during the initial weeks of the brain

injury or after the person awakens from the coma. It is important that the period of rapid recovery does not mislead both the family and treatment staff to predict continued rapid, perhaps complete, recovery. Unfortunately if there is a slowdown of recovery after this stage, it can be very difficult for families; however, each individual progresses at his/her own rate of recovery. It is important to note that a slowdown in progress does not mean an end to recovery. Continued gains in function have been reported for years after the injury.

There are many factors that will affect the level of recovery after brain injury, such as: age at injury, area of the brain affected by the injury, length of time in coma, pre-existing personality characteristics, quality of pre-hospital (paramedic/EMS) and hospital care, speed of entry into brain injury rehabilitation program, nature of the support network, and involvement of family.

### **WHAT CAN THE FAMILY DO TO HELP?**

After the initial crisis, a family should try to return to a routine that is as normal as possible. Family members should stay in contact with friends and stay involved in activities they enjoy. It is important to stay in touch with the outside world.

Family members should ask the medical staff for ways they can be involved in the daily care of the patient. Loving care from family members is important in the recovery process. It is also a productive way to spend time with the patient as well as a learning process for family members.

Families are encouraged to learn about brain injuries so they will be better able to help the individual recover to the fullest extent possible. Families should inquire as to the availability of reading material about brain injury from the hospital, doctor or social worker. Families may also receive helpful information from Brain Injury Association of Florida, or the State of Florida, Brain and Spinal Cord Injury Program

When a brain injury occurs, the family, as well as the patient, can be traumatized. The family is placed under extreme emotional, physical and financial stress. The “Family and Friends” section in this guide addresses these difficulties and also offers suggestions for coping with the changes this injury brings to the family structure.

## **WHAT ARE THE VARIOUS PROCEDURES BEING USED WITH THE PATIENT?**

During the rehabilitation process, rehabilitation specialists may be involved with the care and treatment of the patient. Some rehab programs may use a multi-disciplinary team. The team may include the Physicians, Occupational Therapist (OT), Physical Therapist (PT), Speech/Language Pathologist, Recreation Therapist, Neuropsychologist, and others. Short and long term goals are established by the team based on the patient's abilities.

## **WILL THE BRAIN HEAL ITSELF?**

Brain tissue that is injured can recover over a short period, but once brain cells are dead or destroyed, new brain cells cannot grow. The recovery process of the patient continues to take place, however, even though new brain cells are not growing. The recovery is thought to happen when other parts of the brain take over the function of the destroyed brain tissue. In extensive damage to the brain, it is less likely that the remaining brain can assume the function of the destroyed areas. In this case, the patient must learn how to compensate for this loss through other methods involving adaptations in the environment or in his/her own behavior.

## **HOW WILL WE KNOW WHEN THE CRITICAL PHASE IS ENDING?**

For most patients, as the critical phase is ending, there will be signs the coma is lessening. Evidence of wakefulness and increasing consciousness will occur during this period. The recovery of consciousness is a gradual process and is not just a matter of "waking up" as people often imagine.

The patient begins to open his/her eyes and obey simple commands on an inconsistent basis. Often there will be confusion, disturbed behavior and memory loss even after the patient is fully alert. After a brain injury the patient will generally have no memory of the event and may also have no memory of events for an undetermined period of time before and after the injury.

**SECTION II**  
**REHABILITATION**

## **WHAT IS REHABILITATION? WHEN AND WHERE SHOULD IT BEGIN?**

Rehabilitation is the process of helping the patient achieve a maximum functional potential. As a patient nears discharge from the receiving hospital (acute care hospital), the family should seek the advise of the physician or the social services director for information to plan the rehabilitation. Rehabilitation services may be delivered in different settings, such as specialized brain injury rehabilitation centers, inpatient rehabilitation hospitals, outpatient rehabilitation hospitals, and/or services by professionals providing various therapies in a home setting.

## **WHAT HAPPENS IN A REHABILITATION PROGRAM?**

The course of rehabilitation following acute care varies with the needs of the individual. The patient should be thoroughly evaluated to determine the brain's function, so that a rehabilitation program can be developed for his/her special needs. If there is physical need, it is valuable to continue in physical and occupational therapy. It is important to achieve success in physical capability at the same time the brain is continuing in its slow healing process.

Speech and language therapy is an important part of the rehabilitation process. Brain injury almost always disrupts communication skills. Speech therapy will focus on problems with expressing and understanding language, as well as swallowing problems. Language problems are common and are often long-lasting challenges after a brain injury.

Cognitive rehabilitation is another major aspect of rehabilitation and involves a variety of techniques and programs focused on thinking and reasoning skills. In general, this would include working on organization of thought and time, sequencing, problem solving, decision-making strategies, and improving mental speed and capability.

Psychotherapy is beneficial for persons with brain injuries, as their lives have changed significantly due to their injuries. A period of assistance may be needed for family members as well to help them accept change and develop realistic expectations for their family member. Psychotherapy will assist everyone in understanding changes in behaviors after brain injury, on the basis of physiological damage and not merely as a sign of his/her poor adjustments to the experience.

Other forms of medical attention and rehabilitation needs, such as music, equestrian, and recreation therapies, will be determined by the uniqueness of each brain injury.

Educational and vocational rehabilitation may be required for reintegration into an educational program and for job training.

Each individual will have his/her own rate of recovery with periods where progress may appear to slow and then pick up again as new challenges are presented.

### **HOW ARE THE PROBLEMS EVALUATED?**

A number of professionals will be involved in evaluating the brain's function. Each professional will be evaluating in his/her specialized area. Diagnostic equipment is available to help detect skull fractures and other damage to the brain. Clinical tests and procedures such as EEGs, brain scans, and personality assessment are also used in evaluation. It is desirable that the various professionals operate as a team, if possible, so that their evaluations can be integrated into a cohesive program. *See glossary of neurological tests and procedures.*

A neuropsychological assessment may be one of the evaluations conducted. This is a comprehensive procedure that provides a detailed description of the brain-behavior relationships.

A wide range of psychological tests, interviews, observations, and procedures is used in order that mental functions of the brain can be measured. A typical neuropsychological test may be spaced over several days in consideration of the patient's level of endurance. This assessment helps the professional and the family understand the nature and extent of the brain injury. This information is used to develop an individual rehabilitation program to aid the patient toward maximum recovery.

### **WHAT TYPES OF REHABILITATION FACILITIES ARE AVAILABLE?**

The following is a list of major categories used to describe the array of rehabilitation facilities available. These descriptions should serve only as a guide as it is up to the individual and family to investigate specific programs and facilities to determine their suitability.

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- **ACUTE REHABILITATION** – Facility to treat patients as they become medically stable. This program often exists within an acute care hospital, as a unit of general rehabilitation center and/or as a free standing facility for the rehabilitation of traumatic brain injury.
  
- **INPATIENT/OUTPATIENT REHABILITATION** – Facility for a patient requiring extended, intensive and comprehensive therapies in a structured program, having all the elements found in an acute rehabilitation center. Focus will be on cognitive and memory retraining, speech therapy, daily living skills, restructuring lost social behavior, and continued physical therapies.
  
- **TRANSITIONAL LIVING** – The goal of the transitional program is to prepare individuals for maximum independence, to teach necessary skills for community interaction and to work on educational and vocational training. Programs may be in a variety of settings such as group homes, adult congregate living facilities or special education institutions.
  
- **LONG TERM REHABILITATION** – Facility to provide long term rehabilitation with a non residential-like setting as opposed to a hospital setting. This is a program for the patient who is making slow improvements and needs long term intensive therapy. These facilities are generally not for permanent placement.
  
- **RESIDENTIAL LIVING** – Facility that provides a structured group residential program for those individuals unable to live at home or independently. Few of these facilities are available specifically for individuals with brain injuries.
  
- **DAY TREATMENT SERVICES** – Program created to improve functional skills including physical and occupational therapies, cognitive therapy, social adjustment, pre-vocational training, independent living skills and so on. These programs are community based and may be offered through resources in the local area.
  
- **RESPIRE PROGRAM** – Opportunity for the patient and family to take short “vacation-like” breaks from each other. Respite programs are not plentiful, but are becoming recognized as an important element in long-term rehabilitation.

- *The Florida Brain and Spinal Cord Injury Program provides services to eligible individuals through State designated facilities in these categories. More information about the program and other services available through the Brain and Spinal Cord Injury Rehabilitation Trust Fund can be obtained through your local Department of Health office.*

## **WHAT ARE SOME GUIDELINES FOR SELECTING A FACILITY?**

1. Always try to obtain the names of at least three programs to consider for your family member.
2. Location should be just one of the many factors families consider in regard to selecting a brain injury rehabilitation program. If a nearby facility is not familiar with traumatic brain injury, it may be better to travel a distance to ensure an appropriate program.
3. It is most important that the prospective programs treatment team all have expertise in brain injury rehabilitation. There should be a team approach to planning and treatment.
4. Ask for the names of families of individuals who have recently been clients in the program. Ask these families about their satisfaction with the program, whether it met their expectations, what they were told prior to admission, whether the program achieved the established goals, and what they would do differently.
5. Tour the facilities. Look for a clean environment with a caring staff; adequate space for all disciplines of the treatment team to provide their services; staff and survivors knowing where a person is supposed to be at all times; adequate markers, cues, and reminders for all staff working with survivors; and a system that lets new or temporary staff become familiar with the survivor's program and needs.
6. Be sure there are regularly scheduled family conferences including all disciplines and including family and significant other.
7. Ask if the brain injury program is accredited by a nationally recognized body, such as the Commission on Accreditation of Rehabilitation Facilities (CARF).

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8. Finally, the decision you arrive at must be based on your own individual opinions. They will continue to be the most important criteria in the rehabilitation of your family member.

### **WHERE CAN FAMILIES FIND RESOURCE INFORMATION AND MEDICAL ASSISTANCE?**

There are several agencies to which you can turn for guidance. You should gather as much knowledge as possible about the services available in your community to allow you to make a decision that will best meet the patient's needs. The following two listings are a good place to begin.

#### Brain Injury Association of Florida

Brain Injury Association of Florida (BIAF) is a source of assistance for the families and friends of individuals with brain injuries. BIAF is the official state chapter of the Brain Injury Association of America in McLean, VA. As an information, advocacy, prevention and educational organization, BIAF provides support for persons with brain injuries and their families.

BIAF is comprised of family members, individuals with brain injuries, professionals and friends, concerned about the unique problems of persons with brain injuries as they strive to restore hope and dignity in the midst of tragedy. Specific information can be obtained by calling the BIAF office at (954) 786-2400 or the Family Helpline at 1-800-992-3442.

#### Brain and Spinal Cord Injury Program

The Florida Department of Health, Brain and Spinal Cord Injury Program assists residents of Florida in obtaining rehabilitative services necessary for maximum levels of independent functioning and community reintegration. To find out more about this program, see your local telephone directory under "Florida, State of..." "Department of Health," or go to [www.myflorida.com](http://www.myflorida.com).

## REHABILITATION

After rehabilitation, you may find that the following organizations in your community are helpful:

Local School System	Goodwill Industries
Community Hospitals	United Cerebral Palsy
Easter Seals Society	Local Support Groups

Local Parks and Recreation agencies may have programs for special populations.

## **SECTION III**

### **FAMILY AND FRIENDS**

## **WHAT REACTIONS MIGHT BE EXPECTED FROM FAMILY MEMBERS?**

The family as well as the person with the brain injury is traumatized when a severe brain injury occurs. The family is placed under extreme stress to assume unaccustomed roles, which may include caregiving, becoming breadwinners, and advocating on behalf of the injured person.

This, along with the possible changes in physical functioning and personality suffered by the person with a brain injury, may place an unusual burden of stress on members of the family. It is not uncommon for family members to occasionally react in ways that others do not understand. Some family members may choose to immerse themselves in efforts to help the injured family member, while other family members may be emotionally unable to cope with the situation and need to distance themselves from the trauma.

After a person suffers a severe brain injury, the family reaction will be ever changing as their expectations change. Over the course of hospitalization, rehabilitation, and re-integration into the community, they sense the “loss” of the person they once knew and loved and begin to know and love the person who may be altered somewhat as a result of the trauma. Mourning the loss of that person is important to emotional well being.

Most people go through a grieving process that is a natural and normal part of accepting what has happened. These stages include:

1. Denial: “No, this couldn’t have happened to us...”
2. Anger and frustration: Family members may feel anger toward anyone who could be seen as the cause of the injury. They may feel victimized and frequently develop a hostile attitude directed toward those professionals who are working with the injured person and cannot “fix” the problem.
3. Depression and withdrawal: Family members may lack the motivation to care for themselves, physically and emotionally. They may feel isolated when friends who were very supportive initially become less involved as the process of restoration of the injured person drags on. With few social contacts, the family becomes more hopeless and less functional.

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4. Acceptance: The family, over an indefinite period of time, should begin to accept the changes that have occurred and begin to heal. The process of “mourning” the loss of the person may confuse the issue of acceptance, but ultimately both the family and the person with the brain injury should accept what cannot be changed and learn to get on with a life of the highest quality possible.

## **HOW CAN FAMILY MEMBERS MINIMIZE STRESS?**

The following is a list of guidelines to help family members minimize their stress. Family members should:

- Maintain contact with friends and activities that they enjoy.
- Work out a rotating visitation schedule with other family members. This will allow needed time for themselves.
- Be aware of the needs of other family members. They need to know that they have not been forgotten.
- Ask and accept help from others. This assistance could be such activities as running an errand, mowing the lawn or bringing over a meal.
- Express feelings and do not try to keep everything inside. Talk to other family members, the social worker, a minister, a case manager, or anyone with whom they feel comfortable.

## **WHAT IS THE FAMILY’S ROLE IN RECOVERY?**

The patient’s family should be involved in the recovery, rehabilitation and readjustment process to the greatest extent possible. The primary role of the family and/or significant other is one of advocacy on behalf of the person with the brain injury.

No family is prepared for this unfamiliar task, which might include a commitment of time and effort that is often difficult to maintain for many reasons, the least of which is economic. They may be overwhelmed with uncertainties about the nature and extent of the injury, the

need to understand how the injury will affect the person, and the need to plan for the future.

One of the first tasks the family can perform is that of family historian, to describe the injured person for the benefit of the healthcare professionals so that they can include this “information” in their interpretation of what is occurring with the patient. After all, the family knows this person better than anyone else.

Members of the family should ask the staff for guidance in working with the patient. This might include asking for information about equipment and procedures being used, determining how the family could enhance the therapy which is being delivered by the professionals, and requesting direction to other departments of the hospital that provide assistance (e.g., social services department, family education coordinator, etc.).

Throughout the recovery, which may extend over an undetermined length of time, family members can be supportive even when they are unable to be at the patient’s bedside. Their advocacy efforts can play a major role in securing benefits to which the patient is entitled. These benefits may involve securing financial, insurance, and employment information necessary in determining eligibility for various benefits and programs.

It might include contacting the authorities and collecting information from the accident scene, in the event of possible litigation; gathering information about traumatic brain injury to assist with advocacy and joining with families of other persons with brain injuries for mutual understanding and support.

Family members must realize that even the best medical care is incomplete without the loving concern and encouragement that comes from the patient’s family. There may be years of hard work before returning to pre-injury activity, and possibly physical or cognitive impairment that is never fully corrected. Families of persons with brain injuries must adjust to the fact that the recovery process is a slow “labor of love” for everyone involved. During this painstaking process it is natural for everyone to become impatient. Family members must not feel guilty about these feelings, but must come to understand that a task cannot go any faster than the injured brain. Simple tasks must be mastered before the more complicated cognitive skills can be re-learned. The family members’ role is to be as understanding as possible while still tending to their own needs, and to support the individual’s progress with praise and acceptance.

## BRAIN INJURY: A FAMILY GUIDE

The role of the family will change with an extended rehabilitation process and the family members will need to adjust and adapt to these changes. The more severe the injury, the more drastic these changes will be. All affected persons play changing roles and many will experience periods of isolation, loneliness, grief, guilt and helplessness; but hopefully, in time, and with the support of those who care, all survivors and their families can find laughter and good times again.

### **HOW WILL THE FAMILY BE AFFECTED?**

Families of individuals with brain injuries must realize the inescapable effects on and changes within the family structure. If the person with brain injury is the income provider, there will likely be changes in marriage/family relationships, income, economic stability and social status. One or more family members may be forced to assume the role of provider. When the person with brain injury is the homemaker, role revision again takes place. Other family members must share duties and responsibilities.

Parents of a son or daughter with a brain injury are faced with loss of dreams, in addition to the eventual realization that life-long care may be necessary. They must tackle the task of considering how to provide vocational, emotional and financial support for their child, often for a lifetime in the event of severe injury. Family and friends need to work together to create a supportive environment, maximum recovery and to reduce stress on the people carrying the greatest personal burden.

This may be a time of loneliness and isolation for the family. Family members spend hours at the bedside with the patient in a strange city, or even in their hometown. The worry and fatigue that families experience will leave little time to interact with others. Also, many people in the community are unfamiliar with brain injury and this often leads to gradual withdrawal of contact and support to the family on their part.

Family members' ability to cope is very important, and often professional support and guidance can be helpful. Also, brain injury support groups are available throughout the State for family members who wish to talk to and to interact with others who have gone through similar experiences. Brain Injury Association of Florida can provide callers with a list of statewide support groups (1-800-992-3442).

## **SOME LONG TERM CONSEQUENCES OF TRAUMATIC BRAIN INJURY**

### **COGNITIVE**

- memory loss (short and long term)
- problems in arousal, attention and concentration
- problems in initiating, planning and completing action
- problems with judgment
- difficulty in recognizing one's cognitive deficits/limits
- spatial disorientation (problems with perception, direction, etc.)
- slowness of thought processes
- slowness and/or difficulty with speech

### **PHYSICAL**

- hemiparesis
- seizures
- spasticity
- visual impairments
- reduced endurance
- loss of taste

### **PSYCHOSOCIAL**

- anxiety and depression
- emotional lability
- denial
- inappropriate behaviors (impulsivity and disinhibition)
- egocentricity
- agitation/outburst(short tempered, irritable)
- sexual dysfunction
- loss of social networking, feeling of isolation

## **SUGGESTIONS FOR UNDERSTANDING AND LIVING WITH A PERSON WITH A BRAIN INJURY**

Most individuals with brain injuries need some degree of help and structuring throughout their lives. At first this structure will be provided through a hospital or rehabilitation facility. Families may be called upon to implement a discharge plan and structured environment once the individual returns to the community.

The following is a list of general principles offered to help the person with a brain injury achieve a higher functional level:

- Keep surroundings familiar and consistent.
- Establish and maintain a daily routine of regularly scheduled meals and activities.
- Encourage break periods whenever frustration or fatigue appears, or often enough to prevent them from occurring.
- Use memory aids such as reminder notes, labels, calendars and wall charts.
- Include the person with the brain injury in conversation and family affairs.
- Treat the person as an adult with respect to his/her likes and dislikes about such things as food, clothing, music and recreation. It is important to note these likes and dislikes may have changed.
- Let the person, if capable of speaking, answer for himself/herself and have some control over his/her life.
- Provide specific options from which to choose, rather than requesting an open-ended decision. For example, “Would you like to watch TV or read a book?” rather than “What would you like to do?”
- Keep activities or tasks relatively simple, using one- or two-step directions and repeating them frequently.
- Don’t compare or expect behavior to be as it was before the injury.
- Give praise for desired behavior and brief, to-the-point criticism for undesirable behavior. This is a difficult balance to achieve.

## SUGGESTIONS FOR THE PERSON WITH A BRAIN INJURY

Accepting realistic, needed help from others is necessary while striving for increased independence. Achieving a maximum level of recovery depends on a committed and persistent effort from everyone. The following is a list of guidelines to help make life easier as recovery is taking place:

- Keep a detailed plan of activities you do and intend to do.
- Ask questions, only after you ask yourself first. Asking too many questions will make you dependent and will not encourage your critical thinking.
- Use NO alcohol or drugs. These substances will only dull the brain and are dangerous when used with needed medication.
- Do not use negative thinking such as “I can’t.” Be willing to try new things.
- Do not use words such as “later” or “maybe.” They will keep you from committing to anything.
- Keep a daily schedule. This will help establish and maintain routines as well as offer predictability and consistency.
- Write things down. This will help you to remember and help reinforce learning skills. As you hear it, write it and see it.
- Set realistic goals. Review these goals periodically.
- Do not be afraid to ask for and/or accept help from others.

## AREAS OF THE BRAIN

The brain is the control center for all of the body’s actions and functions. It receives messages and interprets them. The brain responds to messages by enabling a person to perform the vital processes of breathing and moving as well as thinking, judgment and emotional reactions.

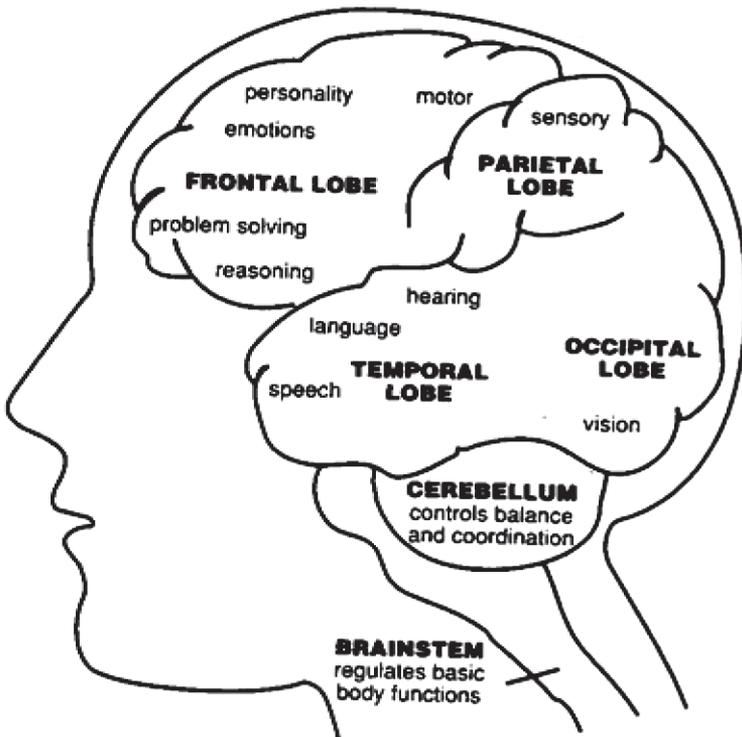
A fundamental awareness of the brain’s structure may help in the understanding of what happens to the brain when a brain injury occurs.

The brain is comprised of three areas:

- 1. Brain Stem** – The brain stem connects the brain to the spinal cord. Structures in the brain stem control consciousness, arousal and vital functions such as breathing, blood pressure and pulse rate.
- 2. Cerebellum** – The cerebellum controls muscle, coordination and balance.

**3. Cortex** – The cortex is the largest area in the brain and is where most thinking functions occur. The cortex is divided into four lobes. Each lobe has a specialized function as shown in the diagram. The cortex is also divided into two halves (hemispheres). The dominant hemisphere, usually the left, controls verbal functions such as speaking, writing, reading and calculating. The right hemisphere controls functions, more visual in nature, such as memory, drawing and copying.

No two traumatic brain injuries are the same, just as no two individuals are identical. This is because different areas of the brain are affected with each injury and the effects are multiple. Because of these multiple effects and the fact that the damage is often widespread, traumatic brain injury differs from other types of brain damage such as stroke, brain tumor, drug or alcohol induced problems and degenerative disease.



## **GLOSSARY OF TERMS**

**ABSTRACT REASONING:** process of generalizing from concrete examples and experiences to larger, broader principles.

**ACALCULIA:** dysfunction or inability to perform mathematical operations, recognize numbers, or count.

**ACUITY:** keenness of sensation.

**AGNOSIA:** loss of ability to recognize familiar people, places and objects.

**AGRAPHIA:** loss of ability to express thoughts in writing.

**ALEXIA:** inability to read or recognize words.

**ANOXIA:** a lack of oxygen that can cause damage to the brain. This can result when blood flow is reduced (such as in electrocution, lightning strike and near drowning).

**ANOMIA:** dysfunction or inability to name objects or recall individual names.

**ANTEROGRADE AMNESIA:** loss of memory for events and periods of time following an injury or traumatic event.

**APATHY:** decrease in motivation, initiation, interest in life and growth; indifference.

**APHASIA:** loss in ability to speak coherent ideas or understand spoken language.

**APRAXIA:** loss of ability to carry out habitual movement or acts that were previously automatic.

**ASTEREOGNOSIS:** inability to recognize objects or shapes by feeling them.

**ASYMMETRY:** discrepancy in function or appearance between sides of organs.

**ATAXIA:** dysfunction in motor coordination and balance.

## BRAIN INJURY: A FAMILY GUIDE

**ATTENTION:** ability for sustaining focus on task for a period of time to allow for coding and storing of information in memory.

**BRAIN STEM:** the lower portion of the brain that connects it to the spinal column. The brain stem coordinates the body's vital functions (breathing, blood pressure and pulse).

**CEREBELLUM:** the portion of the brain that is located below the cortex. The cerebellum is concerned with coordinating movements.

**COGNITION:** process of thinking, understanding and reasoning.

**COMA:** unconsciousness lasting for longer than a brief period of time. A state of unconsciousness where the person cannot be aroused and/or does not respond.

**CONTRA-COUP:** when the brain sustains sufficient force, causing it to "bounce" against the opposite side of the skull; thereby causing injury to both the site of impact, and the part of the brain opposite the impact.

**CORTEX:** the largest portion of the brain consisting of two cerebral hemispheres that are connected by a band of tissue (the corpus callosum). This is the area where most "thinking" and cognitive functioning takes place. It is sometimes referred to as the "cerebrum."

**DIFFUSE:** brain damage that covers many areas of the brain rather than one specific location. Diffuse damage is common in closed brain injuries due to the brain moving about and tissue being torn, stretched or bruised.

**DIPLOPIA:** seeing two images of a single object ("double vision").

**DISINHIBITION:** the inability to control or inhibit impulses and emotions.

**DISORIENTATION:** disturbance in recognition of person, place and/or time and day.

**DYSARRHRIA:** disruption or dysfunction in speech articulation.

**EDEMA:** collection of fluid (water) in the brain tissue causing swelling.

**EMOTIONAL LIABILITY:** intense fluctuations of emotions in response to experiences.

**FRONTAL LOBE:** the area of the brain located at the front on both the left and right sides. This area plays a role in controlling emotions, motivation, social skills, expressive language and inhibition of impulses. The motor controlling movement and motor integration runs along the posterior (back) of the frontal lobe.

**FRUSTRATION TOLERANCE:** amount and degree of frustration; the point at which a person can no longer control his/her anger and responds by yelling, throwing things or displaying aggressive behavior.

**GLASGOW COMA SCALE:** a scale of severity of injury developed by B. Jennett, M.D., and G. Teasdale, M.D. This scale relates the level of consciousness with three factors: motor responses, eye opening and verbal responses.

**HEMATOMA:** when an area of tissue swells and fills with blood.

**HEMIPARESIS:** weakness of one side of the body (or part of it) due to injury to the motor areas of the brain.

**HEMISPHERIC ASYMMETRY:** differences in the type of functions for which the two sides of the brain are responsible. (For example, the left side is usually associated with verbal functions, while the right side is associated with spatial abilities).

**HEMORRHAGE:** bleeding that occurs following trauma. Bleeding may occur within the brain when blood vessels in the skull or the brain are damaged.

**INFLEXIBILITY:** rigidity in thinking; over reliance on stereotypes; difficulty in recognizing alternative possibilities.

**JUDGMENT:** ability for resolving dilemmas and approaching problems; includes values, morals, and interpretation with respect to interaction.

**LIMBIC SYSTEM:** a set of structures (usually considered part of the temporal lobe) which play an important role in memory, attention, emotions and behavior.

**MEMORY:** stored recollections about experiences, events, feelings, dates, etc., from the recent and distant past.

## BRAIN INJURY: A FAMILY GUIDE

**OCCIPITAL LOBE:** the posterior(back) part of each side of the brain, involved in perceiving and understanding visual information.

**PARIETAL LOBE:** the upper middle lobe of each side of the brain, involved in perceiving and understanding sensations, and closely linked to speech fluency and writing.

**PERSEVERATION:** over-reliance on, or repetition of, a specific response or behavior to different tasks.

**PREMORBID:** a term to describe the patient's condition before the injury or illness.

**POST-TRAUMATIC AMNESIA:** loss in memory of events related to a traumatic event and the period immediately following the trauma.

**PROBLEM SOLVING:** skills for employing reasoning, judgment, and discernment in resolving problems.

**PROXIMAL INSTABILITY:** impaired strength or muscle tone of the trunk, shoulder girdle or hip girdle. This can cause poor posture, abnormal movement of the limbs, inability to sit up and inability to hold one's head up.

**QUADRIPARESIS:** a weakness that involves all four limbs.

**RANCHOS LOS AMIGOS SCALE:** an assessment tool that provides a description of the various behavioral stages an individual with brain injury will experience as he/she progresses through rehabilitation.

**RETROGRADE AMNESIA:** loss of memory of events and periods of time before an injury.

**SPASTICITY:** an abnormal increase in muscle tone, causing the muscles to resist being stretched. A patient with spasticity may look "curled up," with his arms held close to his chest, or he may appear very stiff.

**SPONTANEOUS RECOVERY:** the recovery which takes places spontaneously as the brain heals; this type of recovery occurs with or without rehabilitation and it is often difficult to know how much improvement is spontaneous and how much is due to rehabilitative interventions.

**TACTILE DEFENSIVENESS:** being overly sensitive to touch; withdrawing, crying, yelling or striking out when touched.

**TEMPORAL LOBE:** the lower middle part of each side of the brain, involved in receiving information from the auditory system and involved in memory.

**UNILATERAL:** pertaining only to one side.

**UNILATERAL NEGLECT:** unawareness or inattention to one side of the body or the space or events occurring on one side of the body.

**VENTRICLES:** four cavities in the brain that are filled with cerebrospinal fluid, serving as a cushion when the brain is impacted.

**VESTIBULAR:** awareness of movement involving the head. Disorders of the vestibular system can lead to a lack of awareness of movement, a lack of awareness of direction of movement or hypersensitivity to movement.

**VISUAL FIELD DEFICIT:** not visually perceiving information in a specific area of the visual field.

## **GLOSSARY OF MEDICINES THAT MAY BE USED FOR PERSONS WITH BRAIN INJURIES**

**ANTIBIOTICS** – seriously injured people are susceptible to many kinds of infection because of their injuries and the many lines and tubes inserted into their bodies. Several kinds of antibiotics are given through an intravenous catheter (IV) whereas others may be placed on the skin or into the nasogastric tube. Occasionally antibiotics must be given through a ventriculostomy catheter directly into the ventricles of the brain.

**DECADRON (PHENYTOIN)** – an anti-seizure drug that is usually given to prevent seizures.

**DOPAMINE** – a potent drug used to increase blood pressure in critically ill persons.

**LASIX (FUROSEMIDE)** – this drug assists the body in eliminating water. It may be used to treat increased intracranial pressure, too much water in the lungs, or sluggish kidneys.

**MAALOX** – a medicine usually given by the nasogastric (NG) tube to help prevent the stomach ulcers (stress ulcers) that can develop after trauma.

**MANNITOL** – a medicine used to remove water from the brain and thereby lower intracranial pressure (ICP). The mannitol and water are then eliminated by the kidneys.

**MORPHINE (MS)** – a strong sedative that is also an excellent pain reliever. People who receive this narcotic in the ICU almost never become addicted to it because of this treatment. Morphine is often used to sedate patients so they do not “fight the ventilator.”

**PAVULON (PANCURONIUM BROMIDE) AND CURARE** – drugs that temporarily paralyze muscles. These medicines are used to prevent the patient from “fighting” the ventilator to control intracranial pressure (ICP) and to relax the patient while performing medical procedures.

**PENTOBARBITAL (NEMBUTAL)** – a strong sedative that has been used to help control intracranial pressure (ICP). When used in this way, pentobarbital acts as an anesthetic that places the patient in a deeper coma.

**PHENOBARBITAL** – an anti-seizure drug used to prevent seizures in patients, especially children. Phenobarbital may occasionally be used like pentobarbital to control intracranial pressure (ICP).

**STEROIDS** of which **DECADRON** is an example – potent drugs that are used to lessen brain swelling.

**TAGAMET (CIMETIDINE)** – a drug used to help prevent stomach ulcers.

**VALIUM (DIAZEPAM)** – a sedative tranquilizer that is very effective at quickly stopping repetitive seizures when given intravenously.

## **GLOSSARY OF NEUROLOGICAL TESTS AND PROCEDURES**

**BEAM (BRAIN ELECTRICAL ACTIVITY MAPPING)** : a computerized analysis of background EEG activity, much more sensitive than conventional EEG, which is especially helpful in identifying abnormalities of early dementia or suspected damage from brain injury.

**BRAIN STEM EVOKED RESPONSES:** brain stem response to a specific stimulus recorded electronically.

**CT SCAN (COMPUTERIZED TOMOGRAPHY):** computerized x-ray taken at different levels of the brain to yield a three-dimensional representation of the physical shape of the brain

**ELECTROCARDIOGRAM (EEG OR EKG):** electrical measure of heart activity and heartbeat that is produced on a chart recording.

**ELECTROENCEPHALOGRAM (EEG):** an evaluation of electrical activity of the brain.

**MRI SCAN (MAGNETIC RESONANCE IMAGING):** an instrument that develops images from biochemical operations of the brain by using a magnetic field.

**NEUROLOGICAL EXAMINATION:** an assessment of gross nerve functioning via reflexes and reactions; performed by a neurologist or neurosurgeon.

**NEUROPSYCHOLOGICAL EVALUATION:** specialized tests and measures that provide a detailed description of the brain/behavior relationships that are consequences of brain trauma.

## **BRAIN INJURY: A FAMILY GUIDE**

**PET SCAN (POSITRON EMISSION TOMOGRAPHY):** an instrument that records chemical activity in specific regions of the brain.

### **REFERENCES**

Alber, Ann M., M.S.S.W., A.C.S.W. (et al), "Getting Our Heads Together." Thoms Rehabilitation Hospital Inc., Asheville, NC.

Guidelines for Selecting a Rehab Facility. Brain Injury Association, Washington, D.C. (Formerly National Head Injury Foundation)

Hawley, Lenore A., "A Family Guide to the Rehabilitation of the Severely Brain Injured Patient." Healthcare International, Inc., Austin, TX. 1984.

Hutchinson, Ruth, M.S. and Terry Hutchison, M.D., Ph.D., Head Injury, a Booklet For Families. Texas Head Injury Foundation, Houston, TX. 1983

Marshall, Lawrence, M.D., G. Sadler, M.B.A. and S. Bowers, B.S.N., "Head Injury." The Central Nervous System Injury Foundation, San Diego, CA. 1981.

Swiercinsky, Dennis P., Ph.D., Terry L. Price, Ph.D., Leif Eric Leaf, Ph.D., "Traumatic Head Injury, Cause, Consequence and Challenge." The Kansas Head Injury Association, Inc., Shawnee Mission, KS. 1987

Williams, Janet M., M.S.W., Thomas Kay, Ph.D., "Head Injury, a Family Matter." Paul H. Brookes, Baltimore, MD. 1991

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