

Brain Injury Family Education Manual



Patricia Neal

Rehabilitation Center

Restoring Abilities. Rebuilding Lives.

Brain Injury Program Services

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WELCOME

Someone you love and care about has suffered a brain injury. You have made it through the initial phase of the injury, the acute hospital stay and now admission to the Patricia Neal Rehabilitation Center. You may be asking yourself: “What happened, Why are we here, Will we ever regain a normal life again, or What can I do to help my loved one?”

The staff at PNRG wants all your questions to be answered. We believe that the more you know about Brain Injury and the rehabilitation process, the better you will be able to help your loved one and be more equipped to make life care planning decisions. This workbook is designed to answer some of the questions you may have, guide you through your rehab stay, and prepare you for discharge from inpatient services.

It is vitally important that you attend the training and educational sessions offered at the Patricia Neal Rehabilitation Center. This will help you to understand and become familiar with your loved one’s care.

We, the staff, are here for you – so use us to our fullest capacity.

GUIDELINES FOR INTERACTION

- When you enter the room, immediately identify yourself and make physical contact, either by gentle touch of an arm or leg, while simultaneously speaking in a soothing manner.
- Speak in a soothing manner using a steady tone, rate and volume. DO NOT talk loudly or abruptly.
- Keep statements short and simple. Patients with a brain injury may need a longer time to respond to statements – sometimes as long as several minutes.
- Always assume the patient understands everything.
- Always talk to the patient. Initially, tell the patient the time, date, place, who you are, why they are in the hospital, and what you are doing.
- Limit the number of visitors in the room to 2 per patient but not to exceed 4 per room.
- Always observe the patient for signs of overstimulation and if this occurs – “back down” – or it will only get worse. Signs of overstimulation include:
 - The patient may withdraw from the stimulus and/or stop responding
 - The patient may become restless and agitated (flailing, hitting, etc.)
 - Increased tone (stiffness/ drawing-up) or sweating.

REMEMBER, if this occurs – back down once the patient is safe. Bringing more people in will usually just increase the problem.

- Do not exclude the patient from conversation. Even if they do not respond, they probably are aware and should be included. Always explain what you are doing.
- Many behaviors after brain injury are a phase and will pass with time. Be patient and don't take remarks on behavior directed toward you, or others, as personal. During certain times, they do not know what they are doing or saying.

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Chapter 1: BRAIN PARTS AND THEIR FUNCTIONS

This section of your workbook consists of an outline of the parts of the brain and their functions. The outline is followed by a diagram of the brain that shows the brain “mapped” out according to the function of each area. The location of the brain injury will determine the deficits the individual with a brain injury will exhibit. First, the brain is divided into two hemispheres, the left and right hemispheres. The left hemisphere will typically control the right side of the body and the right hemisphere will control the left side of the body.

LEFT HEMISPHERE	RIGHT HEMISPHERE
<ul style="list-style-type: none"> ➤ Speaking ➤ Understanding ➤ Speech production ➤ Language abilities ➤ Reading ➤ Writing ➤ Calculating (math) 	<ul style="list-style-type: none"> ➤ Copying ➤ Drawing ➤ Judging size ➤ Musical Rhythm ➤ Paying attention ➤ Body Language ➤ Reading Maps

CEREBRUM

The cerebrum is the largest part of the brain.
There are four parts to the cerebrum which are called lobes.

FRONTAL LOBE	PARIETAL LOBE:
<ul style="list-style-type: none"> ➔ Judgment ➔ Problem solving ➔ Personality and behavior ➔ Motivation ➔ Initiation ➔ Problem solving ➔ Impulse control ➔ Memory ➔ Voluntary movements of muscles ➔ Emotions <p><i>Damage to this area may cause:</i></p> <ul style="list-style-type: none"> × Aphasia (difficulty with speaking and understanding speech) × Poor inhibition × Poor social judgment × Personality changes × Decreased spontaneity × Memory problems × Paralysis or muscle weakness 	<ul style="list-style-type: none"> ➔ Sense of touch ➔ Awareness of our body parts that belong to us. ➔ Higher analysis of touch-the ability to distinguish between two simultaneous skin contacts. <p><i>Damage to this area may cause:</i></p> <ul style="list-style-type: none"> × Problems with what we feel × Difficulty with constructing/making things × Math problems × Difficulty with movement × Neglect of a part of our body × Distortions of body image × Right-left confusion × Poor spatial ability × Poor drawing ability × Short term memory problems

TEMPORAL LOBE:

- ➔ Hearing
- ➔ Taste
- ➔ Smell
- ➔ Aiding in committing information to memory
- ➔ Understanding verbal language
- ➔ Organization of time
- ➔ Vestibular function (inner ear)

Damage to this area can cause:

- × Hearing and understanding language difficulties
- × Long and short term memory problems
- × Memory disorganization
- × Dizziness and/or vertigo

OCCIPITAL LOBE:

- ➔ Vision
- ➔ Visual recognition
- ➔ Impulses of the retina of the eye.

Damage to this area can cause:

- × Difficulty with eye sight.

CEREBELLUM

The cerebellum sits just below the cerebrum. It's the control center for:

- ➔ Coordination
- ➔ Refines motor movement
- ➔ Balance and equilibrium
- ➔ Helps balance out muscle tone

Damage to this area can cause:

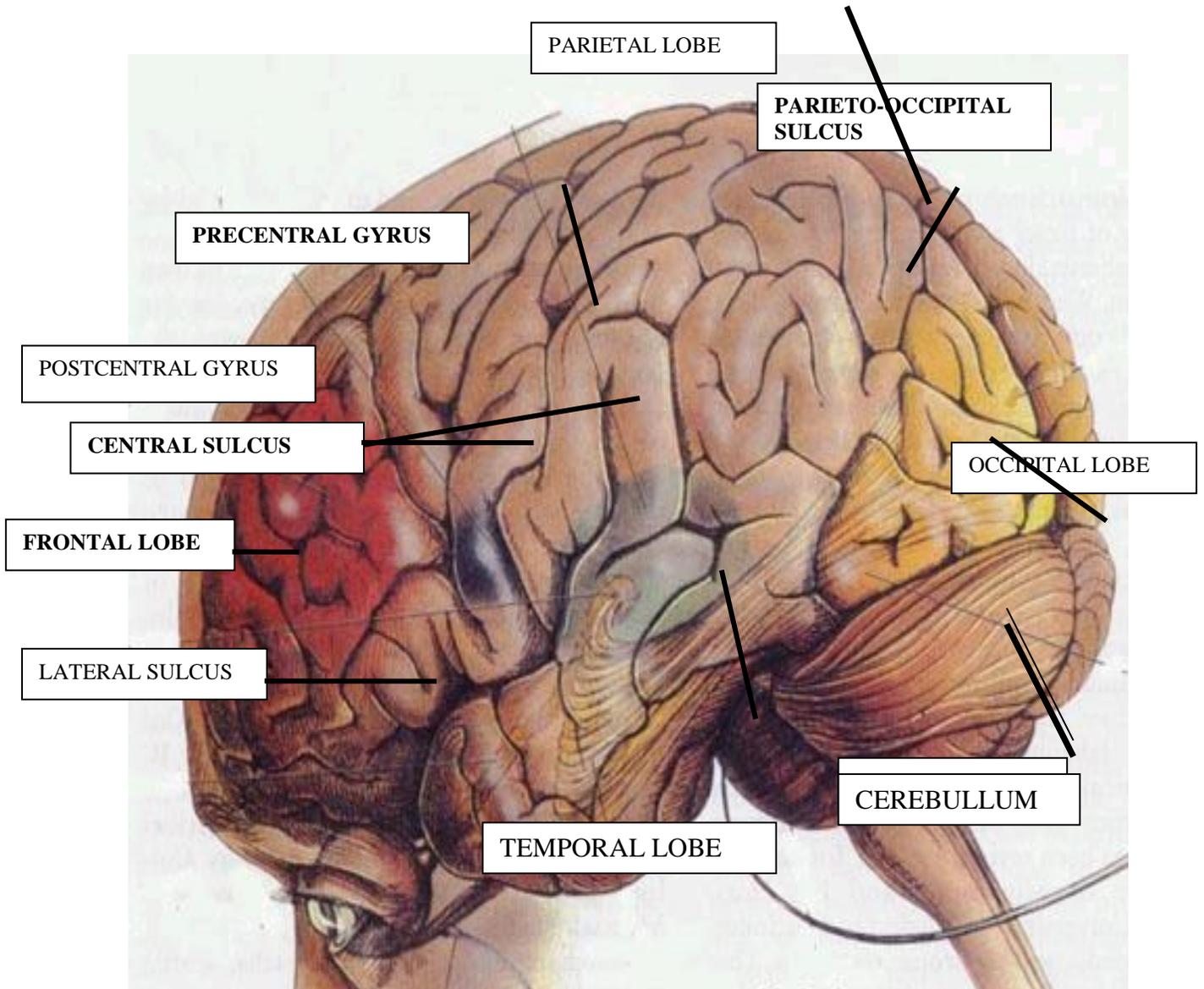
- × Decreased coordination
- × Problems with the quality of muscle movement
- × Decreased balance and equilibrium
- × Abnormal muscle tone
- × Vertigo, dizziness, and/ or motion sensitivity

BRAINSTEM

The brainstem connects the other two parts of the brain (cerebrum and cerebellum) to the nerves (spinal cord) that run to the body. It is the control center for:

- ➔ Nerves that control eye movements, facial movements, the tongue, swallowing and sensations for the eyes, ears and nose.
- ➔ Regulation of metabolism
- ➔ Body temperature
- ➔ Blood pressure (partial responsibility)
- ➔ Appetite
- ➔ Thirst
- ➔ Hunger
- ➔ Sleep patterns
- ➔ Sexual sensation
- ➔ Emotions
- ➔ Partly controls seeing and hearing
- ➔ Postural reflexes (involuntary movements-movements that happen without thinking about it)
- ➔ Coordination of eye movements from left to right and right to left
- ➔ Regulation of heartbeat
- ➔ Breathing rate
- ➔ Sneezing, coughing, vomiting and swallowing
- ➔ Amount of blood flow to different parts of the body

Damage to the this area may cause problems in any of the above areas.



- **COUP** Injury at the site of impact.

- **CONTRA-COUP** When the brain is hit with sufficient force causing it to “bounce” against the opposite side of the skull, causing injury to the part of the brain opposite the impact.

- **ROTATIONAL FORCES** Resulting in twisting of the brainstem.

- **CONCUSSION** Term used to describe a mild brain injury with or without loss of consciousness which is not able to be detected with neuro imaging such as MRI or CT scans.

Chapter 3: MEDICAL COMPLICATIONS

ACNE VULGARIS

Acne can occur for the first time or reoccur following brain injury. Treatment with steroids for brain swelling (i.e., Decadron) leads to red papular acne of the face, chest, and back. Individuals with a brain injury seem to develop acne as a response to a change in hormone levels. Acne is treated by washing the face with soap and water regularly and by applying 5% or 10% benzoyl peroxide. A dermatologist can be consulted for more resistant cases that fail to respond properly to this simple treatment.

TRACHEOTOMY

A tracheotomy (throat opening) is sometimes necessary for patients who need a respirator for an extended period, or who have a poor cough response (problems clearing their secretions). To perform a tracheotomy, a small temporary opening is made in the patient's throat. A tracheotomy tube is placed in the opening. It is either cuffed (with an air-filled balloon surrounding the tube to keep a good seal) or uncuffed (usually a metal device). The tube is connected either to the respirator, to supplemental oxygen, or to moist air. Nurses keep the airway clear of secretions by suctioning through the trachea tube. They will sometimes first place a small amount of sterile saline (salt water) in the throat to moisten secretions and to encourage coughing. This may appear as a cruel treatment, but it is necessary to help keep the airway clear and to help prevent pneumonia.

URINARY CATHETERS

Urinary catheters (tubes used to drain fluid from the bladder) are utilized for many reasons. Often the muscles of the bladder are not functioning appropriately. Various types of indwelling catheters exist, but one of the most common is the Foley catheter, which has a balloon surrounding the end of the tube. After the catheter is inserted into the bladder, the balloon is inflated to prevent the catheter from sliding out. Once there is no longer an urgent need for an indwelling catheter, your physician may try to wean your family member to another system. Indwelling catheters are associated with frequent complications such as urinary tract infection (UTI), urethral injury, and/or a decrease in the volume of urine the bladder can hold. Patients are weaned to briefs (diapers), external catheters, and intermittent catheterization in attempts to prevent these complications. Predominantly used in men, most external catheters are condom-like devices placed over the penis and connected to a drainage tube. Intermittent catheterization involves passing a catheter into the bladder at regular intervals, draining the urine, and then removing the catheter. Usually performed under sterile conditions in the hospital, intermittent catheterizations reduce the risk of infection and urethral injury and allows a more normal pattern of bladder filling and emptying.

NUTRITION

Good nutrition is vital to recovery. Severe brain injury can increase demand for calories and nutrients far beyond normal. When calorie and protein requirements are high and the patient is unable to eat, tube or intravenous feeding is important. Fluids through the veins are not enough to sustain even a healthy person for long. Your doctor must therefore begin tube feeding for your family member, provided they have a healthy stomach and intestinal tract. Tube feeding is usually first attempted by means of a tube passed through the nose and into the stomach. Tube feedings are given either continuously and gradually by a feeding pump or in large amounts by syringe every few hours. Because tube-feeding formulas can cause diarrhea,

they are often started at less than full strength and at a slow rate. If your family member had problems tolerating milk products before the brain injury, your physician will choose a tube-feeding formula that does not contain milk products.

Intravenous feedings to supply all nutrients are given either when the GI tract is not working adequately or when calorie requirements are too high to be supplied through the GI tract alone. This is called total parental nutrition (TPN) and is usually given through large IV's in the neck or upper chest. The feedings contain protein, carbohydrates, fats, vitamins, and essential minerals. The patient on TPN is monitored closely by blood tests for tolerance of the formula.

The increased nutritional requirement following a brain injury is caused by an outpouring of adrenaline and other hormones from glands in the body. Sometimes in this hyper-metabolic state, there is also elevation of heart rate, respiration, high blood pressure, fever and sweating. These responses are treated medically.

FEEDING TUBES

Tubes are sometimes passed through the nose into the stomach for two reasons: 1) suction, to remove substances from the stomach, and 2) feeding. This type of feeding is an important method of providing nutrition to your family member if they are not capable of eating on their own. Feeding directly into the stomach or intestine is important because IV fluids alone are not enough to maintain good nutritional status. X-rays are sometimes checked to confirm that the tube is properly positioned in the stomach or intestine. If your physician has ordered such a tube, ***do not try to feed your family member without checking to be sure it is safe.*** Sometimes patients with a brain injury appear to swallow normally, but are at risk for breathing food and secretions into the lungs due to a weak cough or an abnormal swallowing mechanism (aspiration). The head of the bed should also remain 30 degrees or greater to avoid regurgitation and then aspiration.

Your physician may recommend surgery for placement of a feeding tube when prolonged internal feeding is necessary. A jejunostomy involves surgery to place a thin tube directly into the intestine. Another operation is usually required when the tube becomes displaced. A gastrostomy involves placing a feeding tube through the abdomen directly into the stomach. There are two major types of gastrostomies. The surgical type is permanent and requires no reoperation if the tube becomes dislodged. The other involves only local anesthesia and is easier to reverse, but is not indicated for all patients.

SEIZURES

The incidence of seizures after moderate to severe TBI is approximately 15-20% for the first year (and 25-30% for 4 years, although this time period is not well studied). Seizures occur in 3 time frames after traumatic brain injury: Immediate (within the first 24 hours), Early (24 hours to 1 week after injury), and Late (after 1 week post injury). Things which predispose to early and later seizures are depressed skull fractures, focal bleeding within the brain tissue associated with swelling, focal neurological deficits (hemiparesis), and penetrating injuries. If a patient has an "early" seizure, they are more likely to have a "late" seizure. An "immediate" seizure does not increase your risk of "early" or "late" seizures occurring. A prior seizure disorder significantly increases risk of seizures post injury.

TYPES OF SEIZURES

Generalized: Commonly known as grand-mal seizures, cause stiffening (tonic) and jerking (clonic) movements of the arms and legs. The patient loses consciousness and often loses control of bowels and bladder.

Partial: Also known as focal motor seizures, cause no loss of consciousness, but are demonstrated by movements of a limb or the face only. Head injuries often produce this type of seizure.

Complex partial: Commonly known as petite mal seizures are episodes of changes in behavior accompanied by loss of consciousness. This type of seizure is not common of head injuries.

Complex: Also known as temporal lobe seizures, result in bizarre repetitive activities of which the patient has no memory.

CARE DURING A SEIZURE

Seizures are usually brief. If a focal motor seizure occurs, nothing special needs to be done. If a generalized seizure occurs, you should remove your family member from any dangerous situation in which they might hurt themselves. You should remove their glasses, and loosen the clothes around the collar. You should help them to lie on their side or stomach – not on their back (in case they should vomit). Do not hold them down, let the arms and legs move freely. It is no longer felt necessary to put something in the mouth. You should notify a physician. It is also recommended that you time how long that the seizure lasts. If a seizure persists (status epilepticus) medical attention is needed immediately.

This information is given to you so you will know what to do when you go home if a seizure should occur. If a seizure occurs while your family member is at PNRC, the staff will provide the care required.

The number of seizures can be increased by certain medications. Certain drugs irritate the brain tissue so much that the brain is more likely to have an epileptic seizure. This effect of alcohol and certain drugs is lowers the seizure threshold. Medications are used both to prevent and to treat seizures. Talk with your doctor about any medications you are taking and the potential side effects.

NEURO-STORMING

Storming is an abnormal sequence of medical events that can occur after a severe brain injury. It is sometimes referred to medically as ADS (autonomic dysfunction syndrome) or CAD (central autonomic dysfunction). It produces a rapid pulse, high blood pressure, elevated temperature, sweating, dilated pupils, muscular stiffness (rigidity), and decreased gastrointestinal motility. It occurs because chemicals leak out of the damaged brain causing neurotransmitter depletion and cell damage. If left untreated, it can be life threatening. Storming is controlled by removing excess sources of pain and stimuli, as well as by medications.

IMPAIRED CIRCULATION

This occurs when the blood from your family member's arm or leg is unable to flow back to the heart normally. This can be caused by inflammation of a vein (phlebitis) or by blockage (blood clot or deep vein thrombosis – DVT) in a vein. This can cause swelling and pain and can be dangerous if a blood clot breaks off and flows into a major organ, such as the lungs (pulmonary embolus).

Example: Your family member may be unable to bend his/her knee completely because their calf muscle is swollen, red, and painful due to a blood clot.

A blood clot that travels to the lungs is called a pulmonary embolus (PE). A PE can be life threatening. It is considered a medical emergency.

Chapter 4: PHYSICAL DEFICITS

Few people are aware of the many functions of the brain until they are faced with the results of a brain injury. Along with all of the cognitive or “thinking” and reasoning problems, there are usually physical problems that occur. Some of these problems will resolve gradually and some of them will be with your family member for the rest of his/her life. The following is a list of possible physical problems that your family member may have already or is currently experiencing.

ABNORMAL MUSCLE TONE

Hypotonia or decreased muscle tone: This is felt when there is too little or no muscle resistance to a movement so that the limb (arm or leg) feels limp, heavy, and/or floppy like a “rag doll”. Because muscles are not helping to “hold” the joints in place, protection is very important in this phase.

Example: Your family member’s arm may feel very heavy and falls off of the wheelchair or bed easily. An arm trough or tray may be utilized to prevent the arm being traumatically pulled from the shoulder when it falls

Hypertonia (spasticity) or increased muscle tone: This is felt when there is an increasing resistance to moving the limb (arm or leg) which can range from a slight giving way or require considerable effort to move the limb. Because the joint is not being stretched, stretching and position are important to prevent contractures of the joints during this phase. Your therapist will be teaching ways to prevent contractures as well as reduce tone through positioning.

Example: The knee may feel “stuck” and only be able to bend with a lot of effort by another person.

MUSCLE WEAKNESS/PARALYSIS

This occurs when your family member’s ability to move the limbs, head, or trunk is impaired/ absent. This weakness or paralysis can occur because of brain damage in specific areas, a lack of use of the muscle, and/or from an injury to the muscles or nerves. Muscle weakness can be improved by exercising the limbs, walking, and becoming more mobile. However, this may be permanent or may be a very slow progression of recovery.

Example: Your family member may have difficulty dressing selves self because their arms are too weak or paralyzed or they may be unable to stand up well because the leg muscles feel very weak or the knee “buckles”.

IMPAIRED MOTOR CONTROL

This occurs when your family member's ability to move is impaired because of injury to the brain rather than to the spinal cord or muscles. With motor control deficits, the problem is not weak muscles, but the inability to move the muscles when desired. This lack of control may be demonstrated in a variety of ways such as a complete or partial lack of movement, uncontrolled spontaneous movement (spasms) or the inability to control speed, variety, or accuracy of movements.

Example: Your family member attempts to walk, but their left foot keeps crossing over in front of their right foot because they are unable to completely control the movements of their involved leg.

JOINT CONTRACTURE

This occurs when your family member's ability to move a limb is impaired because of shortening of the muscles and/or other connective tissues at the joint that prohibits normal movement. This can also be due to heterotopic ossification which is a deposit of bone material in muscles and other soft tissues around a joint that prohibits full movement of that joint. Heterotopic ossification usually occurs around the shoulders, elbows, hips, or knees and it can be treated medically in the early stages. Sometimes surgery is required to release the contracture. A good stretching program and appropriate positioning can assist with preventing contractures from forming. Contracture development will prevent the individual from achieving normal function.

Example: Your family member's knee may be "stuck" in a bent position and it can only be straightened with prolonged stretching and heat, or it may not straighten out even with considerable effort from another person.

IMPAIRED BALANCE

This occurs when your family member's ability to support their body weight in normal alignment is impaired in either standing or sitting. There are many factors that effect balance such as vision, proprioception (which is information from your joints that communicates the position of your limbs to the brain), and the vestibular system which communicates to your brain the position of your body (such as standing, sitting, or laying down) in relation to your surroundings.

Example: When standing, your family member may lean to one side and require the help of another person to prevent them from falling, but to your family member it feels like they are standing up straight.

IMPAIRED COORDINATION

This occurs when your family member's ability to perform intricate, detailed activities or to control speed or accuracy of movements is impaired.

Example: Your family member may have difficulty tying their shoes because their fingers move slowly and it is difficult to maneuver them correctly to perform the task.

BREATHING PROBLEMS

This occurs when your family member's ability to breathe normally is impaired because of muscle weakness, abnormal muscle tone, or paralysis of the muscles that perform breathing such as the diaphragm and the muscles attached to the ribs. Your family member's ability to breathe can also be affected by sitting, standing, or lying posture.

Example: It may be easier for your family member to breathe when they are sitting up straight in the wheelchair or standing up straight as opposed to slumping over.

DECREASED ENDURANCE

This occurs when your family member's tolerance of activity is decreased because of a combination of prolonged bedrest, muscle weakness, breathing problems, abnormal muscle tone, fluctuations in blood pressure, etc.

Example: Your family member may only be able to sit in the wheelchair for 2 hours at a time before needing to lie down to rest, or they may only be able to walk 100 feet before needing to sit down to rest.

IMPAIRED SENSATION

This occurs when your family member's ability to feel pressure, touch, pain, temperature, position, deep pain, or to differentiate between sharp and dull objects is impaired. It can either be decreased so that they do not feel the sensations or only partially feel them, or it can be increased so that they are hypersensitive to the sensations.

Example: Your family member may place their hand on a hot stove burner and sustain a serious burn without even feeling it. Or when your family member goes outside, their hands may become "tingly" and almost painful in response to the cold.

DECREASED SKIN INTEGRITY

This occurs when your family member develops an open area of skin ranging from an abrasion to a serious pressure sore (decubitus or bedsore) from friction or excessive unrelieved pressure over a bony area such as the elbows, heels, or bottom. Too much unrelieved pressure on a body part decreases blood circulation to the skin which leads to skin and tissue breakdown that can be very difficult to heal. This can cause serious medical problems that could lead to hospitalization if not promptly and properly treated.

Example: Your family member may sit in a wheelchair for several hours a day, and unless they relieve the pressure on their bottom, they could develop a pressure sore and be placed on bedrest until it is healed.

IMPAIRED HEAD/TRUNK CONTROL

This occurs when your family member's ability to control their head and trunk movements are impaired because of a combination of muscle weakness, abnormal muscle tone, impaired balance, sensation, or coordination. This is also affected by the amount of support that is provided to the head and trunk during sitting, standing, or lying down. This lack of head and trunk control can affect all of your family member's mobility skills.

Example: Your family member may be unable to hold their head up to eat unless they have a headrest on the wheelchair, or they may be unable to sit on the side of the bed without back support.

IMPAIRED MOBILITY

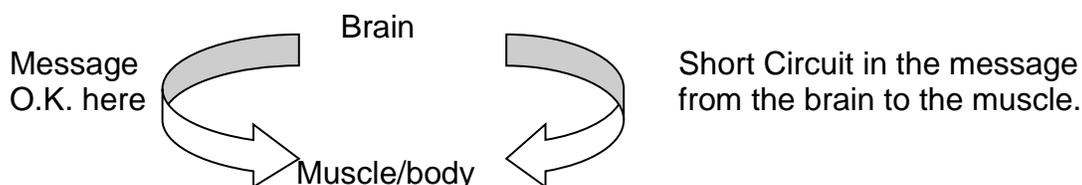
This occurs when your family member's ability to get out of bed, walk, roll a wheelchair, or transfer to the bed, tub, commode, or wheelchair is impaired. This is due to several reasons such as muscle weakness, abnormal muscle tone, breathing problems, joint contractures, impaired balance, coordination, or head and trunk control.

Example: Your family member is unable to stand long enough to take a shower, or is unable to roll the wheelchair from your hospital room to therapies because their arms are too weak and they become short of breath.

APRAXIA

This occurs when your family member's ability to perform voluntary movements is impaired although strength, sensation, and coordination may not be impaired. When movement of a muscle is to occur, the brain receives messages from the body (muscles) and interprets and understands those messages. Next, the brain sends messages to the muscles "telling" what to do and how to move. Apraxia is a "short circuit" in the message from the brain to the muscles which prevents the muscle from knowing what to do. Occasionally the muscle may involuntarily or spontaneously perform a movement which did not require a message from the brain.

Example: When your family member's nose itches, they scratch it. But when someone tells them to scratch their nose, they cannot do it. Your family member's brain understands the request but the brain cannot send the right message to the muscle to scratch.



ATAXIA

This occurs when your family member's ability to perform voluntary movements is impaired because the ability to coordinate or harmonize the arrangement of movements is impaired. Types of associated uncoordinated movements are trembling (tremor), intermittent spasm – like movements (Chorea), vigorous jerking (Ballismus), and twitching (Myoclonus).

Example: Your family member is unable to button their shirt because they cannot control their arm and hand movements due to muscle spasms.

IMPAIRED VISION AND/OR PERCEPTION

This occurs when your family member's ability to see items or perceive them correctly is impaired. This can be caused by specific damage to areas of the brain or the nerves coming out of the lower part of the brain (cranial nerves), injury to the eye or eye muscles, and/or damage to the pathways between the brain and the eye. Types of visual deficits include a visual field cut (hemianopsia) where your family member cannot see items on one side, double-vision (Diplopia), ignoring items located on one side of the body (unilateral neglect), and difficulty judging the distance that items are located from the body (impaired depth perception).

Example: Your family member may have double vision and wear a patch over their eye to enable them to see one image instead of two.

VERTIGO:

Vertigo is often described as a spinning sensation. There are multiple causes for vertigo. It can be caused by damage to a specific area of the brain such as the cerebellum or temporal lobe. It can also be caused by movement of small crystals, call "otoconia." This is called BPPV (benign paroxysmal positional vertigo). Talk to a member of the rehab team if you or your family member is having vertigo.

Chapter 5: Measuring Cognitive and Behavioral Changes

Brain Injuries are often classified by severity of injury using the Glasgow Coma Scale (GCS). The Glasgow Coma Scale is one of the most reliable scales for measuring outcomes for brain injury according to research studies. Essentially, the GCS measures 3 areas of functioning: verbal response, motor response, and eye movement. A score is calculated on the combined response in each area. The lowest score is 3 and the highest is 15 points. The score is reflected as follows: 3-9 a severe injury, 10-12 a moderate injury, and 13-15 a mild brain injury. Remember that each brain injury is individualized and different so there are always exceptions noted.

The Rancho Los Amigos Scale (Rancho Scale) is the most commonly used tool to assess the general level of cognitive and behavioral actions an individual demonstrates during the recovery process. The Glasgow Coma Scale is often used in more the initial injury and acute stages. The Rancho scale will be the most commonly referred to scale while in the rehab setting. Brain injury recovery is more like a marathon race than a sprint to the finish. You, as family, are considered a vital part of the treatment team.

Key Points to Remember:

- **There is no accurate way to predict exact recovery time or final prognosis.**
- **While individuals will progress similarly through the scale, each individuals takes their own pace.**
- **Progress is still progress!**
- **You family member will have good days and bad days which will progress or regress them temporarily within the scale.**

Revised Rancho Los Amigos Cognitive Scale Revised 1997 by Chris Hagan, Ph.D., SLP, CCC.

Level I: No Response

A person at this level:

- No response to pain, touch, sound, or sight.

Level II: Generalized Response

A person at this level:

- Generalized reflex response to pain.

Level III: Localized Response.

A person at this level:

- Blinks to strong light, turns toward/away from sound, and responds to physical discomfort, inconsistent response to commands.

<p>Rehabilitation Focus for Levels I, II, and III:</p> <ul style="list-style-type: none"> • Medical and physical management • Patient Protection • Prevent further complications. 	<p>What can I do?</p> <ul style="list-style-type: none"> • Always explain what you are about to do. • Keep comments and questions short and simple. • Limit visitors • Avoid over-stimulation. • Give extra time for responses
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Level IV: Confused – Agitated.

A person at this level:

- Confused and frightened.
- Alert, very active/ restless.
- Overreacts with aggressive or bizarre behaviors.
- Able to begin simple routine activities such as dressing or talking.
- May require restraints for safety.
- Not able to concentrate for more than a few seconds at a time.

<p>Rehabilitation Focus for Level IV:</p> <ul style="list-style-type: none"> • Reduce confusion and agitation • Manage and decreased environment stimulation. • Develop a sense of safety 	<p>What can I do?</p> <ul style="list-style-type: none"> • Remind him/her that they are safe. • Allow movements in a safe environment. • Avoid over-stimulation. Give breaks to avoid. • Keep the room quiet and calm. • Limit visitors.
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Level V: Confused – Non-agitated.

A person at this level:

- Only be able to concentrate for a few minutes at a time
- May have difficulty with basic tasks such as brushing teeth and will need step by step instructions
- Attempt to fill in gaps in memory with made up memories/stories
- May get stuck on an idea or an activity and have difficulty switching to the next part of the activity
- May become overloaded when tired or from too much stimulation (too many people in the room, too much light, too much noise)
- Have difficulty remembering things told to him/her since the injury

<p>Rehabilitation Focus for Level V:</p> <ul style="list-style-type: none"> • Orient to self, place, time/date, what happened. • Manage environment and needs of client • Develop awareness of self and the environment 	<p>What can I do?</p> <ul style="list-style-type: none"> • Repeat what you say as needed. • Orient to day, date, time, hospital • Avoid over-stimulation. Give breaks to avoid. Limit visitors. • Bring in pictures and personal items.
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Level VI: Confused – Appropriate.

A person at this level:

- Have difficulty with memory and thinking problems.
- May be able to follow a schedule, but become confused with changes in the routine
- May know the month and the year
- pays attention for about 30 minutes, but may have trouble paying attention when there's too much noise or the task has more than 1-2 steps.
- Knows when they need to use the bathroom
- May know they are in the hospital because of an injury, but not understand the problems they are having
- associate their problems/deficits with being in the hospital and that these will be resolved as soon as they go home.

<p><i>Rehabilitation Focus for Level VI:</i></p> <ul style="list-style-type: none">• <i>Orient to self, place, time/date, what happened</i>• <i>Manage environment and needs of client</i>• <i>Develop awareness of self and the environment</i>	<p><i>What can I do?</i></p> <ul style="list-style-type: none">• <i>Discuss what's happened during the day to improve memory</i>• <i>Help with starting and continuing activities.</i>• <i>Encourage him/her to participate in all therapies. They will not fully understand extent of their problems nor the benefit of therapies.</i>
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Level VII: Automatic- Appropriate.

A person at this level:

- Can follow a set schedule
- Be able to do routine care without assistance, but move through these tasks with robot-like movements
- Have trouble paying attention in distracting or stressful situations/ environments
- Have difficulty with recognizing how their thinking and memory problems will affect future plans and goals
- Will continue to need supervision
- May be inflexible and rigid in thinking, may come off as stubborn.
- Be able to talk about doing a task, but have trouble actually completing the task

<p><i>Rehabilitation Focus for Level VII:</i></p> <ul style="list-style-type: none">• <i>Self-management of behaviors</i>• <i>Behavior management with rehab team</i>• <i>Awareness of Others</i>	<p><i>What can I do?</i></p> <ul style="list-style-type: none">• <i>Talk to them and treat them as an adult.</i>• <i>Talk to them about their problems that are due to the brain injury without criticizing.</i>• <i>Continue to encourage them to go to therapy.</i>
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Level VIII: Purposeful – Appropriate.

A person at this level:

- Recognize they have a problem in thinking and memory
- Begin to compensate for their problems
- More flexibility in thinking
- May be ready for driving evaluation by a trained professional and/or job training evaluations
- May show poor judgment in new situations and may need help with this
- Be able to learn new things at a slower rate, but may become overloaded with hard situations or emergencies

<p>Rehabilitation Focus for Level VIII:</p> <ul style="list-style-type: none">• <i>Self guidance</i>• <i>Cognitive and behavioral management</i>• <i>Social competence</i>	<p>What can I do?</p> <ul style="list-style-type: none">• <i>Be sure to check with physician on their restrictions concerning driving and working. Do not rely just on their word as they may feel like they are ready.</i>• <i>Discourage them from drinking or using drugs due to medical complications.</i>• <i>Encourage him to carry out their self-care as independently as possible.</i>
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Level IX: Purposeful and Appropriate with Standby Assistance on Request.

A person at this level:

- Able to accurately shift back and forth between tasks for at least 2 hours at a time
- Able to use assistive memory devices when asked
- May need help sometimes with unfamiliar tasks
- Has awareness of impairments, but able to compensate for these for problems with daily tasks. However requires some assistance with pre-planning and consequences of actions/decisions
- Has decreased self-centeredness
- May still have problems with depression, irritability, low tolerance to frustration when not feeling well/under stress

<p>Rehabilitation Focus for Level IX:</p> <ul style="list-style-type: none">• <i>Autonomy and self-actualization</i>• <i>Counseling and training</i>• <i>Inter-dependence</i>	<p>What can I do?</p> <ul style="list-style-type: none">• <i>Encourage them to use memory aids such as note taking, use of apps, calendars, reminders</i>• <i>Discuss what kinds of situations make them angry and what can be done in those situations to feel more calm.</i>
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Level X: Purposeful and Appropriate – Modified Independent.

A person at this level:

- Is able to handle multiple tasks simultaneously, but requires break to maintain concentration
- Able to independently complete all daily living tasks, but requires more time and use of compensatory techniques
- May have trouble with periods of depression
- May have irritability and low tolerance to frustration when sick or under stress

<p>Rehabilitation Focus for Level X:</p> <ul style="list-style-type: none">• <i>Autonomy and self-actualization</i>• <i>Counseling and training</i>• <i>Inter-dependence</i>	<p>What can I do?</p> <ul style="list-style-type: none">• <i>Talk with them about their feelings.</i>• <i>Learning to live with brain injury can be difficult and it may take a long time for the individual and family to adjust. The case manager/psychologist/team will provide you with information regarding counseling, resources, and support organizations.</i>
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Chapter 6: BEHAVIOR CONCERNS

GENERAL BEHAVIORAL EFFECTS OF BRAIN INJURY

Behaviors often change following a brain injury. These are some of the behaviors you may or may not see in your family member following an injury. They may occur by themselves, together, or not at all. Remember they are results of the injury and should be dealt with as advised by the team.

- Agitation
- Denial/Over-optimism
- Impatience
- Irritability
- Outbursts
- Perseveration
- Excessive Talking
- Inappropriate Social Behavior
- Egocentrism (Self-centeredness)
- Over-dependency
- Lability
- Suspiciousness
- Depression
- Lack of Motivation/ Initiative
- Increased or Decreased Sexual Focus
- Family Abuse

MANAGING BEHAVIOR PROBLEMS

A large majority of individuals with a brain injury have behavioral changes. It is possible that your family member will not have difficulty with all of the areas we are covering, but it is probable that they will experience at least some of them.

Behavior problems associated with brain injury are not easy to identify or understand. Because your family member may have experienced changes in how clearly they can think and how well they can control their emotions, they may behave inappropriately. Frequently, there is at least one person in the family who believes that the person with a brain injury is just being mean, manipulative, or vengeful when they act the way they do.

Research in brain injury shows that a personality characteristic that existed prior to the injury will often be exaggerated after the injury. Individuals with a brain injury can take on a different personality that includes impatience, verbal outbursts, physical threats, and all types of behaviors that you never imagined would ever appear in this person. This is, of course, one of the most difficult changes to live with, as though a complete stranger is coming home to live with you.

BRAIN INJURY BEHAVIORS AND MANAGEMENT TECHNIQUES

All of the behaviors listed below are brain related and may be experienced in varying degrees in your family member. With mild to moderate injuries, some of these behaviors may rarely or never occur, while others will remain for an extended period of time. With greater levels of severity, chances are greater that the behaviors will occur and will demand attention.

While these behaviors are not caused by your interactions with the individual, they may be influenced by your response when the behavior occurs. Because this is such a new experience for you, it is difficult to know how to act and when to act. You can inadvertently contribute to your loved one's inappropriate actions. We want to help you avoid this situation.

Remember: Not all individuals with a brain injury will experience all of these behaviors.

AGITATION

One of the first behaviors that you will notice or may have already noticed is agitation. From a neurological standpoint, what is happening is that the patient is reacting to the environment in

an undifferentiated manner. That is to say, their agitation reactions are due to the fact that they cannot yet understand the difference between a nurse approaching with a shot and a therapist approaching to assist them with range-of-motion therapy. As time goes by, you will gradually notice a decrease in the agitation, particularly when things are going smoothly. However, when things are not, you will see an increase in this behavior. It is possible that you family member may always be much more easily aroused than they were prior to the injury. Increased sensory input such as loud sounds, bright light, and strong smells can increase agitation as well.

MANAGEMENT TECHNIQUES

- Remember that within the first six months after injury, agitation is a stage that must be worked through.
- Do not take personally the agitated behavior that appears to be directed toward you.
- Never allow yourself to become combative in reaction to their agitation – that will only lead to increased agitation.
- Sometimes it helps to first acknowledge their emotion, then try to distract/redirect them with another topic.
- Avoid overstimulation by reducing or removing stimulation (smell, light, touch, sound).

DENIAL/OVER-OPTIMISM

From the time that your loved one began to talk again, you have probably noticed that they are not always realistic about what they are capable of safely doing. In the field of rehabilitation, we call it denial, and it is caused by a combination of decreased ability to self-critique one's behavior and abilities as well as increased feelings of being overwhelmed by their losses. However, as time goes on, it can lead to anger and depression. You may hear your loved one blame a long list of people who are at fault for their lack of progress. It is a delicate proposition to balance the protective quality of denial and the rehabilitative need for reality. It is not usually necessary to take away all hope of living independently, going back to work, etc. The best way to handle these issues on discharge is to indicate that there are a number of steps that the individual must go through before these goals are obtainable.

MANAGEMENT TECHNIQUES

- Allow the individual to hold onto some denial to maintain their motivation to participate in rehabilitation.
- Never out-and-out lie to your family member, for example, saying they will be able to do something that seems very unlikely.
- If the individual insists they can do something and it would not be dangerous to them or anyone else, allow them to try the activity. This can lead to a realization that they are not quite ready to complete this task on their own.
- It is important for you to know that those times when your loved one is obstinate and refuses to be cooperative may be their way of avoiding (denying) facing the fact that the activity is too difficult for them.

- Participation in a brain injury support group is often a good place for the individual to hear other individuals talk about their difficulties and how they have dealt with them. This can make it a little easier to identify their own deficits and admit them.

IMPATIENCE

If your family member did not like to wait for people or events prior to the accident, you are or will be soon, facing some trying times. Your loved one may possibly lose most of the patience they had and, if they were impatient to begin with, they may not want to wait for anybody or anything.

A great deal of recovery from a brain injury occurs during the first year, although progress can continue for years and years. It is usually at quite a different rate of change from early months. Both patients and families can have a difficult time understanding that they may need to be patient over a span of several years, and not hold on to the idea that progress will proceed smoothly and expediently.

There are three additional factors that appear to explain the presence of impatience in the individual with the brain injury's everyday routine. First, the areas of the brain that help them to control their emotions have, in all likelihood, been damaged, leaving the, with little control over frustration and anger. Second, brain injury often leads to self-centered behavior. Because they tends to look at all happenings from only their point of view, they have a hard time understanding other individuals' reasons for being delayed or late in responding to their wants and wishes. Third, because of the cognitive difficulties, they may misinterpret a situation, or find selves very impatient, with what other people think is irrational or poor judgment on their part.

MANAGEMENT TECHNIQUES

- Resign yourself to the fact that you may be living or interacting with a person whose patience may appear nonexistent.
- Remind your family member of the steps that are necessary before he can accomplish the event about which he is complaining.
- Do not let your family member set arbitrary time frames for accomplishing a specific goal. This will only set them up for disappointment and frustration.
- Try to have your family member focus on the fact that recovery from brain injury is a long process that cannot be sped up through anything but hard work.
- Teach other family members to recognize his impatience and, in an adult manner, remind your loved one to try to be polite. You may choose to apologize to others if they were offensive.
- Teach your loved one to discriminate and not blow off steam at innocent individuals.
- When they complain about things not occurring fast enough, remind them of all the positive accomplishments they have achieved.

IRRITABILITY

One of the most prominent and universal personality changes after brain injury is an increase in irritability. This may be temporary or it may last a long time. This can be disconcerting to families who are not used to living with such a grouchy person. Because of damage to the

person's filtering system, they may not be able to block out excessive noises. Because of cognitive deficits, they cannot always figure out why certain things are necessary. Because of memory problems, they may not remember that they just told you 30 minutes ago that they did not want something. Nothing at home may seem to please them. They may complain about everything. They may find it difficult to watch TV because the noise annoys them.

MANAGEMENT TECHNIQUES

- It is useless to ask, "Why are you so grouchy?" They probably do not understand or even realize the magnitude of their personality change.
- If there are certain people that your loved one finds irritating, minimize the time that is spent with them.
- Keep surprises and changes to a minimum, individuals with a brain injury do not react positively to either of these.
- Allow the person to talk through their problems, as this can reduce their agitation. You may have to listen to the same topic over and over and over.
- Keep excessive noise to a minimum.
- Reduce bright lights.
- Do not take the irritability personally. You are not the cause of the bad mood.

OUTBURSTS

When that short fuse causes an explosion, the person can display a multitude of physical and verbal outbursts. Excessive swearing is a common characteristic and it can be very embarrassing to family members. Frequently, the individual with a brain injury will blurt out something that they are sorry for later, but they continue to do this, no matter how badly they say they feel every time it happens.

Although individuals with a brain injury can become physically abusive, this does not mean that you should have to live in terror of this abuse. There are brain-injury facilities set up to deal with this serious behavior problem. If you find physical abuse becoming unmanageable, explore the possibility of a behavioral center. See resource section at the end of this book for further sources.

MANAGEMENT TECHNIQUES

- React calmly, and with a relaxed/calm tone of voice and calm facial expressions ask them to express selves without swearing. If you react too strongly, it may increase the frequency if they are trying to get your attention.
- Let them know that verbal abuse or screaming is not the best way for them to get their needs met.
- Teach the family member the skill of stopping and thinking before they speak. You can devise a signal to get the person to consider carefully what they are going to say. This silent signal is effective in public because it does not have to look like you are treating them like a child.

- Talk to friends and explain to them about these brain injury behaviors. Tell people not to take the behavior personally.
- Learn to build a thick coating around any sensitive feelings you have.
- Do not badger the person about past transgressions – it won't help.
- Do not allow yourself to live with physical abuse – get professional help.
- Be sure to reward the person when you notice the outbursts have decreased.

PERSEVERATION

The definition of perseveration is talking about something over and over or obsessing on an action or idea over and over. Brain injury entails two main characteristics that lead to this type of behavior. First, difficulty with short-term memory causes the individual to have little or no recognition that this issue was discussed less than half an hour before. Second, the cognitive problems related to inadequate problem-solving skills lead the individual into the necessity of rehashing issues incessantly because they are never adequately resolved or solved by the person themselves. Therefore, you will more than likely have three or four conversations that occur over and over again. It may be next to impossible to change this behavior entirely, but there are some ways you can learn to live with and tolerate it.

MANAGEMENT TECHNIQUES

- If there is a certain issue that the individual dwells on, set up a designated time each day for that particular discussion. Then do not participate in any conversation regarding that issue except at that specific time.
- Be firm and say that you refuse to discuss the same topic anymore. Do not feel bad about being up-front with the person.
- Try to divert the conversation to another topic. Frequently, it is easy to lead them into another train of thought.
- Continually talking about an area of concern is a sign of anxiety. In many ways the talking is therapeutic. Take what you can tolerate and then divert the individual.
- When they are constantly talking about a worrisome issue, they are physically experiencing anxiety. We all know that stress and anxiety can have a negative effect on one's physical health. Thus, by diverting the topic, you are actually doing them a favor by minimizing the time they obsess on the issues.
- Audio taping or videotaping the discussion and an agreed upon go-between may also be helpful.
- Have your family member write down the problem, the solution, who they discussed it with, and then "date" the document and keep it available.

EXCESSIVE TALKING

Because of the physical insult to the brain and the effect of anxiety, the patient may engage in excessive talking. In the beginning of the hospitalization and rehab process, family members are usually elated when the patient begins to talk. However, when it becomes excessive talking, it can at times be annoying and inappropriate. Excessive talking happens for several reasons, including poor memory for what was previously said, inability to filter thoughts without

verbalizing them, and poor problem solving ability. Initially, patients have little or no ability to control their excessive verbalizations. If your family member talks excessively, you will need to assist them in establishing new skills to control verbalizations. Helping the patient to know what to say, when to say it, and how long to talk can be a long, drawn-out process. One of the most effective procedures is to use nonverbal cues, such as snapping your fingers, or tapping on the shoulder to indicate that the patient has said enough. Do not use verbal cues or confrontation, as the patient might respond in an argumentative fashion.

MANAGEMENT TECHNIQUES

- Use a nonverbal cue to alert the individual that they are talking excessively.
- Remember that people sometimes talk as a means of reducing tension and anxiety.
- Redirect them to a nonverbal task, such as a household chore or writing a letter to a friend.
- In extreme cases, do not feel that you must respond to your family member. Do not feel guilty for not responding.
- If your loved one is talking on and on about an issue, have them put their concerns on paper.
- Schedule times when they can vent about a particular issue.

INAPPROPRIATE SOCIAL BEHAVIOR

Although your family member may not be recognized as having had a brain injury from outward appearances, it is sometimes the inappropriate social interactions that give them away. There are various reasons for the presence of this deficit. The first, of course, is cognitive issues whereby the individual does not completely understand what is going on, but still joins in the conversation. Another factor that is related to inappropriate social behavior is the area of Egocentrism (being self-centered). Because the individual may interpret everything said from their own viewpoint, there is very little thought about others in their responses. The subtleties of social situations are lost. The person must be retrained to think before they act or talk. They will need to change their interactions, depending on the audience.

MANAGEMENT TECHNIQUES

- You will need to retrain your loved one in the social amenities.
- Do not get discouraged – social skills are not acquired overnight.
- When you get ready to go out, remind your family member that they are not to talk to strangers about personal matters.
- If they use a memory notebook/activity planner, have them write down what other family members' schedules are.
- Remember that bringing your family member back home after the injury is like starting all over again to become socialized in our complex world.

EGOCENTRISM

Often individuals with a brain injury will take a completely self-centered approach to life. The world revolves around them and their problems. All family members must address their issues immediately, if not sooner. No one understands the difficulties they are having. To some degree, it is true that no family member completely comprehends what the individual is experiencing. Nevertheless, this is no excuse for their insisting that their needs be put above the needs of others. Your family member will have to relearn the reality that the world is made up of many other people and their wishes and desires are also important. This job falls on you because you are going to be the one to help them reintegrate into the community. They may need to be told in many different ways that the world does not revolve around them.

MANAGEMENT TECHNIQUES

- Do not let your whole family schedule center around the individual with the brain injury. Let them know that their needs are important, but so are the needs of the other family members.
- Do not allow the person to put you on a guilt trip.
- Help the person to understand the point of view of other people. Sometimes they have to be guided to put themselves in another person's place.
- Help them to realize that people outside of the family may think that they are immature if they act self-centered.
- Participation in a brain injury support group often helps the person to focus on other people's problems and not just their own.

OVER-DEPENDENCY

The role of rehabilitation is to help the individual with a brain injury become as independent as possible. Thus, it is important that on discharge you know exactly what your family member can do for themselves. The minute you give in and do things for them, you will begin to undermine weeks or months of rehabilitation efforts. We all enjoy being waited on at times, and you may feel that you want to show the person that you love him, but doing things for them that they can do on their own is not the way to show this love. Following a brain injury, individuals also become dependent on others in making important decisions. If it is not a critical issue in which your loved one really needs your help to arrive at the right conclusion, force them to make the decision themselves and accept whatever they choose.

MANAGEMENT TECHNIQUES

- Allow the individual to make as many of their own decisions as possible.
- Refuse to tell them what to do unless it is absolutely necessary.
- Encourage outings with people outside the family.
- Do not allow yourself to be overprotective.
- Encourage them to become active in a support group – maybe the individual will find someone they can help rather than concentrate on being helped.
- Assisting and guiding the individual to assume an independent role can be a long, tedious process. Be patient and do not get discouraged.

- Do not allow yourself to get caught up in the “guilt trap”. This is when the loved one manipulates you by saying, “If you really cared about me you wouldn’t make me do this on my own.”

LABILITY

Lability means a loss of control over emotional responses. Many people become concerned about this and believe that the injured person must be tremendously upset about an issue based on the fact that they were openly sobbing. Yes, indeed they are sad, but they may not be feeling as much emotion as it appears. Instead, due to the injury to the brain, they may not be able to maintain the emotional controls they have developed over the years. This lability is due to damage to parts of the brain that allow the person to exhibit control. They may not be any sadder than you or I about the dog that was ran over, but will outwardly appears to be devastated. Another example might be that a joke that is only moderately funny may send the person into an uncontrollable laughing fit. These extremes lead to the presence of intense, quick mood swings that make life with your loved one somewhat unpredictable and can be very wearing.

MANAGEMENT TECHNIQUE

- Never criticize the individual for his excessive emotions – this is something over which they has little control.
- Do not bring the crying to their attention. You can hand them a tissue, but continue on with your conversation.
- If you think a change in the topic of conversation would help, change it.
- If possible, try to keep your emotions under control. This will present a good model for your loved one.
- Remember that the individual has difficulty dealing with stress at any level. Try to modify the stress levels within the home environment so that their emotions can be kept on an even level.
- If the person has trouble with excessive crying, try to notice when things are fairly even, and praise them for maintaining this control.
- Focusing on a physical exercise will sometimes help control the crying.

SUSPICIOUSNESS

Individuals with a brain injury often have difficulty drawing appropriate conclusions regarding social situations. As a result, they may become paranoid (have delusions) to the point that their behavior and thinking bear little relation to reality. This can be disconcerting to family members who are putting everything they have into helping this individual, and are being unjustifiably accused of wrongful deeds. The best way to handle this is to try to separate yourself from these false accusations – do not allow them to get you down.

MANAGEMENT TECHNIQUES

- Try not to show your anger – they will interpret this as an admission of guilt.
- If there is a therapist involved with the individual, ask them to help you work through the issue that is of particular concern to the individual. Sometimes if you talk together, it will alleviate the concern.
- Try to guide your family member's thinking in a more positive direction.
- If their suspiciousness is extreme, the best stance to take is to ignore, ignore, ignore.
- Do not argue about their suspicious thoughts. You will never convince them through arguments.

DEPRESSION

It seems unusual to think of depression as a sign of progress. However, in the field of brain injury it often is. The occurrence of a depressed state indicates that the individual is giving up some of the denial that is often counterproductive to progress. It is important for the person to realize that they do have deficits that will have an impact on their future. Even with the positive effect of letting go of denial, safeguards apply regarding a person experiencing depression. Once you notice that your family member is depressed, you must be able to walk a fine line between keeping them motivated and helping them to realistically modify their goals.

A reduction in energy and excessive sleep are physical changes that often occur following brain injury. It is important for family members to differentiate these normal reactions from depression.

MANAGEMENT TECHNIQUES

- Consult your physician to rule out that the increase in sleep is due to some physical factor.
- Take all expressions of suicidal thoughts and plans seriously – seek professional assistance and guidance immediately
- Do not allow the individual to vegetate – get them out and about as best as you can.
- Do not allow the person to make you feel that you are the cause of the depression. They probably know better. Even so, do not accept the guilt.
- If the depression is extremely severe, consult a physician familiar with brain injury regarding the possibility of medication.
- Do not become over-protective once you have obtained professional help.
- Work on your own mental health. Be optimistic in your thinking as much as possible.
- You may have to remind your family member of the good things that are happening.
- Watch carefully for signs that they may be turning to drugs or alcohol as a method of handling the depression.

LACK OF MOTIVATION

There are two main issues that lead to the appearance of lack of motivation in the individual. First, one cognitive deficit related to head injury is that the brain-injured person has difficulty with planning and goal setting. They do not know where or how to start a project, so they often do not begin. They often also recognize that they do not have the abilities they had before the injury, but do not want to admit to this deficiency. They act like they are not interested – unmotivated. The reality is that they are interested but may be incapable of doing what would have been simple for them before the injury.

MANAGEMENT TECHNIQUES

- Give the individual with the brain injury the needed supervision to start a task, because you now know that getting started can be the biggest hurdle.
- Never assume that because they did a task perfectly before the injury, they are being lazy or obstinate if they do not complete it now.
- If they ask for help on an activity, never assume that they do not need it.
- If possible, break tasks down into smaller parts so that he can easily understand, remember, and master them.
- Get your loved one involved in a brain injury support group.
- Never ask questions such as, “Do you want to?” There is too much opportunity to remain passive and say, “No.” Give them a choice of two or three activities from which they must agree to choose.

INCREASED SEXUAL FOCUS

A person’s sexual orientation and activity level can be modified after a brain injury. In some cases, the area of the brain that regulates various hormones become abnormal. In others, the person’s ability to restrict expressions can be altered. A small percentage of patients turn away or reject sexual activity following a brain injury. However, a large percentage place their major focus on remarks, actions, innuendoes, or anything remotely related to the subject of sex. Individuals in the social circle of both your family and the patient may turn away because they are uncomfortable in the person’s company. The result is usually social isolation. Once this occurs, your family member begins to blame others for the isolation. They will have a difficult time understanding how they were offensive.

MANAGEMENT TECHNIQUES

- Each time the individual behaves inappropriately, a designated family member should tell them in a non-threatening and non-combative manner that the behavior is not appropriate.
- Therapists and attendants should, as much as possible, position selves so that they are not in arm’s reach.
- Telling the patient, “I am a married woman,” or “I will tell your mother,” is generally not helpful.
- Never lecture about the morality of their behavior.

- Keep cool and do not overreact.

FAMILY ABUSE

Managing and coping with brain injury behaviors can definitely be a challenge to the commitment to your loved one. One of the most aggravating things that a family can experience is that the family member can be polite to other people. Once you see that they can act appropriately, it is more difficult to accept the abusive behavior that continues on a regular basis at home. There are different explanations for this that provide a framework for understanding.

First, we all tend to relax more with family, as opposed to strangers or acquaintances. However, the individual with a brain injury's interpretation of that may go beyond what is considered acceptable. They may be in the habit of saying whatever they think to their family, knowing that it is not a problem. However, the family may not be able to cope with the openness and abrasiveness that occurs after a brain injury.

Second, after a brain injury, an individual often loses some of their social judgment capabilities and are not effectively able to reason out the appropriateness of either their own behavior or the behavior they expect from others.

Overall, a family's patience can wear after months of care for this individual. What makes it more challenging is that the individual with the brain injury has little insight into the impact that they are having on the family unit.

MANAGEMENT TECHNIQUES

- Do not allow a pattern of family abuse to become established in your home. You will need to make some allowances, but continued abuse is not acceptable.
- Never continually bring up reminders of their abusive behavior. (Respond to inappropriate behavior, but do not "nag".)
- There should be family rules that the person is aware of prior to coming home.
- Do not take the abuse personally – this will only interfere with your ability to implement effective behavior controls.
- Treat each occurrence as an isolated incident. They probably do not remember that they acted this same way yesterday.
- Keep in contact with your support systems – you need to have someone with whom you can discuss problems of family abuse.
- Remember that almost all threats are made without thinking.
- Do not allow yourself to live in a reign of terror. If problems persist, you may need to consider a residential program geared at behavioral control.
- Join a support group in your area so that you can find out how others have handled this problem.

Chapter 7: COMMUNICATION, COGNITION, AND SWALLOWING PROBLEMS

COGNITION

Brain injury also affects an individual's cognition, the ability to process information. The following is a list of general thought processes that can be affected by such an injury.

- Attention/Concentration
- Perception
- Lack of Initiative
- Slowed responses
- Memory
- Comprehension/Understanding

- Sequencing
- Expression
- Flexibility
- New Learning
- Judgement

MANAGING COGNITIVE PROBLEMS

Cognitive problems refer to difficulties in using the thinking skills that are important in the learning process. More simply stated, our cognitive skills – memory, problem solving, attention/concentration, sequencing (completing activities in the correct order), understanding information, and expressing language, help us live day-to-day without getting into a lot of trouble. After a brain injury, the cognitive problems are the last to resolve, and in many cases, are lifelong.

MEMORY DIFFICULTIES

Your family member’s memory problems may be confusing to you. At first, they may not be able to recall day-to-day information, but as they recover, those memory difficulties seem to resolve. They still may not be able to recall names of therapists, schedules, or recent activities, but they may recall immediate events and names that occur on a regular basis. Memory for incidental information and specific details may remain impaired for a length of time or may never resolve. This inconsistency occurs frequently with a brain injury. It has been named the “Swiss cheese” memory by professionals, because some information “falls through the holes” and other information is retained.

One of the most devastating effects on your family member is the residual memory difficulty. This difficulty affects their ability to learn new information, such as may be needed in their job or in the classroom setting.

Memory difficulties usually do not resolve. Instead, your family member will need to learn compensatory techniques to function in the home, work, or school environment.

MANAGEMENT TECHNIQUES

- Encourage your family member to use a day planner or other memory aid, and to carry it with them at all times. Assist your family member in organizing their days in the planner and recording the pertinent information.
- Encourage your family member to use their day planner. When they meets someone new, have them write the name and a cue, either a drawing or a description, to help them recall the person.
- Keep all important daily items (keys, planner, etc.) in a central location.
- Keep a list of all necessary information in case of an emergency near each phone.
- Develop a centralized information center (calendar, message board, etc.) in a frequently used location (refrigerator, etc.). This is where all information relating to the family (appointments, etc.) should be kept.

PERCEPTUAL PROBLEMS

Perceptual problems result from a difficulty in processing the information obtained through your ears, eyes, touch, or movement.

Your family member's ability to hear sounds clearly may not be affected. However, they may not be able to understand what is said to them. This may happen because they do not perceive the different sounds in words. They may have difficulty understanding similar-sounding numbers and words, particularly new information such as room numbers and addresses. Often, 15 will be confused with 50, 30 for 13, etc. It may seem as if your family member does not hear what you are saying because it takes him longer to process information.

Visually, your family member's ability may be intact ((20/20) vision). However, they may not correctly interpret or perceive correctly what the eyes see. Details may be missed. Different shapes, sizes and angles may not be noticed. A person may under focus or over focus on details, missing the connection of how this detail relates to the entire picture/problem. Your family member may not be able to obtain as much information through touch as they once did. This does not mean they won't feel sensations as they once did, but their interpretation of what they feels may take longer. They may not be accurate at discriminating objects by touch; therefore they may take longer to find keys, lock and unlock doors, and manipulate hand-held tools. They may also take longer to write or type words.

MANAGEMENT TECHNIQUES

- Many perceptual difficulties improve with time; however, some remain. Your family member may continue to have difficulty following directions, either written or verbal, particularly when distractions (i.e. noise, other people talking) are present.
- Make certain that you have your family member's attention before giving them directions.
- Have them repeat numbers, letters, and directions back to you. Encourage them to write down important information so they can refer to it.
- Walk your family member through new environments. Reinforce directions for a new environment with maps and written directions for easy reference.
- Give your family member more time for tasks that require manual dexterity. Remember that activities they once enjoyed may now be frustrating. They may also experience difficulty with fine manipulation skills, such as opening envelopes, unscrewing lids, or working locks.

ATTENTION PROBLEMS

Attention difficulties consistently occur after a brain injury. There are 5 defined levels of attention: focused, sustained, selective, alternating, and divided. These are hierarchical in nature meaning that you must be able to focus before you can maintain your attention. Distractions (i.e. someone talking in the hall) may make it more difficult for your family member to attend. Your family member's ability to focus or attend affects progress in therapy.

MANAGEMENT TECHNIQUES

- Remove anything that your family member does not absolutely need for his present activity. This could include limiting the number of people in the room or turning off the TV.
- Structure your family member's environment so that it is organized. Everything should be kept in its place.
- Designate space in your home in which your family member can work. Clear the work environment of extra clutter. Close doors so they can have the privacy they needs.

LACK OF INITIATIVE

Initially or early in the recovery process, apathy or lack of initiative will often develop. Your family member may be confused and unable to conceptualize and plan activities. All projects or goals, however small, are overwhelming. It is less threatening and less anxiety provoking to just sit and not do anything. This lack of initiative is extremely frustrating to families. Your family member may be content to spend most of the day in front of the TV set. They may say they don't want to do anything else. They may plan activities in great detail but not get past the first activity on the list. It is because it may take them all day to accomplish it. Your family member may no longer be interested in their previous hobbies.

MANAGEMENT TECHNIQUES

- Have your family member make a daily schedule including time frames necessary for each activity.
- Give your family member time to develop new hobbies and interests. More active interests may hold their attention and keep them moving.

COMPREHENSION/UNDERSTANDING DIFFICULTIES

Comprehension difficulties may inhibit your family member's ability to correctly understand what is happening in their environment. They may not appropriately interpret what they hear or see. They may be confused when they attempt to understand what they hear and see. Your family member may appear to be out of the realm of conversations. They may either not answer questions or respond they respond inappropriately. When you discuss a newspaper article with your family member, you may discover that they misinterpreted much of the article or that they did not finish the article. They may have lost interest in the article because they did not comprehend the details or main points. Your family member may find that they have greater difficulty understanding information presented in the classroom.

MANAGEMENT TECHNIQUES

- Your family member will probably have residual (continued) difficulty following conversations. Strongly encourage them to ask for clarification of questions they do not understand.
- Expect your family member to have difficulty with reading. In discussions, reiterate the important details for them through your conversation.

EXPRESSIVE DIFFICULTIES

One's ability to express themselves is a reflection of the integration of concentration, comprehension, memory, and initiation. To express themselves, a person must concentrate on what the other person is saying, understand it correctly, remember it, formulate the appropriate thought, and initiate a verbal, gestured, or written response to the other person. Your family member may have difficulty in one or all of these avenues of expression. Verbally, they may not be able to find the correct word. They may use the wrong word or a nonsense word (a word without meaning). Nonverbal expressions (gestures, body language, eye contact or facial expressions) are as important to communication as the words used.

You may notice your family member not making good eye contact or that their face is not as expressive as it once was. You may also notice that they stand too close to people when they talk to them. The most complicated level of expression is the written word. Putting thoughts on paper may be much more difficult for them than it was before.

MANAGEMENT TECHNIQUES

- Set up a cueing system to let your family member know when they are getting off topic.
- Direct instructions from you on eye contact and other communication skills will be most helpful. Privately discuss these issues with your family member so they can be aware of other's responses to their communications.
- Ask your family member's speech-language pathologist which cues work best for them when they have word-retrieval difficulties.

SEQUENCING PROBLEMS

Sequencing, as it relates to brain injury, refers to the ability to put the steps or processes associated with speech, movement, memory, or daily activities in the proper order. Sequencing difficulties that are related to speech and movement are usually referred to as apraxia. Your family member may be able to recall words, letters, sentences, and numbers, but he may not recall them in the order presented. They may have additional difficulties recalling proper sequences to complete simple activities of daily living, such as cooking.

MANAGEMENT TECHNIQUES

- Sequencing difficulties can often be offset by compensatory methods. Encourage your family member to ask people to repeat numbers and addresses. Request that they write down all numbers and that they recall numbers in chunks of two or three. For example, the phone number 6-8-4-2-3-2-0 becomes 684-23-20. In that way, they only need to recall three series of two or three numbers instead of seven individual numbers.
- Outline the steps in a task for your family member. Place the detailed outline by the activity.

DELAYED RESPONSES

Your family member's ability to respond or react may be a great deal slower because of the brain injury. There are two primary reasons for this slowed response: 1) damage to the motor strip results in a generalized slowing of the physical response, and 2) responses that were automatic before the injury no longer are. Your family member needs more time to process, integrate, and respond than they did before the brain injury. The overall effects of slowed response for your family member will be 1) taking longer to perform most activities, which can

cause significant problems in a job or classroom situation, 2) taking too long to act in emergency situations, and 3) taking longer to formulate a verbal response. = In social situations, your family member may not be as quick or witty as they once were. By the time they process the information, the chance for the joke has probably already passed.

MANAGEMENT TECHNIQUES

- Give your family member the time they need to complete household tasks. Task completion is more important than a quick response.
- Your family member may have difficulty in a job or classroom setting that measures performance by the quantity of work produced.
- Encourage your family member to continue to participate in social outings and interactions.

INFLEXIBILITY

Your family member may become quite inflexible in their thinking. In the early stages of recovery, the inflexibility might be demonstrated by their unwillingness to accept any change in their routine or schedule. This rigidity reflects their need for consistency and structure. As they improve, the inflexibility might be demonstrated by difficulty in problem solving. The family member may only be able to come up with one solution and unable to see alternatives. They will have a tendency to want everything done exactly the way they remember it was done before the injury.

MANAGEMENT TECHNIQUES

- Realize that changes are difficult for your family member, therefore try to prepare them in advance of any changes in their daily routine. Consistency and structure should be the priority.
- Because your family member will have a great deal of difficulty seeing alternatives, they will return to what is safe and comfortable. Gently encourage them to try new ideas and procedures for completing home, school, and work activities.
- Be prepared for problems at work. You cannot handle them for your family member, but you can be supportive when they bring the issues to you.

DIFFICULTY WITH NEW LEARNING

One of the most devastating effects of brain injury may well be the memory difficulty associated with new learning. Your family member may have considerable difficulty learning new job skills, new information in school, new procedures to be used in therapy, and new routines in the home. Difficulties in memory, concentration, organization, sequencing, and problem solving will all slow the new learning process. However, the memory difficulties are the biggest problems to this process. To improve new learning of a task, your family member will need to repeat that particular task over and over again until it becomes automatic.

MANAGEMENT TECHNIQUES

- Your family member will need to allow more time for learning new information.

- Have your family member practice or rehearse the new task several times to increase learning.
- Try to break down the information into smaller chunks of information to learn (i.e., break tasks into steps or develop an outline for information).
- Present a new task in the same sequence each time (i.e., transfer using the same steps in the same order each time).

DYSARTHRIA

Dysarthria is a weakness or paralysis of the muscles related to speech production and swallowing. Your family member may exhibit one or all of the following characteristics:

- ➔ Difficulty with respiration
- ➔ Articulation
- ➔ Voicing
- ➔ Rate of speech
- ➔ Chewing
- ➔ Oral motor movements

Dysarthria can occur as a result of a stroke, brain injury, and other neurological disorders (i.e., Guillian Barre Syndrome).

MANAGEMENT TECHNIQUES

- Have your family member talk slowly and clearly.
- Have your family member overemphasize sounds and words.
- Have your family member repeat information if you did not understand they said.
- Encourage your family member to practice the oral motor exercise program established by the Speech Language Pathologist.
- Encourage your family member to use simple words and phrases when communicating with you.
- Allow your family member enough time to complete their responses. Do not finish sentences for them.

APRAXIA

Apraxia is when a person has difficulty with the planning and sequencing of voluntary muscle movements. There are 2 types of apraxia that can affect a person's communication: (1) verbal apraxia – inability to sequence the movements for speech sounds, and (2) oral apraxia – inability to perform voluntary movements of the tongue, lips, cheeks, and larynx. Your family member's speech may sound distorted or consist of random words/phrases. They may be able to say automatic phrases such as "I'm fine" or "Thank You", but unable to tell you what they had for lunch. This makes communicating basic needs very difficult and frustrating.

MANAGEMENT TECHNIQUES

- Encourage your family member to use simple words and phrases when communicating.

- When your family member is not understood, encourage them to use gestures or drawing to get their message across.
- Allow time for your family member to communicate their thoughts.
- Talk with the speech pathologist about specific cuing techniques that might work with your family member.

SWALLOWING DIFFICULTIES (Dysphagia)

Difficulty with chewing and/or swallowing is a common problem following a brain injury. The problems your family member exhibits may be easy to identify such as severe coughing or choking with foods, liquids, or saliva. Other problems are more subtle and not as easy to identify. Your family member's cognitive deficits may also interfere with swallowing. For example, patients with decreased attention may require supervision to ensure adequate intake. A speech-language pathologist will work with you and your family member to help identify and manage these problems. Patients with swallowing problems are often placed in **dining group** where a speech pathologist provides supervision, education, and training

WARNING SIGNS OF SWALLOWING PROBLEMS MAY INCLUDE:

- ✗ Collection or pocketing of food under tongue or in the cheeks.
- ✗ Spitting food out of mouth/tongue thrusting.
- ✗ Poor tongue control.
- ✗ Excessive tongue movement.
- ✗ Slow oral transit time (more than one second).
- ✗ Delay or absence of elevation of Adam's apple (thyroid cartilage).
- ✗ Coughing or choking.
- ✗ Excessive secretions.
- ✗ Drooling
- ✗ Wet, gargly voice after eating or drinking.
- ✗ Regurgitation of material through nose, mouth, or tracheotomy tube.
- ✗ Inadequate intake of food and/or fluid.
- ✗ Unexplained weight loss.

****Note****

Some persons with dysphagia can aspirate silently without exhibiting any of the above signs.

MANAGEMENT TECHNIQUES

- If your family member is showing signs of a swallowing problem, the Speech Language Pathologist will complete a thorough evaluation. This evaluation may include an x-ray study called a Modified Barium Swallow study.
- If swallowing problems are identified or your family member is at risk for aspirating (food/liquid going into lungs), a swallowing program or exercises will be recommended.
- It is of the utmost importance that the program be followed closely. Close communication with the speech-language pathologists must be maintained.

ORAL HYGIENE:

The person with a brain injury and their family members are often concerned with other problems in motor or cognitive function. Sometimes other concerns such as oral hygiene might seem less important. If your family member has problems with respiration or has prior poor dental health, oral hygiene can present lead to other problems such as gum disease, infection, bone loss, or excessively dry mouth. If your family member has a tracheotomy (a tube which is placed into the trachea to assist with breathing), dry mouth is a frequent outcome. The patient may have a feeding tube (nasogastric tube in the nose, or percutaneous gastrostomy tube in the abdomen into the stomach) and may breathe through the mouth. This can add to a person's dry mouth (called xerostomia) and can cause pain and halitosis.

MANAGEMENT TECHNIQUES

- Brush twice a day with fluoride toothpaste
- Eat a healthy diet limiting sugary beverages and snacks
- Consider an oral rinse. Oral rinses may also be attempted or lemon glycerin swabs may be used for comfort and cleaning.
- Use an electric toothbrush to remove plaque (biofilm or bacteria growing in the mouth)
- Initiate smoking cessation.
- Your family member may not be able to do any of these at first. Your Speech Language Pathologist (SLP) will talk with you about how to best provide oral care.
- If your family member has missing teeth or a mouth injury as a result of a brain injury, gums can be very sensitive or painful. The person may resist having anyone attempt to clean their teeth.
- If the family member has a nasogastric tube or PEG tube, cleaning the teeth and gum surfaces with a toothbrush may not be possible because aspiration (when food or liquid enters the windpipe or lungs instead of the esophagus and stomach) might occur.
- Carefully considered oral care is very important when the family member cannot clean in the usual manner.

JUDGEMENT

One behavior or personality characteristic that can be effected or become more noticeable, is the ability (good or bad) to make judgement calls. Every day, we are forced to make decisions and to use our experiences and knowledge to have good judgement to know when things are right or wrong or when they are good or bad situations. In today's times, the internet, including the information, social media, and accounts that it contains, is very heavily relied upon. This is discussed further in chapter 11.

Chapter 8: RETURN TO RELATIONSHIP AND INTIMACY

This section is about relationships, intimacy, and sexuality. When we talk about sexuality we are talking about more than what goes on behind the bedroom door. Sexuality is the total person! It has to do with appearance, grooming, personality, and basically how a person presents selves to others. It is also what a person thinks about themselves, their body image, and how they interact and get along with people – in fact it is who they are as a person. It even includes the things they feel inside and might not share with others. We all want to be loved by others – it is an important part of life. If your family member is recovering from a brain injury, they may have changed in some ways that have negatively impacted their ability to maintain

healthy relationships, feel good about their sexuality, and interact appropriately with others. It may be difficult for them to feel loved and valued as a person.

There are three ways that a brain injury can affect relationships, intimacy, and sexuality: physical limitations, changes in their behaviors and feelings, and cognitive impairments which decrease the ability to communicate effectively.

PHYSICAL LIMITATIONS:

The following are some of the physical limitations that might interfere with their ability to be sexually intimate or which could affect their self-esteem and relationship with their spouse/ significant other:

1. Sensory deficits in any of the five sensory areas of smell, taste, touch, sight or hearing.
2. Balance or vestibular impairments
3. Spasticity
4. Decrease in voluntary movement or control of movement
5. Incontinence of bowel and/or bladder
6. Sexual dysfunction such as erectile dysfunction
7. Orthopedic injuries, fractures, and precautions

This is a partial list. Keep in mind that some of these limitations may only be temporary, while others may take longer to resolve. It is possible that some of these limitations will be permanent, however there are ways to compensate and adapt to these changes! Please feel free to discuss any of your concerns in these areas with your family member's physician, nurse, or occupational/ physical therapists. They will make recommendations on positioning, medications, and/ or treatment which may help resolve some of these physical limitations.

CHANGES IN BEHAVIORS AND FEELINGS

Here is a list of some of the more common difficulties in this category:

1. Change in sexual interest (more or less than before)
2. Change in personality style or features
3. Agitation/ restlessness
4. Decreased initiation or motivation
5. Sadness/ depression
6. Lowered self-esteem or feelings of not being "normal."
7. Impulsivity
8. Self-centeredness (it's all about them)
9. Aggression or anger (irritability)
10. Worries or fears (going to the worst case scenario)

One of the most frequent difficulties reported after brain injury is an increase in sexual preoccupation by in the individual with the brain injury, while less frequently reported is a decreased sexual interest. If this becomes a significant problem, more extensive counseling and even medication intervention may be indicated. Check with your physician to address these difficulties.

Again, many of these changes may be temporary as your family member moves through the stages of recovery; however some may be more longstanding and even permanent. We encourage you to discuss your concerns with your family member's rehabilitation team. It is important to be patient and try not to take these behaviors personally as it is part of the recovery process.

COGNITIVE AND COMMUNICATION PROBLEMS

The following are some of the more typical problems associated with this area:

1. Confusion
2. Difficulty making decisions
3. Diminished short term or long term memory
4. Sequencing and organizing difficulties
5. Perceptual problems
6. Diminished attention and concentration
7. Difficulty talking or saying what you mean
8. Decreased insight (not understanding what problems you currently have)
9. Difficulty with time management
10. Distractibility

RECOMMENDATIONS:

As a family member, you may find the topic of sexuality and intimacy difficult or embarrassing to discuss with others. You may feel this way for several reasons:

- You think it is not an important part of the recovery process.
- You think it is a taboo subject for rehab.
- You feel uncomfortable discussing such a personal issue.

However, if sexuality and intimacy was an important part of your life prior to the brain injury, we it should continue to be an important part of your life after. On the other hand, if this issue was not important to you before then it may not be now. In either case, the rehabilitation team feels very comfortable discussing these topics with you. If we are unable to answer your questions, we will refer you to someone who is able. Communicate your concerns!

Communication with your loved one is also very important to relationship and intimacy. Here are some recommendations on how to effectively communicate with your loved one:

- Allow them to vent their feelings without over-reacting
- Discuss behaviors, not the person
- Honestly, but gently, tell them how you feel
- Avoid blaming, judging, or condemning
- Realize that they may have difficulty expressing selves because of the brain injury
- Be patient, you may have to repeat yourself several times to be fully understood.
- If there is a memory problem, you may have to communicate in writing.

In many cases time for healing, education, and communicating your concerns is all that is needed to resolve these difficulties you may be having in your relationship, while in other cases professional counseling and/or medication may be helpful.

SAFETY ISSUES RELATED TO SEXUALITY

It is possible that your family member may have diminished judgment and insight when it comes to sexual intimacy. They may not be able to inhibit their sexual urges which may lead to poor decisions in their choice of partners, being taken advantage of by others, and/or not using safety precautions to prevent pregnancy or sexually transmitted diseases. It is very important that they be closely supervised in this area for their own protection. Remember it may take time before they are completely ready to resume dating or be responsible enough to make good decisions about sex.

SUMMARY

As the husband, wife, or significant other of someone with a brain injury, you may be feeling more like a nurse or caregiver than an equal partner in an intimate relationship. It is very possible that you no longer feel attracted to your partner or desire sexual intimacy because of changes in your role (having to be a caregiver instead of partner), fatigue, stress, or changes in the grooming or appearance of your loved one. These feelings are perfectly normal, but often make you feel guilty for having the thoughts. Realize these feelings may only be temporary, but if they persist it is important to talk to your physician or behavioral medicine counselor for guidance and support.

Having a family member with a brain injury can be a difficult adjustment and requires patience and understanding by all involved in the process. The good news is that it is still possible for you and your loved one to enjoy companionship, sexual intimacy, and a healthy relationship! You may have to change your thinking about sexuality and adapt due to limitations, but if you keep a positive attitude, communicate, and seek professional help if needed, it is possible to *return to relationship and intimacy!*

Chapter 9: SUBSTANCE ABUSE

Surveys of alcohol consumption in the general population indicate that approximately two thirds of all Americans drink at least occasionally. Interestingly, about two thirds of all people with traumatic brain injury had significant blood alcohol levels at the time of their accidents. It is also important to take into account the studies demonstrating the likelihood of a family predisposition to developing problems related to alcohol and other substances. These statistics, and the fact that alcohol has been found to complicate both the injury and the

subsequent recovery, highlight the importance of accurate assessment and honest family reporting of the nature and extent of problems from the onset. This will enable the rehabilitation team, which includes the family, to plan the best course of treatment for your family member.

TREATMENT

The problems associated with substance abuse need to be considered during every stage of the recovery process. There are many similarities between the symptoms of intoxication and brain injury. For instance, a person who has too much to drink will often exhibit slurred speech, decreased coordination, impaired balance, decreased reaction time, and visual-perceptual problems. In addition to these physiological changes, impaired insight, judgment, and the unpredictable behavior (abrupt mood swings, aggression, etc.) are frequently seen. Ironically, these physiological, cognitive, emotional, and behavioral changes are the most predominant deficits caused by brain injury. Adding alcohol to a brain that is already impaired magnifies these problems tremendously.

COMPLICATIONS

Nutritional, metabolic, and medical aspects are other areas essential to consider. Following a brain trauma, the body may not be able to absorb, use, and store nutrients, medications, and toxins as it once did. Alcohol or substances further complicate the body's ability to metabolize necessary medications and nutrients. For instance, a person on medications to prevent seizures will decrease the effectiveness of the medicine if he drinks. In fact, he may increase the chance of further seizures. As a central nervous system depressant, alcohol may combine with other medications to increase the depressive effects.

OPTIONS

First, you must emphasize to the individual with a brain injury that they should not drink any alcohol during the first year or two following their injury (some sources list up to 5 years). There are two main reasons for this precaution:

- Alcohol poisons the brain. Alcohol destroys brain cells. The use of alcohol may interfere with the recovery process by slowing.
- Alcohol may cause the brain-injured individual to have increased seizure activity.

There are theories on how best to address the issue of substance abuse following a traumatic brain injury. Nevertheless, the treatment team must know when there is a history of personal or family use, when a person may have been described as a social drinker (having a few drinks on the weekend), and even when the teenager who had not yet begun to drink may return to an environment that encourages it. There are some approaches such as the traditional support group models (Alcoholics Anonymous) that advocate participation in their own structured program. However, because individuals with a brain injury often demonstrate unique cognitive problems (memory, attention/concentration, and problem solving), traditional approaches may not be effective unless modified to take into account the special needs of this population. It has been our experience in a rehabilitation setting that treatment must be incorporated into the patient's daily schedule. An educational approach that recommends abstinence, random drug screenings, and the use of healthier and more effective coping strategies is important.

FAMILY RECOMMENDATIONS

- Encourage them to socialize with positive role model friends who are not active users or who will not use the substance in the presence of your family member.

Following a brain injury, it is easy to be persuaded to go along with the crowd for better or worse.

- Educate family members and friends about what has happened, either by talking to them or by giving them reading material.
- Help your family member strengthen the positive alternatives to drinking or drug use.
- Do not have alcohol in the home, or perhaps store it in a less accessible place.
- Be aware of your own drinking habits to help your family member maintain abstinence. It will be easier for the individual to abstain if people do not drink in their presence.
- Help your family member broaden their leisure skills by investigating local brain injury support groups, or encouraging their participation in recreation programs, art classes, and so forth, to replace time previously spent drinking.
- Keep a variety of hobbies, other interests, and activities available to help them to improve self-esteem and explore possible new areas of interest. Avoid letting your family member have too much unstructured time.
- Allow the survivor of brain injury to help with household chores to the extent that they are able. This will further enhance self-esteem and help them feel productive, needed, and part of the family.

Like Alcoholics Anonymous, it is our belief that for a patient with a history of significant addictive behavior or a family history of addiction, one drink is all that it would potentially take to return an individual to a self-destructive cycle of addiction. Therefore, the best way for family and friends to help is by fostering abstinence rather than encouraging a relapse or a return to problematic drinking by allowing them to drink occasionally. It has been our experience that even after years of abstinence, even individuals who have not had brain injuries who try to drink occasionally fall right back into problematic drinking patterns. It follows that, given their deficits, the brain injury survivor is at even greater risk. There are no easy answers to either substance abuse or brain injury. Both problems may go on for a lifetime, resulting in great emotional and financial costs to everyone concerned. We encourage family members and survivors to never stop trying, and to remember that a journey of a thousand miles begins with a single step. Please be open to our staff so that we may help you along this journey.

Chapter 10: STRUCTURE AND ITS ROLE IN RECOVERY: HELPFUL HINTS TO MAXIMIZE PERFORMANCE IN YOUR FAMILY MEMBER'S WORLD

Structure helps to compensate for our lack of memory and organization. We are creatures of habit and routine. Each of us has our own system for when we arise in the morning. We usually put on the same shoe on the same foot first but never think about it. These habits compensate for our lack of memory. You dial phone numbers from routine and repetition without thought. Structure and practice is what has assisted you to accomplish this. These

hints are meant to facilitate life for anyone but especially for someone with a brain injury to help once again make things a routine.

WHAT IS STRUCTURE?

Variables in the environment that you can control to maximize performance (examples: time, noise, number of people, choices).

HELPFUL HINTS AND IDEAS FOR MAXIMALLY STRUCTURING THE ENVIRONMENT:

1. Try to keep 1 or 2 consistent people with the patient.
 - Minimize number of people with them at a time (recommend no more than 2 in most circumstances)
2. Try to keep a consistent schedule, including meals, showers, getting dressed, bedtime. This lets an individual who is confused know what to expect and establish routines. Keep in mind that some variances are unavoidable. Also, at some point your therapists will probably be working on increasing patient's tolerance for variance in structure, as life is not predictable. However, this should not be done until short term memory is improved and initial confusion has passed.
3. Control the physical environment.
 - Dullness and repetition are preferred when patients are confused.
 - Turn off radio and TV when patient is needing to transfer, get dressed, or anything requiring concentration.
4. If patient is impulsive and confused:
 - Anticipate. Keep environment quiet and free of clutter. Do not give instructions until YOU are ready for the patient to perform them. Give instructions step-by-step.
 - Limit choices. NEVER give a choice you are not fully prepared to live with! Example: "You can drink water or milk, which do you want?"
 - Provide boundaries (time, how many...always stick to the parameters you've provided) Examples: "We're going to take 3 more bites, and then you can lie down." "I'm going to hold this stretch until the count of 10, and then I'll let go."

Together we must balance increasing the individual's tolerance for activity to "normal" while providing rest breaks to allow patients to calm themselves and process information. Progression to "normal" activity tolerance is usually done slowly, with significant observation to each person's response. Patients can actually regress if pushed too hard. The treatment team will assist you in deciding how much rest is needed overall, particularly during the day.

IMPORTANCE OF SLEEP HYGIENE AND BEHAVIOR

People who have had a brain injury often experience difficulties or changes in their sleep patterns, including difficulty falling or staying asleep at night, excessive tiredness or drowsiness during the day, or insomnia. Research has shown that an individual with a brain

injury will need approximately one more hour per day than they did prior to the injury. The brain needs time to rest and heal, good sleep is essential to recovery. One way to help address this is to practice good sleep hygiene.

Sleep hygiene involves the practices and routines that a person has prior to sleep, and how well someone practices good sleep hygiene can make a difference in the quality and amount of sleep that the individual gets each night. Some practices for good sleep hygiene include:

1. Going to bed at the same time every night, and setting an alarm to get up at the same time every morning. This includes on the weekends or other days when it is tempting to stay up late or to sleep in. Keeping a set schedule helps to establish a daily sleep routine.
2. Making your sleeping area comfortable, including limiting light and noise and keeping the room at a cool temperature. If outside lighting is an issue, consider blackout curtains or an eye mask. Consider using a fan or white noise app if needed.
3. Avoiding caffeine and nicotine several hours before bedtime. Avoid eating/drinking about 1 hour before bedtime to limit disturbances in sleep.
4. Limiting or eliminating time spent on screens prior to bedtime, including TVs, phones, tablets, and e-readers. The lighting from these devices can trick the brain into thinking that it is daytime and make it difficult to sleep.
5. Dedicating the sleeping area to sleep only. Avoid eating, watching TV, talking on the phone, paying bills, or reading while in bed.
6. Following a relaxing bedtime routine. This may include laying out clothes/items for the next morning, reading a book by low light, or aromatherapy, as well as other things to help the body and mind relax and prepare for sleep.
7. Limiting napping during the day to no more than 20-30 minutes total. Excessive daytime napping makes sleeping at nighttime more difficult.
8. Exercising everyday for at least 30 minutes. However, intense workouts 2-3 hours before bedtime should be avoided as this can energize and “wake up” the body, making it difficult to fall asleep
9. Getting outside in the sunlight if possible during the day. During colder months, light box therapy may be appropriate.
10. If you don't fall asleep in 20-30 minutes, or if you wake up during the night and cannot fall back asleep, get out of bed and do something relaxing until you feel tired. Avoid TV or other screens during this time.

If you continue to have difficulty with sleeping or feeling tired during the day, consult your doctor to assist.

Chapter 11: RECREATION FOR THE BRAIN INJURED

You and your loved one, the brain injured survivor are in the group of 72% of all brain injuries each year who make it to a hospital and who have a chance to get back involved in society. The term “survivor” means that the individual with a brain injury has beaten the odds and literally survived a life-threatening event. Most families are told in intensive care that if your loved one survives the next 24 hours, they may have a chance. Life with a brain injury is often complex and unpredictable. The majority of brain injury survivors may not return to the work force. What is left for these individuals is a large amount of free time.

What can recreation do for these individuals? It can provide constructive use of this unobligated time. It provides an outlet for social contacts. It builds self-esteem and self-confidence. Most people do not think about it, but what it takes to recreate are the same cognitive, behavioral, and physical skills it takes to work. Not one person with a brain injury is exactly the same as another. Survivors normally have a deficit or a combination of impairments dealing in cognition, behavior, and/or physical functioning. Recreation is a preceptor for developing work skills. Think about it. When you were a child, your social behaviors and attitudes were most often developed as you imitated parents' work behaviors. Playing hard was a way in which to develop coordination, endurance, and strength. Strategies required to win a game are often dealing with cognitive problem solving. Do you see the connection?!

You have read the impact of brain injuries on functioning in a day to day struggle in the previous chapters. You see what is occurring as your loved one goes through therapy. One key principle you will learn in working with a brain injured survivor is the need to develop routines or what may be termed as patterns.

Routinization of life helps the brain injury survivor to compensate for memory loss and life stresses. We are all creatures of habit. We put our shoes on the same way each day. We each have a morning and evening routine which helps us remain calm and limits the amount of memory we need to function daily. When we break these rituals, we usually experience some stress and have to compensate for change if possible. Essentially, most routines have been forgotten or changed after a brain injury. Initially, the brain injury survivor needs to reestablish these life patterns.

These patterns should reflect a real life situation. It has not been conclusively proven that transfer of skills has a direct correlation since most tasks require lots of brain functioning. For example, if you wanted a brain injury survivor to learn how to plant tomatoes in a garden, you will need to have him work in a tomato garden versus having him planting shrubs around the house. Otherwise, you may have tomato holes for planting too deep and large. The brain injury survivor may not be able to transfer their planting skills from one similar task to another because of the differences in the two tasks.

How do we develop activity patterns? We train the brain injury survivor in routines or structured activities daily. We like to start them on a business planner to structure time and events. We adapt or adjust lifestyles to compensate for problem areas. We use context specific information for the task at hand. In other words, we work on one life skill at a time. Training requires lots of motivation, association with familiar activities, repetition, and the use of all the senses.

In most cases, the brain injury survivor will want to try to return to their recreational interests prior to the brain injury. Considerations which may influence this possibility are the physical, cognitive, and behavioral functioning of the survivor as well as resources. Resources include assistance from others, transportation, finances, and safety concerns. There are often hidden agendas in activity participation. It is important to find what is expected from the recreative/leisure experience and from whom it is expected.

In relearning recreation skills, there are several approaches to training which are available to make the adventure a success. One technique for skill training is simply like the Nike ads, "Just do it". You would demonstrate the entire skill and see how well the brain injured survivor functions. The second training technique is task analysis and training by parts. You will look at

the steps it requires to do the activity so that you may instruct the survivor in an appropriate sequence. Substitution is another technique in which you would substitute a simpler skill for a more complex skill. An example, may be to teach the game of Newcomb before we teach volleyball. In some cases you may need to teach a more complex skill to obtain a simpler skill. Finally, we may need to adapt to circumvent a problem.

HERE ARE SOME HINTS FOR TRAINING:

- Be calm, flexible, and creative.
- Don't assume that skills will transfer.
- Direct your efforts on the precise task or outcome desired.
- Be very concise and clear on verbal and written commands.
- Use verbal, visual, and physical prompting as needed to master a skill.
- Try to demonstrate and repeat the modeling of skills you want to master.

When you are going to integrate the brain injury survivor into a community or private agency for a recreation experience, try to do the following preparation:

- Review the activities and obtain medical clearance if necessary.
- Talk to the instructor of the activity to discuss concerns.
- Introduce the survivor to the setting for orientation.
- Allow the survivor to observe the activity before starting.
- Allow the survivor to participate as much as possible in the activity.

When preparing staff who are not aware of brain injury, discuss the following with the instructors:

- Discuss expectations, abilities, best method of communication, and concerns.
- Educate the staff on brain injury.
- Review safety.
- Familiarize the survivor with terminology that will be used to do the activity.
- Discuss adaptations to the activity if necessary.
- Review the expectations of participation while in the activity.

We encourage brain injury survivors to develop a BUDDY SYSTEM for participating in recreational activities. A buddy is another individual who is familiar with the brain injury survivor's medical and functional limitations in the event of an emergency during the recreational adventures. Most people do not understand a brain injury survivor's impairments since many of them look physically fine in social situations. It is recommended that high-risk activities be observed initially in a controlled environment and cleared by the physician for participation. The Recreation Therapist may be of assistance adapting activities, equipment, or skills for participation.

Remember that isolation and boredom are major issues upon discharge back to home and the community. You must plan ahead and be motivated to have a balanced lifestyle. Re-create your life through recreation and leisure.

PHISHING

One of the keys for safety in today's world is to be aware of predators who will take advantage of those with changes in memory and problem solving including those who have sustained a brain injury. What we are talking about is phishing.

Phishing is "the attempt to obtain sensitive information such as usernames, passwords, and credit card details (and, indirectly, money), often for malicious reasons, by disguising as a trustworthy entity in an electronic communication." These individuals are constantly adapting and adjusting ways to obtain information.

Phishing is something that was rarely thought of before, but now is something that happens more often. It is a way in which people can access accounts and information and use them for their own benefit without the owner knowing or granting access. If a person has poor judgement, this is not a hard trap within to fall. Even if one does have good judgement skills, it can still happen. These people that do the phishing can "scam" or contact and gain access through responding to an email or click on a link. All of that to say, when checking emails, don't open those that you do not know the sender and when presented with popups or links that you don't recognize, don't open or click on them. Any of this can be a phishing attempt disguised as any sort of email or website. In just a few clicks, a "phisher" can have all the access he needs to personal accounts and information.

DOs and DON'Ts to protect against email and phishing scams:

DON'T send passwords or any sensitive information over email

No legitimate business or organization will ask you to send your password, account information, social security number, or other sensitive data over email. *NEVER* respond to an email requesting personal, financial, or other protected information, even if it appears to be from your bank, or another trusted institution.

Instead, directly contact the institution that the email appears to be coming from, using the number listed on your credit card or bank statement (or equivalent document, such as your cell phone bill if the email claims to be from your mobile provider).

DON'T click on "verify your account" or "login" links in any email

Always open a new window and use the institution's official home page to log into any account.

Links in an email may appear to go to the trusted site, but actually redirect to a page that steals your login information.

DON'T reply to, click on links, or open attachments in spam or suspicious email

Clicking through or replying to spam can verify your email address and encourage more such attempts in the future. Send spam straight to the trash or report it to the FTC at spam@uce.gov. NEVER open attachments from senders you don't know.

DON'T call the number in an unsolicited email or give sensitive data to a caller

The risks associated with email phishing apply equally to phone calls. By using Voice over Internet Protocol technology, scammers can disguise their true phone number just as they can disguise their email or web address. Don't assume that a familiar area code or prefix is safe to call.

Phone phishing can be even harder to detect than email phishing. Callers may impersonate institutional personnel, employees (or students) needing your assistance, or even police officers. Never give sensitive information to a caller you don't know personally. If the need is legitimate, you will be able to call the person back using trusted numbers or email addresses you look up on the official institutional website.

DO report impersonated or suspect email

If you receive an email asking for personal, login or financial account information and appearing to be from your bank, or another trusted institution, forward the email to the Federal Trade Commission (FTC) at spam@uce.gov. Also forward the email to the organization being impersonated. (Most organizations have information on their websites about where to report problems. You might start by searching on the website for "fraud protection" or "spam" to find the correct email address.)

You also may report phishing email to reportphishing@antiphishing.org. The Anti-Phishing Working Group is a consortium of ISPs, security vendors, financial institutions and law enforcement agencies that is building a database of common scams to which people can refer.

DO be cautious about opening attachments, even from trusted senders

Email accounts can be hacked or impersonated by scammers and files and attachments that have been infected with viruses and malware can be embedded in your account or email. If opened, these can access your data and/or harm your computer. Be wary of opening unsolicited attachments or downloading materials from an email, even if they appear to come from someone you know. If there is any doubt about the legitimacy of the message, consider whether the value of the attachment is worth potentially endangering your personal data.

If you cannot find the information in the attachment elsewhere, examine the file extension on the attachment before opening it. If the extension is among the extensions listed below, it is more likely to be malicious. (*This list is non-exhaustive.*)

- .exe

- .msi, .bat, .com, .cmd, .hta, .scr, .pif, .reg, .js, .vbs, .wsf, .cpl, .jar
- .docm, .xlsm, .pptm (may contain macros).
- .rar, .zip, .7z

Caution: no file types are 100% safe-especially if your operating system or any of your programs / apps have not been adequately patched. Consider verifying the legitimacy of the email and attachment with the sender before opening it.

DO install anti-virus and firewall programs

Anti-virus software and a firewall can protect you from inadvertently accepting malicious files.

Anti-virus software scans incoming communications and files for malicious content. Look for anti-virus software that updates automatically and can perform real-time protection.

A firewall helps make you invisible on the Internet and blocks all communications from unauthorized sources. It's especially important to run a firewall if you have a broadband connection.

DO check financial statements and credit reports regularly

Read your monthly bank account and credit card statements to be sure all charges are authorized, and request free annual credit reports to be sure there are no unauthorized accounts open in your name.

DO restrict who can send mail to email distribution lists

Chapter 12: PATIENT AND FAMILY ADJUSTMENT

A Severe Head Injury can be one of the most devastating experiences that a family can have. With the founding of the National Head Injury Foundation there has been a realization that the family suffers as much or more than the injured party. One of our family members said, "when something like this happens, the whole family has a brain injury." He, of course, was referring to the extreme feeling of disorientation and confusion that results after the initial shock and medical crisis have passed. A loss has occurred, but there is no time to grieve because a "new" person has developed whose needs are immense and immediate. The person whom they loved and depended on is no longer the same. Their personality, abilities, interaction styles and goals may no longer exist in the way they did. The family is placed under emotional,

physical, and often financial stress. The family affairs and needs may go unattended. Psychologically, people often react to trauma in their lives by experiencing a series of grieving states. These stages include:

Denial:

“No, this couldn’t have happened to us...”

Anger and Frustration:

Family members may feel anger toward anyone who could be seen as the cause of the injury, or have anger toward the hospital staff. Feelings of being victimized may arise.

Depression and Withdrawal:

Family members may withdraw from friends and social contacts, and may lack the motivation to take care of their own needs and relationships. Family members may stop eating properly, not get enough sleep and be ineffective in their jobs.

Acceptance:

Hopefully, with time, the family will come to accept the changes that have occurred in their loved one and in their lives. Only with acceptance can the family begin to tend to its own recovery.

Many family members may find it difficult to accept such feelings and psychological reactions within themselves. They may feel guilty and think that they must remain strong. It is important to point out that such psychological reactions are normal and quite “acceptable.” After all, the family is recovering from a trauma also.

The acquisition of new or unaccustomed behaviors is required because the old methods of dealing with your family member may no longer be effective. Moreover, subtle interrelationships of family members may be thrown off without an awareness of how to get moving in a positive direction. You may be experiencing or will soon be aware of feelings and actions in yourself that you never dreamed were possible. It is hopeful that by knowing these possibilities you will experience less guilt, confusion, or frustration over “the new you.” Again, we have described these four behaviors; you may have to deal with only a portion of them.

We encourage you to attend all of the Brain Injury Family Education Sessions. The more knowledge you receive on Brain Injury the more comfortable you will be with dealing with the changes in your family member.

Family Rights and Responsibilities:

Within the limits of state and federal laws, family members have rights. However, you may have felt at the time of your family member’s brain injury that hospital personnel were in control of making decisions and you felt left out in the decision making. The need for regaining control is real but, if not channeled properly, can develop into a nightmare for you as a family member.

Goals of Rehabilitation:

For the person with a brain injury to become as independent as possible, and to train the family to assist as needed with their care. Rehabilitation is a learning process, be patient. Caring for a seriously ill loved one can be a very frightening experience. We are here to help you train to care for your loved one.

You're Not Alone

Many people in the community are unfamiliar with brain injury. Therefore, family members often feel isolated and may find it difficult to get support from their friends and community. Many families have banded together for support and to share information. The Brain Injury Association of USA now has chapters in almost every state and provides information. In addition, family members may seek professional help through counselors, social workers, and other mental health professionals in their community. The case manager assigned to your family member's rehab team may be able to assist you in locating such services. Also, enclosed in your education packet is a resource list for the Knoxville area. If you live somewhere other than Knoxville, members of your team will assist you in finding resources in your area.

RESOURCE NUMBERS

Brain Injury Association of America: www.biusa.org	1-800-444-6443
Brain Injury Association of Tennessee: www.braininjurytenn.org	1- 615-955-0673
Traumatic Brain Injury Program Tennessee Dept. of Health:	1-800-882-0611

Knoxville Area Brain Injury Support Group: 1-865-331-1499

Vocational Rehabilitation – Regional Office: 1-865-594-6060

TennCare Advocacy Program 1-800-758-1638
www.tenncareadvocacy.com

Brain Injury Community Services
Coordination 1-865-331-1499
www.patneal.org/brain-injury/

Brain Injury Program at Patricia Neal
Rehabilitation Center 1-865-331-1135

Definitions

<https://www.neuroskills.com/education-and-resources/glossary/>

Pharmacology

<https://www.neuroskills.com/education-and-resources/pharmacology-guide/>

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Websites:

Brain Injury Association of America	<u>http://www.biausa.org</u>
Brain Injury Association of Tennessee	<u>http://www.braininjurytn.org</u>
Center on Measures in Brain Injury	<u>http://www.tbims.org/combi</u>
Patricia Neal Rehabilitation Center	<u>http://www.patneal.org</u>
Patricia Neal Innovative Recreation Cooperative	<u>http://www.patneal.org/pnrc-irc.cfm</u>