

# Brain Injury Family Education Manual



*Patricia Neal*  
Rehabilitation Center

Restoring Abilities. Rebuilding Lives.  
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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 PNRRC 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 classes offered at the Patricia Neal Rehabilitation Center. This helps 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.

## **ACKNOWLEDGEMENTS**

This manual is the property of the Brain Injury Program of the Patricia Neal Rehabilitation Center at Ft. Sanders Regional Medical Center. The information contained in this manual was created, edited and reviewed by the staff of the Brain Injury Program for use in Family Education. This information is designed to provide the family with general information on Brain Injury. Special thanks goes to the following individuals for their assistance in the creation of this manual, their time, and expertise.

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# **Chapter 1: YOU AND YOUR REHABILITATION TEAM**

## **THE FAMILY**

The family has many roles in the rehabilitation effort of a brain-injured person. This is the reason you are the most important member of the rehabilitation team. The family provides continuous support for the patient throughout the rehab process. Also, you give information needed to individualize the treatment as no one else can. You are the source of the patient's life history. This is essential to the rehab process because the team needs to be aware of the patient's personality, interests, and learning style before the injury. The team uses this very important information to decide what treatment styles should be used and what goals should be set for the patient. Another important role of the family is involvement in the treatment plan. Other team members can develop plans for the patient, but only the patient and family can decide if those plans are financially and emotionally realistic. The family provides emotional support for the patient. Family members are familiar faces that provide reassurance and motivation to keep the patient going. They can also provide the patient with constant feedback on his/her progress. The family can function as an advocate for the patient. The family can identify additional resources in the community that may be helpful in the patient's rehabilitation. They may be helpful by increasing public awareness of the needs of the brain-injured population. Many families do this through organized groups, such as the Brain Injury Association of America. At Patricia Neal Rehabilitation Center, we encourage family participation in the rehab process. We hope that we can assist you as well as your loved one through this difficult time.

## **PHYSICIAN**

The physician in rehabilitation is a physiatrist – a medical doctor with special training and experience in rehabilitation. The physiatrist is your team leader.

## **REHABILITATION NURSES**

Nursing care is provided on a 24-hour basis by a nurse with experience and specialized training in rehabilitation. The rehab nurse is responsible for planning care, setting goals, and providing patient and family education. He/she is also a coordinator, insuring that the goals of the other team members are reinforced in all aspects of care while encouraging the maximum level of independence for every patient.

## **PHYSICAL THERAPISTS**

Physical therapists are skilled professionals who focus on overcoming the physical effects of disease, injury, developmental abnormality or amputation. They help with regaining muscle strength, lost function, joint range-of-motion, mobility such as walking, and motor skills through a variety of techniques. Therapeutic exercise is their primary method of treatment. The physical therapist will also be involved in the recommendation of equipment to assist in maximum function of the patient.

## **OCCUPATIONAL THERAPISTS**

Occupational therapists provide a variety of therapeutic activities designed to improve or restore functional loss, which can be translated into practical everyday activities. The programs are tailored to help your family members function at the highest level of independence possible in those activities of daily life which are usually taken for granted. Occupational therapy includes retraining in such skills as dressing, grooming, eating, homemaking, hygiene, toileting, and vision. Often the therapists design and fabricate special adapted or orthotic devices that make these skills easier for transition to a more independent life style.

## **SPEECH-LANGUAGE PATHOLOGISTS**

Speech-language pathologists treat and evaluate a wide range of communication problems. These may include difficulties in speaking, hearing, comprehension of oral or written material, memory and swallowing. This team member can even evaluate and train in the use of computers and other devices that take the place of the human voice. The speech pathologist may be able to offer various means of alternative communication devices for your loved one.

## **PSYCHOLOGISTS**

All brain-injured patients at the Patricia Neal Rehabilitation Center may receive Behavior Medicine services that speed the rehabilitation process. The psychologist will conduct personality, cognitive, and interest assessment which will let you and the rest of the team know how to set goals and best proceed with the rehab plan. The focus of this team member is to help patients and families overcome difficulties brought on by his/her physical injuries and illnesses and to adjust to the necessary changes in lifestyle, which inevitably occur.

## **RECREATIONAL THERAPISTS**

The Recreation Therapy Services is a vital and integral element in the treatment of patients at the Patricia Neal Rehabilitation Center. The recreational therapists offer programs in three basic areas:

- Therapeutic services for treatment to improve and maintain functional abilities.
- Leisure education to develop skills and attitudes for a healthier lifestyle with compensation for abilities from illness or injury, and
- General leisure opportunities to promote independence, adjustment to the rehab process, improve self-esteem, socialization and just plain old fun.

The therapeutic strategies prescribed for the patients are as varied as the patients themselves. Community reintegration and social skills are areas of concentration with the brain-injured population. Activities are designed to suit the patient's individual needs.

## **PERSONAL CARE ASSISTANTS**

These men and women are nursing technicians who assist the nurse in providing care. They have received special rehabilitation training allowing them to help the patient practice many of the skills learned from the therapists. They offer support for the patient and family as well as efficient hands on care.

## **CASE MANAGER**

Case managers at the Patricia Neal Rehabilitation Center help patients and families deal with social, emotional and adjustment problems. The case manager plays an important role in answering a question in the forefront of the patients'/families' minds. "Will my insurance cover this treatment?" They act as a liaison with insurance carriers to provide updates of progress and the length of stay recommended by the treatment team. The case manager communicates with the patient and family any issues that pertain to the rehab process and transition to the next level of care and coordinates the discharge plan. Case managers facilitate arrangements and transportation for physician visits while an inpatient and schedules physician follow-up visits and provides doctors with inpatient records for preparation for discharge. The case manager arranges home or out-patient follow-up therapy; assists with community resource referrals; schedules family training for preparation for discharge; gathers information for patient and family; assists with Family Medical Leave Act (FMLA) forms; and provides information on how to apply for Social Security Disability. The case manager orders the supplies and medical equipment, as recommended by the physical and occupational therapists, for your next level of care and arranges follow-up lab work as needed.

### **MEMBERS OF THE CORE REHAB TEAM INCLUDE:**

**Physiatrist:**

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**Rehab Nurses:**

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**Physical Therapist:**

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**Occupational Therapist:**

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**Speech Therapist:**

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**Psychologist:**

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**Recreational Therapist:**

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**Patient Care Assistants:**

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**Case Manager:**

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**Brain Injury Community  
Service Coordinator**

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## RECOVERY BEGINS

The recovery and prognosis of brain-injured patients is very individualized. Much depends on the area of the brain injured and the extent of the tissue damage. As a patient progresses through the stages of recovery outlined in the Ranchos Los Amigos Scale of cognitive and behavioral function (that you will learn about later), he/she may display different behaviors and cognitive changes. Because of this, the team may state the need for changes in the immediate environment. These changes would be requested in the patient's best interest for facilitating recovery. This immediate environment refers to the patient's room and surroundings which are within sight, sound, touch, smell or taste.

As you have already noticed (and have probably been told), all schedules are individually designed. The therapeutic team designs the individual program based on the results of their completed initial evaluations as well as patient/family goals. The results of the evaluations may indicate a need for any or all of the following:

- Changes of the room design (e.g., changing the bed position or type of bed)
- Limit the number of visitors at a time.
- In room therapy to enhance/reinforce learned skills
- Limit pictures, etc., put on the wall in the room
- Limit the type and amount of music, TV, conversation etc., in the room
- Limit foods, smells, etc., brought to the room
- Request familiar personal objects from home are brought in to assist in memory work.

To you, as a family member, some of our work requests may seem unnecessary. However, please bear with us as we have the patient's best interest in mind. We have specific purposes for these requests. If our purpose is not clear, please ask us. We value your opinions as an important member of the team and hope that we do not leave any question unanswered. You may find that we also ask a lot of questions. This is so we can provide meaningful individualized care during your family member's stay. Remember we are working together with you to help your loved one improve as much and as quickly as possible.

There are things you can do as a family member to help us maintain a therapeutic environment for your loved one. Use these guidelines to shape your personal interaction with your family member.

## 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. Brain injured patients may need a longer time to respond to statements – as long as several minutes.
  - Always assume the patient understands everything.
  - Always talk to the patient and initially orient the patient to time, date, place, who you are, why he is in the hospital and explain 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 or sweating, may also indicate overstimulation
- 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 he does not respond, he probably is aware and should be included. Always explain what you are doing.
    - ✓ Many behaviors after brain injury are a phase and will pass after time.  
Be patient and don't take remarks on behavior directed toward you, or others, as personal.

## Chapter 2: 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 brain-injured individual will exhibit. After reading this outline write down the area(s) of the brain your family member had injured, and the possible deficits related to the injury.

**CEREBRUM:** the cerebrum is the largest part of the brain. It is divided into two halves, the right and the left, which are called hemispheres.

**LEFT HALF** – The left half of the cerebrum controls the right side of the body. In general, it also controls:

- Speaking
- Understanding
- Speech production
- Language abilities
- Reading
- Writing
- Calculating (math)

**RIGHT HALF** – The right half of the cerebrum controls the left side of the body. In general, it also controls:

- Copying
- Drawing
- Musical rhythm
- Judging size
- Paying attention
- Body language

**There are four parts of the cerebrum called lobes:**

**FRONTAL LOBE** – Control centers for:

- Judgment
- Reasoning
- Personality
- Motivation
- Initiation
- Problem solving
- Inhibition of certain behaviors
- Voluntary movements of muscles

Damage to this area can cause:

- Aphasia – difficulty with speaking and understanding speech
- Poor inhibition
- Poor social judgment
- Personality changes
- Decreased spontaneity
- Memory problems
- Paralysis or muscle weakness

**PARIETAL LOBE:** Control center for:

- The 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.

Damage to this area can cause:

- Problems with what we feel
- Problems with what we see and how we see things.
- Problems with construction or making things
- Math problems
- Problems with moving when we want to move
- 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:** Control centers for:

- Hearing
- Taste
- Smell
- Aiding in committing information to memory
- Receives and interprets sounds as words
- Organization of time

Damage to this area can cause:

- Problems with the way we hear
- Problems with understanding language
- Long and short term memory problems
- Memory disorganization

**OCCIPITAL LOBE:** Control centers for:

- Vision-interpreting impulses from the retina of the eye

Damage to this area can cause:

- Problems with sight

**CEREBELLUM:** 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

**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 (only partly responsible)
- 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 brainstem may cause problems in any of the above areas.

The area(s) of the brain injury in my family member are \_\_\_\_\_

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The problems related to this area(s) that my family member has:

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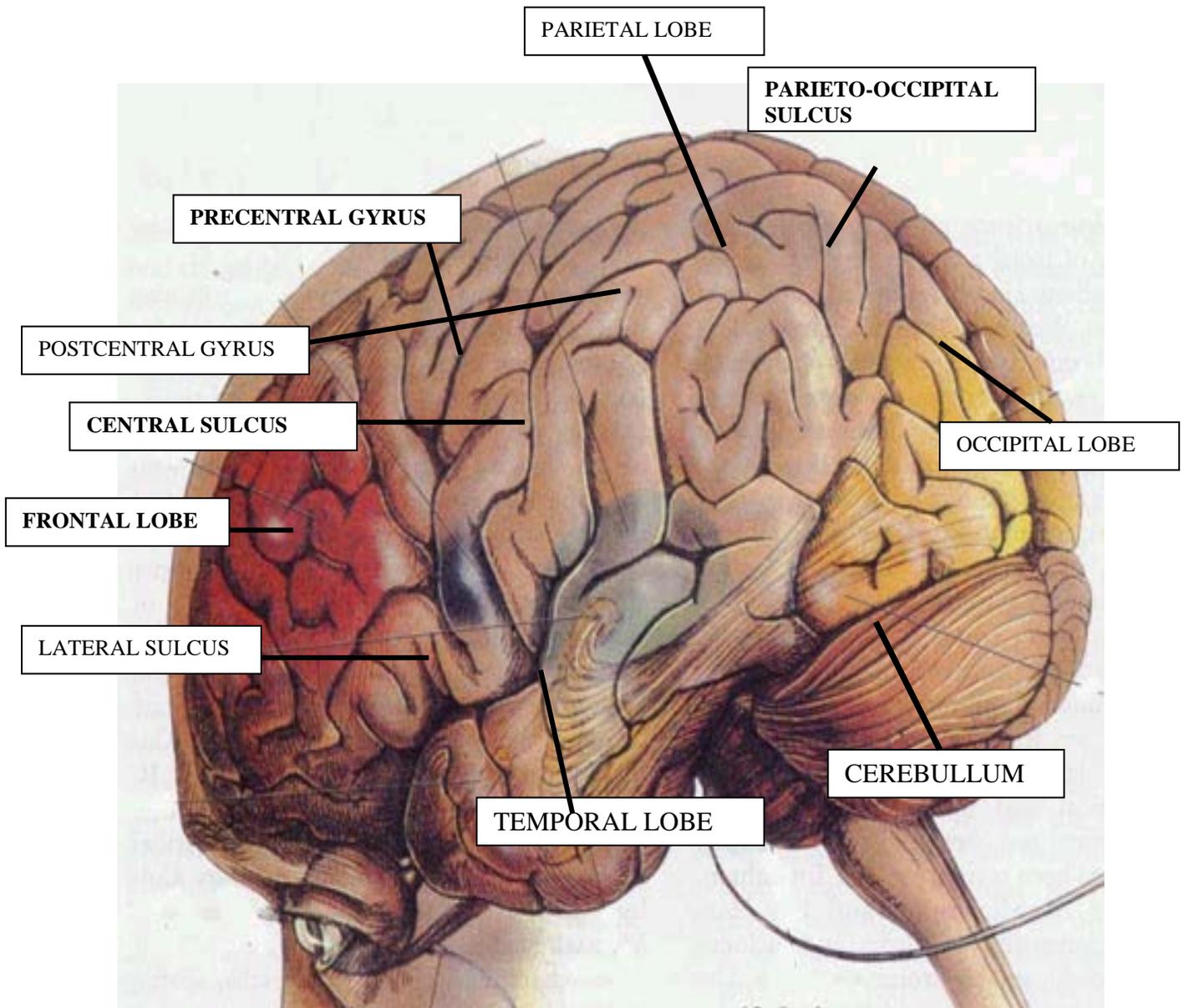
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## Chapter 3: BRAIN INJURY OVERVIEW

There is one brain injury in the United States every 21 seconds. There are approximately over 5.5 million individuals living with a brain injury in the US. The number one cause of traumatic brain injury is a fall followed by motor vehicle accidents and then assaults. In the state of Tennessee, there are over 7,000 reported cases of brain injury that require hospitalization overnight annually. Half of the injuries reported by the military from the Iraq conflict are a result of blast concussions. Brain Injury is the leading cause of death in individuals under the age of 34. Most individuals do not understand brain injury since often, there are little physical residuals from appearance but the behavior and cognitive changes remain. Thus it is known as the "Silent Epidemic."

### HOW BRAIN INJURY OCCURS:

- **TRAUMA** a direct blow to the head such as in a motor vehicle accident, falling, or assault.
- **ANOXIA** lack of oxygen to the brain as in drowning, choking, seizures, or heart attack.
- **VASCULAR DISORDERS** rupture or clogging of blood vessels, a collection of blood (hematoma) that presses on brain tissue
- **DISEASES** inflammations, tumors, or degenerative Diseases, such as Meningitis or Multiple Sclerosis.

### TYPES OF INJURY:

- **CLOSED HEAD INJURY** Brain injury with or without skull fracture
- **OPEN HEAD INJURY** Injury where something penetrates into the brain (such as a bullet) or the skull fractures so that fluids leak out (i.e., basilar skull fracture).
- **POLAR INJURY** Usually the tip of the frontal and temporal lobes suffer more injury than the back of the brain.
- **SHEARING** Movement of part of the brain on other parts of the brain causing tiny tears.
- **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.

**What happened to my family member?**

**Cause of Brain Injury?** \_\_\_\_\_

**Type of Brain Injury?** \_\_\_\_\_

\_\_\_\_\_

## Chapter 4: 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.

Brain Injury Programs for rehabilitation across the country use the Rancho Los Amigos Scale to assess where a brain-injured individual is functioning with relation to their ability to think and to act. This scale is often referred to as the Ranchos. It provides clinicians an idea of the general level of cognitive and behavioral actions an individual demonstrates during the recovery process. Brain injury recovery is more like a marathon race than a sprint to the finish. The characteristics to describe the different levels of the Ranchos are below as well as the treatment focus, team role, treatment approach, and treatment goal. You, as family, are considered an important part of the treatment team. Treatment Focus is what we hope the patient should gain from intervention. Team Role is the manner in which the team will work. Treatment Approach is the method that will be incorporated into how we work with the patient and Treatment Goal is what we hope to see the patient achieve. You can look at the characteristics described below to assess where you may think a person is in relation to the Ranchos level.

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

**Level I: No Response** No response to pain, touch, sound, or sight.

Treatment focus – Patient Protection

Team Role – Protection

Team Approach – Medical physical management

Treatment Goal – Prevent further medical complications

**Level II: Generalized Response** Generalized reflex response to pain.

Treatment focus – Patient Protection

Team Role – Protection

Team Approach – Medical physical management

Treatment Goal – Prevent further medical complications

**Level III: Localized Response.** Blinks to strong light, turns toward/away from sound, and responds to physical discomfort, inconsistent response to commands.

Treatment focus – Patient Protection

Team Role – Protection

Team Approach – Medical physical management

Treatment Goal – Prevent further medical complications

**Level IV: Confused – Agitated.** Alert, very active, aggressive or bizarre behaviors, performs motor activities but behavior is non-purposeful, extremely short attention span.

Treatment focus – Reduce confusion and agitation

Team Role – Nurture

Team Approach – Manage environmental stimulation

Treatment Goal – Develop a sense of safety

**Level V: Confused – Non-agitated.** Non-goal oriented without external structure, requires continual redirection, agitated by too much stimulation, difficulty learning new tasks; may engage in social conversation but with inappropriate verbalizations; severe memory impairment.

Treatment focus – Orientation

Team Role – Support

Team Approach – Client and Environmental Management

Treatment Goal – Awareness of Self and Environment

**Level VI: Confused – Appropriate.** Demonstrates some awareness of situation, time, and place; remote memory impaired; begins to recall past; consistently follows simple directions; demonstrates goal directed behavior with assistance; maximum assist for new learning.

Treatment focus – Orientation

Team Role – Support

Team Approach – Client and Environmental Management

Treatment Goal – Awareness of Self and Environment

**Level VII: Automatic - Appropriate.** Unable to grasp consequences of an action or decision; self-centered; unaware that impairments and disabilities exist, which may lead to oppositional/uncooperative behavior; performs daily routine in highly familiar environment in a non-confused but automatic, robot-like manner.

Treatment focus – Self-management

Team Role – Assist

Team Approach – Behavior Management

Treatment Goal – Awareness of Others

**Level VIII: Purposeful – Appropriate.** Initiates and carries out familiar routines with intermittent assistance for at least one hour with distractions; difficulty with self-monitoring of behaviors and recognizing and correcting problems as they occur; requires minimal assistance with cause and effect situations; may exhibit low frustration tolerance, irritability, or depression.

Treatment focus – Self-guidance

Team Role – Coach

Team Approach – Cognitive and Behavior Management

Treatment Goal – Social Competence

**Level IX: Purposeful and Appropriate with Standby Assistance on Request.** Able to accurately shift back and forth between tasks for at least two consecutive hours; able to use assistive memory devices (daily schedule, “to do” lists) when requested; initiates and carries out steps to complete familiar personal, household, work, and leisure tasks independently and unfamiliar tasks with intermittent assistance; aware of impairments and disabilities and

compensates for these appropriately when completing daily problem solving tasks; requires assistance with preplanning & self-evaluation skills and consequences of actions or decisions; decreased self-centeredness; may still have problems with depression, irritability, and low frustration tolerance when sick/fatigued/under emotional stress.

Treatment focus – Autonomy and Self-actualization

Team Role – Empower for independence

Team Approach – Counseling and Training

Treatment Goal – Inter-Dependence

**Level X: Purposeful and Appropriate – Modified Independent.** Able to handle multiple tasks simultaneously but requires breaks to sustain attention and concentration; able to independently complete all daily living activities but may require more than usual amount of time and use of compensatory strategies; periods of depression may occur; irritability and low frustration tolerance when sick, fatigued, and/or under emotional stress.

Treatment focus – Autonomy and Self-actualization

Team Role – Empower for independence

Team Approach – Counseling and Training

Treatment Goal – Inter-Dependence

It is important to remember that not all individuals will reach all the levels on the Ranchos scale. It is noted that on a bad day, you too could be ranked as a Ranchos IX or X due to circumstances like not getting enough sleep the previous night could cause you to not concentrate well the next day. The Ranchos scale looks at common characteristics over a period of time. If a patient is assessed as a Rancho IV, one episode of agitation or aggressive behavior will not cause this rating but several over a period of time. Patients may have characteristics between two different levels as they transcend levels. Overall, the Ranchos Scale is used as an index to identify where the patient is in the recovery process.

## Chapter 5: MEDICAL TERMINOLOGY

**ABSTRACT REASONING:** The ability to consider evidence and draw conclusions with ideas or thoughts that are not concrete in nature. Example, “While waiting for her test results, the girl was sitting on pins and needles.” – You know from past experience that the girl is not actually sitting on pins and needles; this is just an expression that means she was anxious or nervous.

**ACTIVITIES OF DAILY LIVING:** Activities or tasks that a person does every day to maintain personal independence. They include activities such as: bathing, grooming, dressing, toileting, feeding, home management, and community re-entry skills [i.e. using electronic devices, budgeting, transportation and time management].

**AGITATION:** A heightened level of arousal which may produce a behavioral pattern of restlessness and increased activity intermingled with anxiety, fear or tension.

**AGNOSIA:** The failure to recognize and know how to use familiar objects perceived by vision, feeling and hearing.

**AGRAPHIA:** Inability to write – often seen with aphasia.

**ALEXIA:** Inability to read.

**AMBULATION:** Walking

**AMNESIA:** Memory loss. Please see Retrograde and Anterograde Amnesia

**ANOMIA:** Inability to remember and express names (nouns) of persons and objects.

**ANOSOGNOSIA:** This refers to an unawareness of the hemiplegia. The patient may deny that the hemiplegic arm/leg belongs to him or he may admit that they are his limbs but refer to them in the third person.

**ANOXIA:** Lack of oxygen to tissue, particularly brain tissue, which may result in brain or central nervous system damage.

**ANTEROGRADE AMNESIA:** Inability to remember events that occurred after the brain injury.

**ANTICOAGULANTS:** Medications used as “blood thinners” to slow down normal blood clotting and thus to prevent blood clots. [i.e. Heparin, Coumadin, Lovenox]

**ANTICONVULSANTS:** Medications used to treat and prevent seizures. [i.e.: Dilantin, Phenobarbital, Tegretol]

**ANTI DEPRESSANTS:** Drugs which help fight depression. [i.e.: Paxil, Prozac]

**APATHY:** Lack of feeling, emotion, interest or concern.

**APHASIA:** Language disorder caused by brain damage that affects the production [expressive] and/or comprehension [receptive] of written or spoken language.

**APRAXIA:** Disorder of the voluntary control and organization of movement. (For more detail see pg. 51)

**ASPIRATION:** When food or liquid goes into the windpipe [trachea] and lungs instead of the esophagus and stomach. This can cause a lung infection or pneumonia.

**ASSOCIATED REACTIONS:** Involuntary movement and a change of limb position on the hemiplegic side. Most commonly seen in stressful situations, while coughing or yawning, and when other parts of the body are resisted during movement. [i.e.: a patient may be unable to move his arm, but when he yawns, his elbow, wrist and fingers bend]

**ASTEREOGNOSIA:** Inability to identify objects through sense of touch and object manipulation. [i.e.: with eyes closed, using one hand, patient is unable to feel an object and verbalize what the object is]

**ATAXIA:** Inability to perform coordinated muscle movements. [i.e.: when walking, your legs don't move like you want them to]

**ATTENTION SPAN (Also called SUSTAINED ATTENTION):** The length of time an individual is able to maintain attention to a specific task without being distracted.

**AUDITORY AGNOSIA:** Inability to recognize differences in sounds.

**AUGMENTATIVE COMMUNICATION:** A system to enhance oral / verbal / written / communication.

**AUTOMATIC SPEECH:** Items said without thinking on the part of the patient. These may include songs, numbers, social communication [i.e.: "hello" or "how are you?"] or can be items previously learned through memorization. Another example is spontaneous swearing in individuals who did not do so pre-injury.

**BASILAR SKULL FRACTURE:** Breakage of the bones at the base of the skull. Sometimes this breakage does not show on X-rays, and can lead to leakage of fluid from the brain and become a source of infection [meningitis].

**BEHAVIOR MODIFICATION:** Interaction with a person in a deliberate way, which either decreases, increases or maintains a specific behavior.

**BRAIN INJURY ASSOCIATION of America (BIAA)** National organization made up of patients, family and professionals to aid brain injury members and their families.

**BILATERAL:** Both sides.

**BITE REFLEX:** A primitive reflex in which the patient bites in response to any stimulus and is unable to release volitionally.

**BODY SCHEME:** Awareness of body parts, position of body and its parts in relation to themselves and objects in the environment.

**BODY PART IDENTIFICATION:** Able to identify parts on self and / or others.

**BOTOX BLOCK:** Medication injected into a muscle to decrease hypertonicity causing temporary relaxation; requires increased time to take effect versus a phenol block.

**BRAIN STEM:** An area at the base of the brain before the spinal cord begins that contains several centers vital to consciousness and life, as well as being; the origin of all nerves to the face controlling sight, smell, hearing, taste, swallowing and movements of the eyes and face.

**CATHETER:** A narrow tube frequently inserted into the bladder to drain urine.

**CENTRAL NERVOUS SYSTEM (CNS):** Part of the nervous system made up of the brain and spinal cord.

**CEREBROSPINAL FLUID (CSF):** A clear, continuously produced and reabsorbed fluid that fills the ventricles within the brain and circulates down the spinal cord.

**CLOSED HEAD INJURY (CHI):** Occurs when the brain collides with the skull, however the skull itself is unbroken.

**COLOR AGNOSIA:** Inability to recognize differences in color.

**CONFABULATION:** Making up facts or events. This differs from lying in that the individual is not attempting to deceive.

**COGNITION:** Ability to perceive, understand, organize, recall, problem solve, reason and make judgments in response to daily activities.

**COMA:** State of unconsciousness.

**COMPREHENSION:** Ability to 'understand' auditory, visual and tactile information as it is presented.

**COMPUTERIZED AXIAL TOMOGRAPH (CAT OR CT):** A special (form of) X-ray used to look at soft structures within the body that do not show up well on standard X-rays.

**CONCENTRATION:** Ability to attend to a task for an extended period of time.

**CONCUSSION:** A disruption of brain function, which occurs when the brain is jarred within the skull.

**CONSTRUCTIONAL APRAXIA:** Difficulty in putting objects together and in assembly. [i.e.: difficulty setting a table, wrapping a gift or making a sandwich]

**CONTINENT:** The ability to control urination and bowel movements.

**CONTRACTURES:** Shortening of muscles and connective tissue that limit range of motion at a joint.

**CONTRECOUP:** Upon impact, the brain bounces against the skull and injury results at the site of impact (coup) and the part of the brain opposite the impact (contrecoup).

**CONTUSION:** Injury similar to a bruise on the surface of the brain.

**CEREBRAL CORTEX:** Most complex and organized center of the brain, which consists of the frontal, temporal, parietal and occipital lobes.

**CORTICAL BLINDNESS:** Blindness due to a brain injury even though the eyes are normal.

**COUP:** Upon impact, the brain bounces against the skull and injury results at the site of impact. [See also CONTRECOUP]

**CRANIOTOMY:** A surgical procedure that removes a piece of the skull bone in order to reach the brain.

**DECUBITUS ULCERS: [ALSO CALLED BEDSORES]:** Open sores in the skin and tissue, usually related to decreased circulation to the area secondary to maintained pressure on the tissue. [Usually found from prolonged pressure of lying in bed or sitting in a chair]

**DEEP VEIN THROMBOSUS (DVT):** Blood clot typically found in the legs that can result in death if not treated immediately. Symptoms include swelling, redness, warmth, pain, tenderness to touching in one leg. See PULMONARY EMBOLUS.

**DENIAL:** Refusal or inability to recognize a patient's disabilities following a brain injury.

**DEPARTMENT OF VOCATIONAL REHABILITATION:** A state administered program based on federal grant that assists with vocational potential. Serves to help those with brain injury return to work if able. (is this still relevant?)

**DEPRESSED SKULL FRACTURE:** Occurs when a piece of skull is pushed inward against the brain.

**DEVELOPMENTAL SEQUENCING:** Used in therapy to assist patients in regaining motor control lost after a brain injury. The term "developmental sequencing" is based on the early development of a child during the first year of life. These positions challenge a patient's balance while also working on muscle group activation and co-activation. Examples of these positions: lying on the stomach while propped on elbows or being on the hands and knees.

**DIFFUSE BRAIN INJURY:** Common in head injury. This is injury to the cells in many different areas of the brain instead of one specific location.

**DIPLOPIA:** Double vision – caused by inability of both eyes to focus on the same point.

**DISINHIBITION:** Inability to control emotions or impulses.

**DISORIENTATION:** The patient is unable to identify/state his/her name, the correct date, place and situation.

**DIX-HALLPIKE TEST:** Clinical test for diagnosing peripheral or inner ear vestibular dysfunction (please see definition of vestibular dysfunction)

**DRESSING APRAXIA:** The patient is unable to dress himself. Attempts are made to put the clothing on backwards, inside out, in the wrong order or dresses only one half of the body.

**DYSARTHRIA:** “Slurred” speech due to paralysis or weakness of tongue, lips, soft palate and/or other facial muscles involved in the production of speech.

**DYSPHAGIA:** A swallowing disorder characterized by difficulty in oral preparation for the swallow or in moving the material from mouth to stomach.

**DYSMETRIA:** When a patient overshoots a target because of an inability to control movement. [i.e.: when reaching for an object, the patient may reach past the object].

**DYSSYNERGIA:** “Choppy movement” - incoordination

**EDEMA:** Collection of fluid in the tissue causing swelling. There is often edema or swelling of brain tissue after a severe injury to the head. This is dangerous because the brain is in a confined space and does not have room to swell without pushing against the hard surface of the skull. This pressure on the brain cells has potential to cause further brain damage.

**ECHOLALIA:** Repeating words or sentences.

**ELECTROCARDIOGRAM (EKG):** A test measuring the electrical activity of the heart.

**ELECTROENCEPHALOGRAM (EEG):** A test measuring the electrical activity of the brain.

**EPIDURAL HEMATOMA:** Bleeding between the skull and the dura.

**EXTREMITY:** An arm is an upper extremity and a leg is a lower extremity.

**FIGURE GROUND PERCEPTION:** Ability to distinguish foreground from background. This skill helps you pick out a brush from a cluttered drawer, find a washcloth on a white towel, and find food in the refrigerator.

**FRONTAL LOBES:** The largest area of the cerebral cortex that lies in the front of the skull. The frontal lobes are responsible for the control of voluntary movement and activity. The left frontal lobe controls the action on the right side of the body and the right frontal lobe controls the action on the left side of the body. The frontal lobes are also involved in organization, problem solving, some parts of language use, attention, and regulating emotions and behavior. Damage to these areas may cause movement deficits, reduced ability to reason, short attention span, poor memory, lack of interest in surroundings, emotional and behavioral changes, and reduced ability to plan and control actions.

**FRUSTRATION TOLERANCE:** Ability to maintain a sense of control when challenged. Many persons who have a brain injury have decreased frustration tolerance.

**GASTROSTOMY TUBE:** A tube inserted through a surgical opening into the stomach. It is used to introduce liquids, food or medication into the stomach when a patient is unable to take these by mouth.

**GENERALIZATION:** The ability to transfer what is learned in the treatment session into everyday activities and situations.

**GLASCOW COMA SCALE (GCS):** System for assessing consciousness level immediately following injury. Scale rates communication, motoric and eye opening responses.

**GRAY MATTER:** Areas of the brain and spinal cord that contain mostly nerve cells.

**HEMATOMA:** A collection of blood inside the brain tissue or on the surface of the brain. This can cause pressure to build up resulting in damage to brain cells and interruption of blood flow.

**HEMIPARESIS:** Weakness on one side of the body caused by brain damage.

**HEMIPLEGIA:** Paralysis on one side of the body caused by brain damage.

**HEMORRHAGE:** Bleeding into or on the surface of the brain following damage to the blood vessels in the brain.

**HEMOTHORAX:** Blood within the chest – usually seen with lung injury.

**HOMONYMOUS HEMIANOPSIA:** Visual field deficit in which the patient is unable to perceive half of the visual field of each eye. [Please see definition for visual field]

**HYDROCEPHALUS:** A buildup of pressure in the fluid filled cavities within the brain.

**IMPULSIVITY:** Acting too fast without thinking whether it is safe or appropriate.

**INCONTINENCE:** Unable to control bowel movements and/or urination.

**INFARCTION:** A loss of blood supply to the tissues, resulting in death of the tissues.

**INITIATION:** The ability to begin a task. [i.e.: if you are hungry, to pick the fork up, scoop up the food and bring it to your mouth.]

**INTRACEREBRAL HEMATOMA:** Bleeding within the brain.

**INTRACRANIAL HEMATOMA:** Bleeding within the skull.

**JUDGMENT:** The ability to make appropriate decisions based on information and possible consequences. Judgment is affected by a person's ability to use appropriate problem solving approach.

**LABILITY:** Inappropriate excessive expression of emotion. [i.e.: suddenly laughing or crying]

**LEISURE:** Components of life free from work and self-care activities.

**LETHARGY:** Drowsiness and sluggishness.

**LIMBIC SYSTEM:** System within the brain that mediates moods, emotions, motivation, attention and memory.

**MAGNETIC RESONANCE IMAGING (MRI) SCAN:** A detailed picture of the brain taken with powerful magnets. No X rays are used.

**MEMORY:** Process of perceiving events, organizing stimuli and storing information to be used at a later time.

Memory has been classified into two categories as follows:

Short Term Memory:	The part of memory that allows you to recall day-to-day information, such as names of therapists, therapy schedules or recent events. Sometimes referred to as immediate recall.
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Long Term Memory:	The part of Memory that allows you to recall past events, names, and facts.
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Memory is very important in and will affect the ability to learn new information.

**MNEMONICS:** Strategies used to aid in recalling information from short and long term memory: a mental thought connector or code used to store and retrieve information. [Example: an acronym – M.A.D.D. stands for “Mothers Against Drunk Drivers”]

**MODIFIED BARIUM SWALLOW ASSESSMENT (MBSA):** A **MBSA** is an x-ray procedure used to examine problems with swallowing. Liquid **barium** is a white, chalky solution that helps healthcare providers see the pictures more clearly. **Barium** is mixed with liquids and foods to show how they are **swallowed**.

**MOTOR CONTROL:** Regulating the timing and amount of contraction of the muscles to produce smooth and coordinated movements.

**NASOGASTRIC TUBE (NG TUBE):** A tube passed through the nose, down the esophagus, and into the stomach. It can be used for feeding or for suction.

**NEOLOGISM:** Nonsense or made up word used when speaking. The person often does not realize that the word makes no sense.

**NEUROGENIC BLADDER:** Abnormal bladder function due to nerve damage.

**NEUROPSYCHOLOGY:** A branch of psychology that deals with the assessment and rehabilitation of the brain-behavior relationships and cognitive functions.

**NON-DOMINANT PARIETAL LOBE SYNDROME:** A set of abnormal behaviors usually caused by an injury to the right side of the brain. Typical problems are: keeping track of time,

remembering faces, paying attention to the left side of the body, insight, decrease attention span, and a tendency to be more argumentative.

**NPO:** Latin abbreviation for “nothing by mouth”.

**OCCIPITAL LOBES:** Located in the back of the brain. These areas receive and process visual information. Damage to this part of the brain may cause distorted vision, trouble interpreting visual information, partial, or rarely, complete blindness.

**ORIENTATION:** Oriented times four refers to knowledge of person, place, time and situation.

**PARAPHASIAS:** Substitution of an incorrect sound [i.e.: tree for free] or related word [i.e.: chair for bed] or jargon [nonsense words].

**PARALYSIS:** Muscle paralysis; the appendage or muscle does not move actively.

**PARESIS:** Muscle weakness, the appendage or muscle is weak but can actively move.

**PARIETAL LOBES:** Located between frontal and occipital lobes. These are important in the processing of information from the sense of touch as well as bringing together information from various other senses [i.e.: hearing and seeing]. This includes specific information about the position of body parts [proprioception], the organization of space around the body, and the relationship of one’s self in space. [spatial relations].

**PERCUTANEOUS ENDOSCOPIC GASTROSTOMY (PEG)** is an endoscopic medical procedure in which a tube (**PEG tube**) is passed into a patient's stomach through the abdominal wall, most commonly to provide a means of feeding when oral intake is not adequate (for example, because of dysphagia or sedation).

**PERSEVERATION:** Being “stuck” on a word, idea or task and not being able to switch to a new word, idea or task.

**PHENOL BLOCK:** Medication injected into a muscle or nerve to decrease hypertonicity causing temporary or long-term relaxation.

**PHYSIATRIST:** A physician specializing in physical medicine and rehabilitation.

**POSITRON EMISSION TOMOGRAPHY (PET) SCAN:** A picture of the brain using radioactive oxygen, sugar (glucose) or other substances to evaluate brain function.

**POST-ACUTE REHABILITATION:** A facility that provides rehabilitation on a long-term or community re-entry basis.

**POST-TRAUMATIC ANMESIA (PTA):** The period of time when patients are unable to form new memories.

**PRE-MORBID STATUS:** Characteristics of an individual prior to the accident.

**PROBLEM SOLVING:** The ability to consider several alternatives of handling a situation and choosing the best one.

**PROPRIOCEPTION:** The perception of the position of a body part in space or in relationship to another body part. [i.e.: is the arm hanging at the patient's side?, is the elbow bent or straight?]

**PROSTHESIS:** Artificial replacement for parts of the body lost in injury, such as prosthetic eyes, dentures, arms/hands, hips, and legs/feet.

**PULMONARY CONTUSION:** Traumatic bruising of the lung.

**PULMONARY EMBOLUS:** A blood clot that passes to the lung.

**“RANCHO LEVELS”:** Levels I – X of behavior and cognitive functioning developed by Rancho Los Amigos Hospital in 1979 and revised in 1998, used to characterize the patients present state in the recovery process of brain injury.

**RANGE OF MOTION (ROM):** Amount of movement possible at a joint.

Active ROM: The patient is able to move the extremity without assistance.

Passive ROM: The patient requires assistance to move the extremity because of weakness or increased tone.

**RIGHT/LEFT DISCRIMINATION:** The ability to understand the concept of right and left. Sometimes a brain injury will impair this skill.

**REFLEX:** An involuntary response to a stimulus. In a person with a brain injury, abnormal reflexes can be common because the brain affects the ability to control the reflexes. Some therapeutic activities that reduce reflexes are proper positioning in bed, positioning patient correctly in the wheelchair, or being careful of the way the patient is moved or where the patient is touched, as any of these may trigger a reflex.

**RESTRAINTS:** Devices used to keep someone with a brain injury from hurting him/herself and others. [i.e.: enclosure bed, hand mitts, crossover belts, wrist restraints]

**RETROGRADE AMNESIA:** Inability to remember events that occurred prior to the brain injury.

**SCANNING:** The active search of the environment for information; usually refers to “visual scanning” which is a skill used in reading, driving and many daily activities.

**SEIZURES:** [Also called epileptic seizures] Rhythmic body movements or rigidity caused by abnormal electrical discharges in the brain.

**SELF CARE ACTIVITIES:** Activities such as feeding, grooming, bathing, dressing and toileting.

**SENSORY STIMULATION:** Providing the patient with stimulation through various senses (touch, smell, taste, hearing and vision) to elicit a response.

**SERIAL CASTING:** A process of applying casts, of increasingly greater degrees of joint position, every few days to stretch a limb away from a contracted spastic position.

**SHUNT:** A small tube placed in the brain to drain excess fluid from inside the brain. This prevents excessive swelling of the brain [hydrocephalus].

**SPASTICITY:** See TONE.

**SPATIAL RELATIONS:** Difficulty in perceiving angles and rotation of shapes. Also could be ability to perceive self in relation to other objects. Impairment in this area may make transfers and ambulation unsafe.

**SPLINT:** Type of orthosis that is placed on a joint(s) to protect the integrity of the arches and of the joint. [i.e.: a hand splint may be fabricated to protect the wrist and fingers.]

**SUBARACHNOID HEMORRHAGE:** Bleeding between the brain and the thin arachnoid membrane lying over it. A subarachnoid hemorrhage is usually caused by a rupture of blood vessels that lie in this space.

**SUPERVISION:** Refers to assistance provided when a person needs no physical help but requires a person nearby for safety.

**SWALLOW RESPONSE:** Protects the airway while allowing food to enter into the esophagus.

**SYNERGISTIC PATTERN:** Refers to movements that occur together in a set pattern and may be difficult to isolate due to abnormal muscle tone.

**TEMPORAL LOBES:** Located on each side of the brain. Both right and left temporal lobes play an important part in processing memory information and hearing. In addition, the dominant temporal lobe [in most people, the left hemisphere] is of special importance in speech and language functions. Damage to these areas may cause memory problems and disturbances in speech and language.

**TETRAPLEGIA:** Paralysis of all four extremities, also referred to as quadriplegia.

**THOUGHT FLEXIBILITY:** The ability to come up with several solutions to a problem versus just the most obvious one. Thought flexibility ties in with problem solving and with abstract reasoning. An example might be that a person with a brain injury has hemiplegia. When dressing himself, the person sees that the only way to dress himself is the way he did before the injury instead of realizing that he needs to implement a new way because one side of his body is not working normally.

<b>TONE:</b> Spastic/Hypertonicity:	High tone, increase in muscle tension as a result of brain or spinal cord damage.
Flaccid/Hypertonicity:	Low tone, decrease or absent

muscle tone as a result of brain or spinal cord damage.

**TOPOGRAPHICAL ORIENTATION:** Ability to find one's way from one place to another [i.e.: difficulty finding his way from his room to therapy or from one room to another]

**TRACHEOTOMY:** An operation in which a surgeon places a breathing tube through the neck – directly into the trachea.

**UNILATERAL NEGLECT:** The tendency to ignore things on one [the affected] side. [i.e.: The patient may fail to notice food on the left side of the tray or bump into things on the left side.]

**VENTRICLES:** Fluid filled cavities in the brain.

**VENTRICULOPERITONEAL (VP) SHUNT:** A neurosurgical procedure to relieve buildup of pressure within the brain [hydrocephalus]. A tube is placed in one ventricle, tunneled through the neck and under the skin into the abdomen.

**VERBAL APRAXIA:** Difficulty in forming and organizing intelligible words although the necessary muscles remain intact.

**VESTIBULAR DYSFUNCTION:** A dysfunction of the inner ear, which affects balance, thus creating a sense of dizziness or of the room spinning.

**VIDEOFLUOROSCOPY (MODIFIED BARIUM SWALLOW):** A swallowing procedure for evaluating the cause of dysphagia. Using controlled amounts of barium, the actual swallow can be observed and problem areas identified to prevent further aspiration. This procedure is usually completed by a speech therapist in cooperation with a radiologist.

**VISUAL ATTENTION:** Ability to voluntarily focus and fixate on an object for a period of time.

**VISUAL FIELD:** The portion of space where objects can be perceived while the person is visually focusing on a specific object that is usually located directly ahead. [i.e.: While looking straight ahead, the person can still see other people and/or objects within his surroundings through his peripheral vision.]

**WORD FINDING DIFFICULTIES:** Difficulty recalling a specific word or words.

**XEROSTOMIA** is the medical term for the subjective symptom of dryness in the mouth, which may be associated with a change in the composition of saliva, reduced salivary flow, or have no identifiable cause.

## Chapter 6: COMMON MEDICATIONS

These are some common medications that are used with brain injury. If your specific medication is not listed, please ask your pharmacist, physician, or nurse for its application in recovery.

**ARB (ANGIOTENSIN RECEPTOR BLOCKERS) – (COZAAR, DIOUAN, AUAPRO, MICAARDIS, TEVETEN, INSPRA, ATACAND, BEMICAR)** – Used in the treatment of hypertension and heart failure. Side effects: Increased potassium levels, cough (less than ACEs), low BP, dizziness, headache, drowsiness, diarrhea, abnormal taste, and rash; more rare serious side effects include: kidney and liver failures, allergic reactions, decreased WBC, swelling of tissue.

**ACE (ANGIOTENSIN-CONVERTING-ENZYME) INHIBITORS – (CAPOTEN, CAPTOPRIL, ENALAPRIL, LISINOPRIL, PRINVIL, LOTENSIN, VASOTEC, ZESTRIL)** – used to treat high blood pressure and heart failure. Side effects: appetite loss, change in taste sensation, constipation, bronchial spasm, cough, swelling, itching, rash, dizziness, low blood pressure, rapid or slow pulse, chest pain.

**ACETAMINOPHEN (ANACIN-3, EXCEDRIN, TYLENOL)** – Used to decrease fever and pain. Side effects: rare, causes liver damage in overdose.

**ADRENOCORTICOIDS (DECADRON, DEXAMETHASONE, METHYLPREDISONE, PREDISONE, SOLU-CORTEF, SOLU-MEDROL)** – Used to reduce swelling in the brain or spinal cord. Used topically for rashes. Side effects: acne, fluid retention, poor wound healing, stomach upset, and ulcers. Inform your physician if there is a history of blood clots, diabetes, glaucoma, heart disease, peptic ulcer or tuberculosis.

**ALPHA-ADRENERGIC BLOCKERS (CARDURA, HYTRIN, FLOMAX, MINIPRESS)** – Used to treat hypertension and avoid heart failure by relaxing and expanding walls of the blood vessels. Also used to relax muscles in the bladder neck to improve voiding. Common side effects: ANTICHOLINERGICS, dizziness, drowsiness, weakness, vivid dreaming, rapid heartbeat, low blood pressure – sometimes even causing blackout spells with the first dose, bladder accidents, inability of the erect penis to relax.

**ANTACIDS (AMPHOGEL, MAALOX, MYLANTA, TUMS)** – Medications used to treat “heartburn” and stomach upset by neutralizing acid in the stomach and esophagus. \*\*Antacids should be used with caution with other medications, as they affect absorption. Also use caution with renal patients.

**ANTIARRHYTHMICS (DIGITALIS, LANOXIN, QUINIDINE, NORPACE, PROPRANOLOL)** – A large and varied group of medications used to treat irregular beating of the heart.

**ANTIBIOTICS (ALSO ANTIBACTERIALS)** – A varied group of medications used to treat or prevent infections. It includes several classes. Most share common side effects: nausea, vomiting, stomach upset, diarrhea, allergic reaction and rash.

**ANTICHOLINERGICS** – Used to relieve cramps and spasms of the stomach, intestines, and bladder, decrease peptic ulcers with other meds, pain relief during menstruation. Side effects: dry mouth, dry eyes, blurred vision, constipation, nausea, vomiting, difficulty urinating, fatigue, headaches, insomnia, confusion, hallucinations, rapid pulse. Problems with asthma, bronchitis, glaucoma, heart disease, liver disease, myasthenia gravis, peptic ulcers, or prostate may be worsened.

**ANTICOAGULANTS (COUMADIN, WAFARIN SODIUM)** – Used to reduce blood clots. Side effects: bleeding!! Bleeding may be obvious or hidden, such as showing up in the stomach with dark stools. This class interacts with many other classes to affect the case of bleeding as well as the other drug's effect. **HEPARIN (LOVENOX, FRAGMIN)** is an anticoagulant given intravenously or by injection. Its primary side effect is also bleeding. Other side effects: dark stools or urine, easy bruising, fatigue, fever, hair loss, nausea, sore throat, rash and yellow jaundice.

**ANTICONVULSANTS (CARBAMAZEPHINE, DEPAKENE, DEPAKOTE, DILANTIN, PARADIONE, PHENOBARBITAL, PHENYTOIN, TEGRETOL, VALPROIC ACID)** – Used to treat and prevent epileptic seizures. Side effects: dizziness, drowsiness, interactions with other medications, rash.

**ANTIDEPRESSANTS, TRICYCLICS (CELEXA, LEXAPRO, PAXIL, LUVOX, AMITRIPTYLINE, DESYREL, PAMELOR, PROZAC, TRAZODONE)** – Used to treat depression, pain due to nerve damage, and sometimes bedwetting or insomnia. Side effects: fatigue, change in appetite or weight, constipation, dizziness, drowsiness, confusion, dry mouth, headache, tremors, hallucinations, insomnia, irregular heartbeats, itching, rash, seizures, sore throat, yellow jaundice due to effect on the liver. It may take 3 weeks to obtain a significant effect from the medications. \*\*Elavil is often used in the treatment of abnormal nerve pain.

**ANTIEMETICS (COMPAZINE, DRAMAMINE, PHENERGAN, REGLAN, VISTARIL)** – Used to treat motion sickness, nausea, and vomiting. Side effects: drowsiness, abnormal eye or facial movement.

**ANTIHISTAMINES (BENADRYL, CLARITIN, AND MANY OTHERS)** – Primarily used to treat allergies, itching, rashes and insomnia.

**ANTIPSYCHOTICS (RISPERDAL, XYPREXA, SEROQUEL, CHLORPROMAZINE, HALDOL, MELLARIL, NAVANE, THORAZINE)** –Used to reduce severe anxiety, agitation, and psychotic behavior. Side effects: abnormal movements of face, limbs, or tongue, constipation, dizziness, drowsiness, interactions with many other drugs, jaundice, restlessness.

**ASPIRIN (ANACIN, BAYER, BUFFERIN, ECOTRIN, EMPIRIN)** – Used to reduce fever, inflammation, joint stiffness, swelling, and pain of various types. (Also used as anticoagulant “blood thinner”.) Side effects: black stools, heartburn, indigestion, nausea, stomach pain, ulcers, vomiting, ringing in the ears. Rare, but dangerous, are severe allergic reactions and, in children, Reye’s syndrome-confusion, coma, kidney and liver damage.

**BACLOFEN (LIORESAL)** –Used to relieve muscle cramps and spasms: sometimes used to reduce hiccoughs or pain. Side effects: confusion, dizziness, drowsiness, lightheadedness, nausea, numbness and tingling, rash, weakness of muscles.

**BENZODIAZEPINES (ANTIVAN, DALMANE, LIBRIUM, RESTORIL, SERAX, VALIUM, XANAX)** – Uses: mild tranquilizers for anxiety, nervousness, and tension: muscle spasm; and acute treatment of epileptic seizures. \*\*May be addictive if used over prolonged periods.

**BETA BLOCKERS (CORGARD, INDERAL, TENORMIN, ATENOLOL, LOPRESSOR, PROPRANOLOL)** – Used to lower blood pressure, stabilize an irregular heartbeat, reduce angina, reduce the frequency of migraine headaches, and reduce agitation after head injury. Side effects: cold hands and feet, constipation, depression, diarrhea, dizziness, dry eyes or mouth, fatigue, nausea, low blood pressure, slow pulse, tingling of hands and feet, weakness. Do not stop this medication suddenly. \*\*Inderal is often used for treatment of “storming”.

**BUTETANIDE (BUMEX)** – Uses: a strong “fluid” pill used to reduce fluid retention (edema). Side effects: cramps, dehydration, fatigue, irregular heartbeats, unsteadiness, weakness.

**CALCIUM CHANNEL BLOCKERS (CALAN, CARDIZEM, NORVASC, SULAR, PLENDIL, CARDENE, ISOPTIN, PROCARDIA)** – Used to prevent angina attacks and hypertension by reducing spasm of blood vessels. Also used to stabilize irregular heartbeats. Side effects: constipation, dizziness, nausea, headache, swelling, slow heart rate, low blood pressure, shortness of breath, fatigue, rash, soreness and swelling of the breasts.

**CANTROLENE SODIUM (DANTRIUM)** – Used to relieve muscle spasticity caused by conditions such as head injury, multiple sclerosis, spinal cord injury, and stroke. Side effects: abdominal pain, appetite loss, blurred vision, confusion, constipation, depression, diarrhea, difficulty with erection or emptying of the bladder, headache, hepatitis, insomnia, rapid pulse, rash, sore muscles and back. It should not be used by people with liver disease such as cirrhosis or hepatitis.

**CARBAMAZEPINE (TEGRETOL)** – Used to treat and prevent epileptic seizures. Side effects: blurred vision, nausea, vomiting, diarrhea, confusion, slurred speech, headache, rash, sensitivity of sunlight. A rare side effect is lowering of blood counts causing easy bleeding or bruising, excessive fatigue, sore throat, fever. Alcohol increases the sedation. \*\*New research has shown it is effective in the treatment of agitation and nerve pain.

**DILANTIN (PHENYTOIN)** – Used to prevent and treat epileptic seizures. It is also used to stabilize irregular heartbeats. Side effects: blurred vision, bruising, confusion, constipation, diarrhea, dizziness, drowsiness, hallucinations, headaches, increased body or facial hair, jumping movements of the eyes (nystagmus), nausea, rash, slurred speech, staggering, swollen gums, vomiting. Many of these side effects are signs of overdose. The medication interacts with many other drugs and vitamins to cause other side effects. \*\*Good dental hygiene is important.

**DIPHOSPHONATES (DIDRONEL, FOSAMAX, AREDIA, ACTONEL)** – Used to prevent or treat heterotopic ossification (HO). HO is the abnormal formation of bone in areas that usually have only muscle. It usually occurs around joints and can restrict motion and cause pain. Also

known as myositis ossificans, it can be seen following head injury, spinal cord injury, hip replacement, and some other medical conditions. This medication is also used to treat osteoporosis (thinning of the bones). Side effects: constipation, diarrhea, stomach upset, and, rarely, rash and swelling. No food should be eaten within 2 hours of dosing.

**DIURETICS (BUMEX, DYZIDE, LASIX, MAXZIDE)** – Water pill used to reduce fluid retention (edema) and treat high blood pressure (hypertension). Side effects: blurred vision, bleeding or bruising, dizziness, fatigue, low blood pressure, rash, lightheadedness, nausea, vomiting, weakness, stomach pain, thirst, yellow jaundice.

**FLUOROQUINOLONES (TEQUIN, LEVAQUIN, CIPRO)** – used to treat bacterial infections. Side effects: abdominal pain, diarrhea, headache, nausea, rash and vomiting.

**GABAPENTIN (NEURONTIN)** – Used to treat seizures and neuropathic pain. Side effects: nausea, anorexia, arthralgia, CNS effects.

**H2 BLOCKERS (PEPCID, TAGEMET, AXID, ZANTAC)** – Used to treat and prevent peptic ulcers by reducing acid production by the stomach. Side effects: breast swelling or soreness in men, confusion, decreased sex drive or impotence, diarrhea, dizziness, hair loss, muscular pains. Rare side effects that necessitate calling the doctor right away: unusual bleeding or bruising, unusual fatigue, fever, sore throat. H2 blockers can interact with many other medications, and usually increase their effects.

**LITHIUM (CARBOLITH, ESKALITH, LITHANE, LITHOBID, LITHOTABS)** – Used to treat manic-depressive psychiatric illness and manic behaviors following head injury such as hyperactivity, aggressiveness, and a reduced need for sleep. It works by normalizing mood and behavior. Side effects: confusion, dizziness, drowsiness, dry mouth and increased thirst, decreased sexual function, increased urination, hand tremors, diarrhea, nausea, vomiting and weakness. Notify the physician right away if you note balance problems, blurred vision or loss of vision, rash, stomach pain, or a very large urine output. There are many drug reactions. Salt should not be restricted.

**METOCLOPRAMIDE (REGLAN)** – Used to speed passage of food through the stomach and reduce nausea. Side effects: confusion, drowsiness, jerking movements of face, head, muscle spasms and tremors.

**NARCOTIC ANALGESICS (DARVOCET N-100, DEMEROL, OXYCONTIN, LORTAB, VICODIN, PERCOCET, MORPHINE)** - Used to relieve moderate to severe pain. Side effects: confusion, dizziness, drowsiness, constipation, nausea, vomiting, sweating, headache, weakness, and addiction in long term use – more than 2 weeks.

**NITROFURANTOIN (MACRODANTIN)** – Commonly used for bladder/urinary tract infections. May commonly color urine a brown or rust color. Contact your physician for these symptoms: diarrhea, nausea, vomiting, chest pain or breathing difficulty, numbness or tingling of skin or limbs, unusual weakness or fever.

**NITROGLYCERIN (NITRO-BID, NITRO-DUR)** – Used to prevent or treat angina attacks of heart pain. Side effects: dizziness, flushing, bad headaches, nausea, vomiting, rash and low blood pressure.

**NSAIDS, NONSTEROIDAL, ANTI-INFLAMMATORY DRUGS (ADVIL, CLINORIL, FELDENE, INDOCIN, MOTRIN, NAPROSYN, VOLTAREN, TOLMETIN, MECLOMEN, NAPROXEN, DICLOFENAC, VIOXX, CELEBREX, BEXTRA, RELAFEN, DAYPRO)** – Used as a general pain reliever as well as to treat the stiffness, swelling, and joint pain of arthritic conditions. Some must be taken several times daily, some once daily. Side effects: abdominal pain, constipation, heartburn, nausea, stomach upset, ulcers, dizziness, headache, fluid retention. Prolonged use is more likely to cause stomach problems, including fatal aplastic anemia (failure of the bone marrow to produce blood cells) than the other drugs. Diclofenac causes more liver problems than the other drugs.

**NYSTATIN (MYCOSTATIN)** – Used to treat fungus infections such as thrush involving the mouth or throat. Side effects: diarrhea, nausea, vomiting and stomach pain.

**PHENOBARBITAL** – Used to prevent or treat epileptic seizures. Side effects: confusion, dizziness, drowsiness, depression, slurred speech, diarrhea, nausea, vomiting, rash, swelling of the eyelids, muscle or joint pain. There are many interactions with other medications – many producing dangerous over sedation. Avoid alcohol.

**PROTON PUMP INHIBITORS (PPI):** Proton pump inhibitors (PPIs) are a class of drugs used to treat GERD, peptic ulcers, and h pylori which may be common problems after a brain injury to treat reflux.

**RITALIN** – In children, Ritalin is prescribed for decrease in motor restlessness and increase in attention span. In adults, it is used to increase motor activity and mental alertness and decrease fatigue. Side effects: nervousness, insomnia, headache, dizziness, drowsiness, psychologic depending on increased heart rate, chest pain, high/low blood pressure, nausea, anorexia, abdominal pain, rashes, fever, hair loss, abnormal liver function.

**SULCRAFATE (CARAFATE)** – Used to treat peptic ulcers by coating the ulcer site and protecting it from stomach acid. Side effects: abdominal pain, constipation, indigestion, nausea, vomiting, dizziness, sleepiness and rash. It will absorb other medications so it should be taken 1 hour before meals and at bedtime – at least 2 hours apart from other medications.

**SULFA DRUGS (BACTRIUM, GANSTRISIN, SEPTRA)** – For those who are very allergic, some sulfa drugs that are not antibiotics include DISULFURAM (ANTABURE), FUROSEMIDE (LASIX), AND SULFONURIA drugs used for treatment of diabetes. Side effects of the antibiotics include: appetite loss, diarrhea, nausea, vomiting, dizziness, headache. Contact your physician right away for rash, peeling, blistering, painful urination, unusual bruising, fatigue, sore throat or fever which could reflect an effect on the blood count. It can increase the effects of alcohol.

**TETRACYCLINE** – an oral antibiotic often used to treat skin diseases. Side effects: abdominal pain, diarrhea, nausea, vomiting, headaches, sore mouth and tongue, itching around rectum and genitals due to development of a fungal infection. It may make the skin extra sensitive to sun. It can interact with other drugs and food.

**THEOPHYLLINE (THEO-DUR, THEOLAIR, SLOPHYLLIN)** – Used for bronchial asthma. Side effects: seizures, anxiety, confusion, irregular heartbeat, stomach upset. It is better absorbed if taken on an empty stomach, but can be taken with food to lessen stomach upset.

**VALPROIC ACID (DEPEKENE, DEPAKOTE)** – Used to treat and prevent epileptic seizures. Side effects: irregular menstruation, depression, emotional changes, headaches, incoordination, rash, hair loss, nausea, liver damage, and weakness.

**WELLBUTRIN (BUPROPIN)** – Used to treat depression. Its side effects are similar to the TRICYCLICS, but there are fewer ANTICHOLINERGIC and sedative effects as well as less sexual dysfunction. It does not affect heart rate or cause weight gain. Other side effects include appetite loss, constipation, dizziness, headache, insomnia, psychotic reactions, seizures, and weight loss. The incidence of seizures is higher than with the tricyclic antidepressants.



# Chapter 7: MEDICAL COMPLICATIONS

## ACNE VULGARIS

Acne often occurs for the first time or recurs following brain injury. Treatment with steroids for brain swelling (i.e., Decadron) leads to red papular acne of the face, chest, and back. Others with 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- sometimes first placing a small amount of sterile saline (salt water) in the throat to moisten secretions and to encourage coughing. This may look like cruel treatment to you, 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 important, because the severely injured patient cannot readily get up to empty the bladder. 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. This is because 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 diapers, external catheters, and intermittent catheterization. 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 important 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 he has 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 huge nutritional requirement in 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 he is not capable of eating on his 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 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.

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 you have an "early" seizure, you 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 seizures** – 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 seizures** – 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 seizures** – 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 seizures** – 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 he might hurt himself. You should remove his glasses, and loosen the clothes around the collar. You should help him to lie on his side or stomach – not on his back (in case he should vomit). Do not hold him 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. 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 called lowering the seizure threshold. Medications are used both to prevent and to treat seizures. Usual medications are Phenobarbital, Phenytoin (Dilantin), Carbamazepine (Tegretol), and Valproic Acid).

## **HETEROTROPHIC OSSIFICATION**

Redness, heat, and swelling of a limb can be due to heterotrophic ossification (HO), a deposit of bone material in muscles and other normally soft tissues around major joints. If it does not surround a joint, and is located in a muscle belly, it is referred to as myositis ossificans (MO). Both occur frequently in spastic patients with moderate to severe brain injury, and usually are found around the shoulder, triceps, elbow, hip, thigh, and knee. This problem can occasionally be treated with a medication that slows down (but does not reverse) the deposition of new

bone material where it does not belong. Therapy can address the problem with range of motion.

## **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.

## **Chapter 8: 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”.

Example: Your family member’s arm may feel very heavy and falls off of the wheelchair or bed easily.

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.

Example: The knee may feel “stuck” and only be straightened out 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 or absent due to decreased or absent strength in the muscles. 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 themselves. 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 him/her self because his/her arms are too weak or paralyzed or he/she 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. In 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 his/her left foot keeps crossing over in front of his/her right foot because he/she is unable to completely control the movements of his/her left 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.

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 his/her body weight in normal alignment either in standing or sitting is impaired. 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 him/her from falling, but to your family member it feels like he/she is 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 his/her shoes because his/her 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 he/she is 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 he/she 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 he/she does not feel the sensations or only partially feels them, or it can be increased so that he/she is hypersensitive to the sensations.

Example: Your family member may place his/her hand on a hot stove burner and sustain a serious burn without even feeling it. Or when your family member goes outside, his/her 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 he/she relieves the pressure on his/her bottom, he/she 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 his/her head and trunk movements is 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 his/her head up to eat unless he/she has a headrest on the wheelchair, or he/she may be unable to sit on the side of the bed without back support.

## IMPAIRED MOBILITY

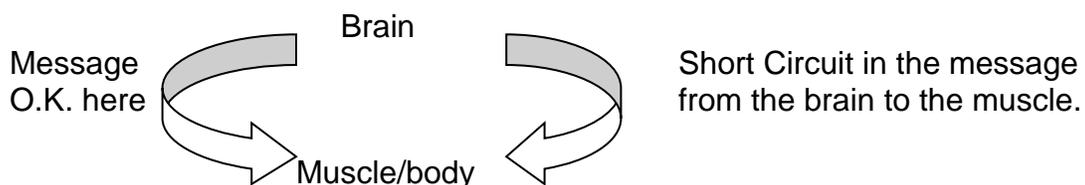
This occurs when your family member's ability to get out of bed, walk, roll a wheelchair, or transfer to the bed, tub, commode, or wheelchair is impaired. This is due to several reasons such as muscle weakness, abnormal muscle tone, breathing problems, joint contractures, impaired balance, coordination, 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 his/her arms are too weak and he/she becomes 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" them 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, he/she scratches it, but when someone tells him/her to scratch his/her nose, she 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 his/her shirt because he/she cannot control his/her 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 his/her eye to enable him/her to see one image instead of two.

## **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 embolism).

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

**PHYSICAL DEFICITS OF PEOPLE  
WHO HAVE SUSTAINED BRAIN INJURIES  
WORKSHEET**

Give a personal example of each of the physical deficits that your family member has experienced or is currently experiencing.

1. Abnormal Muscle Tone: \_\_\_\_\_
2. Muscle Weakness: \_\_\_\_\_
3. Impaired Motor Control: \_\_\_\_\_
4. Joint Contracture: \_\_\_\_\_
5. Impaired Balance: \_\_\_\_\_
6. Impaired Coordination: \_\_\_\_\_
7. Breathing Problems: \_\_\_\_\_
8. Decreased Endurance: \_\_\_\_\_
9. Impaired Sensation: \_\_\_\_\_
10. Decreased Skin Integrity: \_\_\_\_\_
11. Impaired head/trunk control: \_\_\_\_\_
12. Impaired Mobility: \_\_\_\_\_
13. Apraxia: \_\_\_\_\_
14. Ataxia: \_\_\_\_\_
15. Impaired Vision or Perception: \_\_\_\_\_
16. Impaired Circulation: \_\_\_\_\_

According to how you feel, list your family member's top three physical deficits:

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## PHYSICAL PROBLEMS WORKSHEET I

### \*SEEK AND FIND RELATED WORDS TO PHYSICAL PROBLEMS

21 Words to find

BALANCE  
BRAIN  
BREATHE  
COMMODE  
DECUBITUS  
ENDURANCE  
FEET

INJURY  
JOINT  
LIMB  
LIMP  
MUSCLE  
PAIN  
PARALYSIS

POSTURE  
SKIN  
SPASMS  
TONE  
WALK  
WEAK  
WHEELCHAIR

A	S	P	A	S	M	S	I	S	Y	L	A	R
L	I	A	B	P	O	M	R	N	M	U	K	I
C	S	I	L	A	M	T	E	C	J	O	I	W
S	Y	N	E	A	N	I	K	S	O	U	A	H
U	L	B	M	I	L	B	L	E	I	B	R	E
M	A	T	O	C	A	U	N	F	E	E	T	E
U	R	J	T	L	P	O	S	T	U	R	E	L
S	A	I	A	N	T	E	D	O	M	M	O	C
C	P	N	S	I	T	W	A	L	K	C	E	H
L	C	A	N	A	A	D	E	N	W	M	R	A
E	N	D	U	R	A	N	C	E	E	E	L	I
D	E	C	U	B	I	T	U	S	A	K	A	R
B	M	I	L	B	E	H	T	A	E	R	B	K

\*If you are unable to complete this worksheet, please go to the next page Worksheet II and use the clues to help you.

## PHYSICAL PROBLEMS WORKSHEET II

### SEEK AND FIND RELATED TO PHYSICAL PROBLEMS

21 words to find. Clues are given beside each word in the form of an arrow pointing in the direction in which you will find the word.

	WORD CLUE	SEEK AND FIND	ANSWERS
Example:	POST BOAT HOP FIT	P O S T H T A P S O G I B Y P T	

### THE WORDS

BALANCE ↙	INJURE ↘	POSTURE →
BRAIN ↑	JOINT ↗	SKIN ←
BREATHE →	LIMB ←	SPASMS →
COMMODE ←	LIMP ↙	TONE ↗
DECUBITUS →	MUSCLE ↓	WALK →
ENDURANCE →	PAIN ↓	WEAK ↘
FEET →	PARALYSIS ↑	WHEELCHAIR ↓

A	S	P	A	S	M	S	I	S	Y	L	A	R
L	I	A	B	P	O	M	R	N	M	U	K	I
C	S	I	L	A	M	T	E	C	J	O	I	W
S	Y	N	E	A	N	I	K	S	O	U	A	H
U	L	B	M	I	S	B	L	E	I	B	R	E
M	A	T	O	C	A	U	N	F	E	E	T	E
U	R	J	T	L	P	O	S	T	U	R	E	L
S	A	I	A	N	T	E	D	O	M	M	O	C
C	P	N	S	I	T	W	A	L	K	C	E	H
L	C	A	N	A	A	D	E	N	W	M	R	A
E	N	D	U	R	A	N	C	E	E	E	L	I
D	E	C	U	B	I	T	U	S	A	K	A	R
B	M	I	L	B	E	H	T	A	E	R	B	K

## **Chapter 9: COMMUNICATION & COGNITIVE 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, he may not be able to recall day-to-day information, but as he recovers those memory difficulties seem to resolve. He still may not be able to recall names of therapists, schedules, or recent activities, but he 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 his ability to learn new information, such as may be needed in his job or in the classroom setting.

### **MANAGEMENT TECHNIQUES**

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:

- Encourage your family member to use a day planner as a memory aid, and to carry it with him at all times. Assist your family member in organizing his days in the planner and recording the pertinent information.
- Encourage your family member to use his day planner. When he meets someone new, have him write the name and a cue, either a drawing or a description, to help him 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, he may not be able to understand what is said to him. This may happen because he does not perceive the different sounds in words. He 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, he/she 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 he once did. This does not mean he won't feel sensations as he once did, but his interpretation of what he feels may take longer. He may not be accurate at discriminating objects by touch; therefore he may take longer to find keys, lock and unlock doors, and manipulate hand-held tools. He 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 him directions.
- Have him repeat numbers, letters, and directions back to you. Encourage him to write down important information so he 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 he once enjoyed may now be frustrating for him. He may also experience difficulty with fine manipulation skills, such as opening envelopes, unscrewing lids, or working locks.

## **ATTENTION PROBLEMS**

Attention difficulties consistently occur when one suffers a brain injury. There are 5 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 he can have the privacy he needs.

## **LACK OF INITIATIVE**

Initially or early in the recovery process from injury to the brain, 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, so it is less threatening and less anxiety provoking to just sit and do nothing. 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. He says he doesn't want to do anything else. He may plan activities in great detail but may not get past the first activity on the list because it may take him all day to accomplish it. Your family member may no longer be interested in his 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 his attention and keep him moving.

## **COMPREHENSION/UNDERSTANDING DIFFICULTIES**

Comprehension difficulties may inhibit your family member's ability to correctly understand what is happening in his environment. He may not appropriately interpret what he hears or sees, or he may be confused when he attempts to understand what he hears and sees. Your family member may appear to be out of the realm of conversations. He may either not answer

questions or respond with off-the-wall comments. When you discuss a newspaper article with your family member, you may discover that he misinterpreted much of the article or that he did not finish the article. He may have lost interest in the article because he did not comprehend the details or main points. Your family member may find that he has greater difficulty understanding information presented in the classroom.

### ***MANAGEMENT TECHNIQUES***

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

### **EXPRESSIVE DIFFICULTIES**

One's ability to express himself is a reflection of the integration of concentration, comprehension, memory, and initiation. To express himself, 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, he may not be able to find the correct word. He 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 his face is not as expressive as it once was. You may also notice that he stands too close to people when he talks to them. The most complicated level of expression is the written word. Putting thoughts on paper may be much more difficult for him than it was before.

### ***MANAGEMENT TECHNIQUES***

- Set up a cueing system to let your family member know when he is 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 he can be aware of other's responses to his communications.
- Ask your family member's speech-language pathologist which cues work best for him when he has 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 movements are usually referred to as apraxias. Your family member may be able to recall words, letters, sentences, and numbers, but he may not recall them in the order presented. He 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 he write down all numbers and that he 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, he only needs 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.

## **SLOWED 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 the 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 he 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 he once was. By the time he processes the information, the chance for the joke has probably already passed.

## **MANAGEMENT TECHNIQUES**

- Give your family member the time he needs 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 his thinking. In the early stages of recovery, the inflexibility might be demonstrated by his unwillingness to accept any change in his routine or schedule. This rigidity reflects his need for consistency and structure. As he improves, the inflexibility might be demonstrated by difficulty in problem solving. He may only be able to come up with one solution and unable to see alternatives. He will have a tendency to want everything done exactly the way he remembers it was done before the injury.

## **MANAGEMENT TECHNIQUES**

- Realize that changes are difficult for your family member, therefore try to prepare him in advance of any changes in his daily routine. Consistency and structure should be the priority.

- Because your family member will have a great deal of difficulty seeing alternatives, he will return to what is safe and comfortable. Gently encourage him 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 he brings the issues to you.

## **NEW LEARNING PROBLEMS**

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).

## **SPEECH DIFFICULTIES**

### **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**

When interacting with your family member who exhibits dysarthria, the following are suggested:

- 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 what he/she 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 his/her response. Do not finish his/her sentence.

## **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. He may be able to say automatic phrases such as "I'm fine" or "Thank You", but unable to tell you what he 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 him to use gestures or drawing to get his message across.
- Allow time for your family member to communicate his thoughts.
- Talk with the speech pathologist about specific cueing techniques that might work with your family member.

## **SWALLOWING PROBLEMS**

Difficulty with chewing and/or swallowing is a common problem following a brain injury. Another name for this is **dysphagia**. 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 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 and close communication with the speech-language pathologists be maintained.

## **ORAL HYGIENE:**

The person with a brain injury and his family members are often concerned with issues like muscle weakness/paralysis, impaired motor control and mobility, abnormal muscle tone, balance, coordination, impaired vision or hearing, difficulty with respiration, or difficulty with eating or speaking clearly. Sometimes other concerns like oral hygiene might seem less important.

If your family member has problems with respiration or has prior poor dental health, oral hygiene can present 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 brain injured person 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.

The American Dental Association provides the following oral care recommendations to reduce

the risk of caries (cavities) or gingivitis (gum disease): Brush twice a day with fluoride toothpaste, eat a healthy diet limiting sugary beverages and snacks, consider a mouth rinse, use an electric toothbrush to remove plaque (biofilm or bacteria growing in the mouth), and 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.

Remember, 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 and the person may resist having anyone attempt to clean their teeth. Oral rinses may be attempted or lemon glycerin swabs may be used for comfort and cleaning. But 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.

Your speech language pathologist will evaluate the ability of your family member to drink liquids, consume foods and receive oral care safely. The SLP will examine the face, neck, and mouth during an oral motor assessment and conduct a thorough swallowing assessment in Radiology to determine if your family member is ready to safely receive oral nutrition. The SLP will also make recommendations regarding appropriate oral care for your family member.

## **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. We use the internet nearly every day whether it be to look up information, to pay bills, or to contact a friend or family member. While all of these are great and innovative ideas, they can also have some problematic outcomes.

*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.”

Phishing is something that was rarely thought of before, but now is something that happens more often. It is ways 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 an email response or a 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” man 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](mailto: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 like they can disguise their email or web address, so 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](mailto: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](mailto: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 10: 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 such 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 brain injured individuals 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 he/she 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 he can think and how well he can control his emotions, he may behave inappropriately. Frequently, there is at least one person in the family who believes that the brain injured person is just being mean, manipulative, or vengeful when he acts the way he does.

Research in brain injury shows that a personality characteristic that existed before the injury is often exaggerated after the injury. Brain injured individuals can take on an altogether 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. Listed are personality traits which may have described your family member before they were injured (see next page). Circle all the personality traits that describe your family member prior to their injury. You may want to bring this list to your behavioral medicine staff person at your first meeting.

Absent-minded	Efficient	Insightful	Self-centered
Active	Energetic	Intolerant	Self-confident
Adventurous	Enterprising	Inventive	Selfish
Affectionate	Enthusiastic		Show-off
Aggressive	Exciting	Jolly	Shrewd
Alert			Shy
Aloof	Fault finding	Kind	Sociable
Anxious	Fearful		Soft-hearted
Argumentative	Flirtatious	Lazy	Spontaneous
Artistic	Forceful	Loud	Spunky
Assertive	Forgiving		Stubborn
Autocratic	Friendly	Methodical	Suspicious
		Mild	Sympathetic
Careless	Gentle	Mischievous	
Cautious	Generous	Moody	Talkative
Charming			Tense
Cheerful	Handsome	Nervous	Thorough
Clear Thinking	Hard-hearted		Timid
Clever	Hasty	Optimistic	Tolerant
Confident	Headstrong	Organized	Trusting
Complicated	Humorous	Original	
Conservative	Hurried	Outgoing	Unconventional
Contented		Outspoken	Unstable
	Idealistic		
Daring	Immature	Peaceable	Versatile
Defensive	Impatient	Pessimistic	
Demanding	Industrious	Pleasure-seeking	Warm
Determined	Inhibited	Praising	Wary
Distractible	Irritable	Precise	Wide-interests
			Withdrawn
		Resourceful	Worrying
		Sarcastic	

## **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 patient, 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 brain-injured individuals 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, his agitation reactions are due to the fact that he cannot yet understand the difference between a nurse approaching him with a shot and a therapist approaching him to assist him 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. However, it is possible that he may always be much more easily aroused than he was prior to the injury.

### **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 his 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.

### **DENIAL/OVER-OPTIMISM**

From the time that your brain injured loved one began to talk again you have probably noticed that he is not always realistic about what he is capable of 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 ability and of feeling 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 his 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 his motivation to participate in rehabilitation.
- Never out-and-out lie to your family member, saying he will be able to do something that seems unlikely.
- If the brain-injured person insists he can do something and it would not be dangerous to him or anyone else, allow him to try the activity. This can lead to a realization that he is not quite ready to complete this task on his own.
- It is important for you to know that those times when your loved one is obstinate and refuses to be cooperative may be his way of avoiding (denying) facing the fact that the activity is too difficult for him.
- Participation in a head injured support group is often a good place for the individual to hear other people talk about their difficulties and how they have dealt with them. This can make it a little easier for him to identify his 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 pretty trying times. Your loved one may possibly lose most of the patience he had and, if he was impatient to begin with, he may not want to wait for anybody or anything.

A great deal of recovery from a brain injury occurs during the first six months, although progress can continue for years and years but at a quite different rate of change from early months. Both family and patient 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 brain-injured individual's everyday routine. First, the areas of the brain that help him to control his emotions have, in all likelihood, been damaged, leaving him with little control over frustration and anger. Second, brain injury often leads to self-centered behavior. Because he tends to look at all happenings from only his point of view, he has a hard time understanding other individuals' reasons for being delayed or late in responding to his wants and wishes. Third, because of the cognitive difficulties, he may misinterpret a situation, or find himself very impatient, with what other people think is irrational or poor judgment on his 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. He will only set himself 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 he was offensive.
- Teach your loved one to discriminate and not blow off steam at innocent individuals.
- When he complains about things not occurring fast enough, remind him of all the positive accomplishments he has achieved.

## **IRRITABILITY**

One of the most prominent and universal personality changes after brain injury is an increase of irritability. This may be temporary or 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, he may not be able to block out excessive noises. Because of cognitive deficits, he cannot always figure out why certain things are necessary. Because of memory problems, he may not remember that he just told you 30 minutes ago that he did not want something. Nothing at home may seem to please him, he may complain about everything. He may find it difficult to watch TV because the noise annoys him.

## **MANAGEMENT TECHNIQUES**

- It is useless to ask, "Why are you so grouchy?" He probably does not understand or even realize the magnitude of his 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, brain injured individuals do not react positively to either of these.
- Allow the person to talk through his problems, as this can reduce his agitation. You may have to listen to the same topic over and over and over.
- Keep excessive noise to a minimum.
- 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 brain-injured person will blurt out something that he is sorry for later, but he continues to do this, no matter how badly he says he feels every time it happens.

Although brain injured persons can become physically abusive, this does not mean that you should have to live in terror of this abuse. There are brain-injured facilities set up to deal with this serious behavior problem. If you find physical abuse becoming unmanageable, explore the possibility of a behavioral center.

## **MANAGEMENT TECHNIQUES**

- React calmly, and with a relaxed/calm tone of voice and calm facial expressions ask him to express himself without swearing. If you react too strongly, it may increase the frequency if he is trying to get your attention.
- Let him know that verbal abuse or screaming is not the best way for him to get his needs met, by not meeting them when he acts this way.
- Teach the family member the skill of stopping and thinking before he speaks. You can devise a signal to get the person to consider carefully what he is going to say. This silent signal is effective in public because it does not have to look like you are treating him 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 brain injured individual into the necessity of rehashing issues incessantly because they are never adequately resolved or solved by the person himself. So, 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 it 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 him 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 he is constantly talking about a worrisome issue, he is 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 him a favor by minimizing the time he obsesses 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 he 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 hospital rehabilitation 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 him 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 he is talking excessively.
- Remember that people sometimes talk as a means of reducing tension and anxiety.
- Redirect him 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 him put his concerns on paper.
- Schedule times when he can vent about a particular issue.

## **INAPPROPRIATE SOCIAL BEHAVIOR**

Although your family member may not be recognized as brain injured from outward appearances, it is sometimes the inappropriate social interactions that give him 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 brain-injured person may interpret everything said from his own viewpoint, there is very little thought about others in his responses. The subtleties of social situations are lost. The person must be retrained to think before he acts or talks. He will need to change his 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 he is not to talk to strangers about personal matters.
- If he uses a memory notebook/activity planner, have him write down what other family members' schedules are.
- Remember that bringing the brain-injured person back home is like starting all over again in helping him to become socialized in our complex world.

## **EGOCENTRISM**

Often a brain-injured individual will take a completely self-centered approach to life. The world revolves around him and his problems. All family members must address his issues immediately, if not sooner. No one understands the difficulties he is having. To some degree, it is true that no family member completely comprehends what the brain injured person is experiencing. Nevertheless, this is no excuse for his insisting that his 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 him reintegrate into the community. He may need to be told in many different ways that the world does not revolve around him.

## ***MANAGEMENT TECHNIQUES***

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

## **OVER-DEPENDENCY**

The role of rehabilitation is to help the brain injured individual become as independent as possible. Thus, it is important that on discharge you know exactly what he can do for himself. The minute you give in and do things for him, 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 him that he can do on his own is not the way to show this love. Brain injured 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 him to make the decision himself and accept whatever he chooses.

## ***MANAGEMENT TECHNIQUES***

- Allow the individual to make as many of his own decisions as possible.
- Refuse to tell him what to do unless it is absolutely necessary.

- Encourage outings with people outside the family.
- Do not allow yourself to be overprotective.
- Encourage him to become active in a support group – maybe the individual will find someone he 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 he is openly sobbing. Yes, indeed he is sad, but he may not be feeling as much emotion as he shows. Instead, due to the injury to the brain, he may not be able to maintain the emotional controls he had developed over the years. This lability is due to damage to parts of the brain that allow the person to exhibit control. He may not be any sadder than you or I are about the dog that got run over, but he will appear outwardly to be devastated. A joke that is only moderately funny can 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 he has little control.
- Do not bring the crying to his attention. You can hand him 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 brain-injured person has difficulty dealing with stress at any level. Try to modify the stress levels within the home environment so that his emotions can be kept on an even level.
- If he has trouble with excessive crying, try to notice when things are fairly even, and praise him for maintaining this control.
- Focusing on a physical exercise will sometimes help control the crying.

## **SUSPICIOUSNESS**

Brain injured individuals 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 – he will interpret this as an admission of guilt.
- If there is a therapist involved with the individual, ask him to help you work through the issue that is of particular concern to the brain injured loved one. Sometimes if you talk together, it will alleviate the concern.
- Try to guide your family member's thinking in a more positive direction.
- If his suspiciousness is extreme, the best stance to take is to ignore, ignore, ignore.
- Do not argue about his suspicious thoughts. You will never convince him 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 that denial that is often counterproductive to progress. It is important for the person to realize that he does have deficits that will have an impact on his future. Even with the positive effect of letting go of some 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 him motivated and helping him to realistically modify his 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.
- Do not allow the individual to vegetate – get him 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. He probably knows 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 he 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 of the cognitive (thinking) deficits related to head injury is that the brain-injured person has difficulty with planning and goal setting. He does not know where or how to start a project, so he does not begin. Also, he understands to some degree that he does not have the abilities he had before, but does not want to admit to this deficiency. He acts like he is not interested – unmotivated. The reality is that he is interested but may be incapable of doing what would have been simple for him 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 problem.
- Never assume that because he did a task perfectly before the injury, he is being lazy or obstinate if he does not complete it now.
- If he asks for help on an activity, never assume that he does 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 support group.
- Never ask questions such as, “Do you want to .....?” There is too much opportunity to remain passive and say, “No.” Give him a choice of two or three activities from which he must agree to choose one.

## **INCREASED SEXUAL FOCUS**

A person’s sexual orientation and activity can be modified after a brain injury. In some cases, the area of the brain that regulates various hormones can be thrown off. In others, the injured person’s ability to restrict expressions can be altered. A small percentage of the brain injured turn away or reject sexual activity. However, a large percentage place their major focus on remarks, actions, innuendoes, or anything remotely related to the subject of sex. Social contacts of both your family and the patient may turn away because they are uncomfortable in his company. The result, of course, will be social isolation. Once this occurs, your family member begins to blame others for the isolation. He will have a difficult time understanding how he was offensive.

### ***MANAGEMENT TECHNIQUES***

- Each time the individual behaves inappropriately, a designated family member should tell him in an unthreatening and non-combative manner that the behavior is unacceptable.
- Therapists and attendants should, as much as possible, position themselves 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 his behavior.

- Keep cool and do not overreact.

## **FAMILY ABUSE**

The behaviors previously addressed all have an impact on what is probably the greatest deterrent to a family who continues to provide long-term support for the brain injured individual. This is out-and-out family abuse. Putting up 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 he can act appropriately, it is more difficult to accept the abusive behavior that may be dished out on a regular basis. There are different explanations for this that provide a framework for understanding.

First, we all tend to let our hair down with family, as opposed to strangers or acquaintances. However, the brain injured person's interpretation of that may go beyond what is considered acceptable. He is in the habit of saying whatever he thinks to his family, knowing that it is not a problem. However, the family may not be used to the openness and abrasiveness that occurs after a brain injury.

Second, the brain-injured individual often loses some of his social judgment capabilities and is not effectively able to reason out the appropriateness of either his own behavior or the behavior he expects from others.

Overall, a family's patience can be quite worn after months and months of care of this individual. What makes matters worse is that the brain-injured person has little insight into the impact that he is having on the family.

## **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 his 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. He probably does not remember that he 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.



## TRACKING RANCHO LEVELS

The Rancho Level my family member is currently in is \_\_\_\_\_.

Responses that will be helpful to my family member during this level:

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The progression of Rancho Levels of my family member:

Date \_\_\_\_\_ Level \_\_\_\_\_

Responses helpful: \_\_\_\_\_

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Date \_\_\_\_\_ Level \_\_\_\_\_

Responses helpful: \_\_\_\_\_

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Date \_\_\_\_\_ Level \_\_\_\_\_

Responses helpful: \_\_\_\_\_

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Absent-minded	Efficient	Inventive	Self-centered
Active	Energetic		Self-confident
Adventurous	Enterprising	Jolly	Selfish
Affectionate	Enthusiastic		Show-off
Aggressive	Exciting	Kind	Shrewd
Alert			Shy
Aloof	Fault finding	Lazy	Sociable
Anxious	Fearful	Loud	Soft-hearted
Argumentative	Flirtatious		Spontaneous
Artistic	Forceful	Methodical	Spunky
Assertive	Forgiving	Mild	Stubborn
Autocratic	Friendly	Mischievous	Suspicious
		Moody	Sympathetic
Careless	Gentle		
Cautious	Generous	Nervous	Talkative
Charming			Tense
Cheerful	Handsome	Optimistic	Thorough
Clear Thinking	Hard-hearted	Organized	Timid
Clever	Hasty	Original	Tolerant
Confident	Headstrong	Outgoing	Trusting
Complicated	Humorous	Outspoken	
Conservative	Hurried		Unconventional
Contented		Peaceable	Unstable
	Idealistic	Pessimistic	
Daring	Immature	<b>Pleasure-seeking</b>	Versatile
Defensive	Impatient	Praising	
Demanding	Industrious	Precise	Warm
Determined	Inhibited		Wary
Distractible	Irritable	Resourceful	Wide-interests
	Insightful		Withdrawn
	Intolerant	Sarcastic	Worrying

## **Chapter 11: 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 themselves to others. It is also what they think 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 head injury can affect relationships, intimacy, and sexuality: physical limitations, changes in their behaviors and feelings, and cognitive problems which decrease their 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 or significant other:

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

This is just 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 for 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 and physical therapists. They can make recommendations on positioning, medications, 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 on the part of the brain injured person, 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 this issue.

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. Please feel free to discuss your concerns with your family member’s behavioral medicine counselor or physician. 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

We encourage you to discuss any concerns with your family member’s speech and language pathologist, behavioral medicine counselor, occupational or physical therapist or physician. Also remember that some of these problems may only be temporary and will eventually resolve, while others may be more longstanding, even permanent. Try to be patient and realize that recovery will take time.

## **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 then it probably still is. 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 issues with you and if we are unable to answer your questions we will refer you to someone who can. 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:

- Communication is key to healthy relationships
- 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 themselves 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 the problems 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 babysitter than an equal partner in a marriage or 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 them. 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 to physical limitations as well as behavioral and cognitive changes in your loved one, but if you keep a positive attitude, communicate, and seek professional help if needed, it is possible to *return to relationship and intimacy!*

## Chapter 12: 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 treatment 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, incoordination, 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 brain injury survivor that he should not drink any alcohol during the first year or two following his injury. 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.
- Alcohol may cause the brain-injured individual to have epileptic seizures.

There are several schools of thought 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 him/her 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 brain injury survivor to abstain if people do not drink in his/her presence.
- Help your family member broaden his/her leisure skills by investigating local head injury support groups, or encouraging his 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 him/her 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 he/she is able. This will further enhance self-esteem and help them feel productive, needed, and a 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 the head injury survivor 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, non-brain injured individuals 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 13: 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 brain-injured individual 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, he/she 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. No one brain injured person is exactly the same as another. Brain injured survivors normally have a deficit or a combination of problems 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 injured 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 injured 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 injured 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-injured person may not be able to transfer his 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 injured 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-injured survivor will want to try to return to his/her 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 recreative 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, maybe we 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 injured survivor into a community or private agency for a recreative 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 injured, 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 injured survivor's medical and functional limitations in the event of an emergency who goes along on the recreational adventures. Most people do not understand a brain injury survivor since a lot 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.

# **Chapter 14: 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 them.
  - 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 the confused person know what to expect and establishes 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 STM 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."

**\*\*Please remember the importance of rest. It is essential to restore the sleep/wake cycle. Also, 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. Because 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 they get 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 15: FAMILY ADJUSTMENT AFTER A TRAUMATIC BRAIN INJURY AND DISCHARGE PLANNING**

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. His/her 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 Classes. 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 head injury. Therefore, family members often feel isolated and may find it difficult to get support from their friends and community. Many families of the head injured 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. You may want to begin by considering the questions below:

### **Questions to ask at our next therapy session or doctor’s appointment:**

1. Question: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Person to ask: \_\_\_\_\_

Answer: \_\_\_\_\_

2. Question: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Person to ask: \_\_\_\_\_

3. Answer: \_\_\_\_\_  
Question: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Person to ask: \_\_\_\_\_

Answer: \_\_\_\_\_

### **Discharge Planning (When We Go Home)**

Our discharge plan: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Equipment needed at home: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

List changes that you will need to make in your home and your lifestyle when you take your family member home: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Who is my family member's primary care doctor? \_\_\_\_\_  
\_\_\_\_\_

How do I get a referral to a primary care doctor if I do not have one for my family member?

1-865-673-FORT (3678) – Doctor referral service.

Will I see my rehabilitation doctor again? \_\_\_\_\_

Follow up doctor appointments will be made at the discretion of your rehab physician. Any doctors that your family member had been seeing prior to admission to rehab you should continue to see as previously scheduled. Any appointments that were missed while they were

in the hospital should be rescheduled upon your discharge. Your family member's nurse or your case manager will review the follow-up doctor appointments that were recommended on your discharge day.

**Home Medications:**

What medication will be ordered upon discharge?

Will my family member or myself be instructed with any medication that is needed?

What are the side effects of the medications? Your nurse, doctor, and pharmacist can assist you with answering these questions.

**Home Health Care and Outpatient Therapy**

Your family member's doctor may discharge them home with follow-up therapy. This can be either home health care or outpatient therapy. Your case manager will arrange for the therapy of your choice.

Home Health Care: Must be home bound to be eligible.  
Therapist will come to your home for treatment.

Outpatient Therapy: Your family member's insurance may determine where  
Treatment will be initiated.

**RESOURCE NUMBERS**

Brain Injury Association of America:	1-800-444-6443
Brain Injury Association of Tennessee:	1- 615-248-2541
Traumatic Brain Injury Program Tennessee Dept. of Health:	1-800-882-0611
Knoxville Area Brain Injury Support Group:	1-865-541-1499
Vocational Rehabilitation – Regional Office:	1-865-594-6060
TennCare – Mainline	1-800-342-3145
TennCare Solutions	1-800-878-3192
TennCare Advocacy Program	1-800-758-1638
Medicare	1-800-633-4227

Social Security Administration	1-800-772-1213
Brain Injury Community Services Coordination	1-865-541-1499
Brain Injury Program at Patricia Neal Rehabilitation Center	1-865-541-1135
Project B.R.A.I.N.	1-615-585-2998

**Transportation Information:**

Transportation: If transportation is needed, it can be arranged for a small fee in your community. Please see information below:

Knox County Community Action Committee (CAC) Transportation	1-865-524-0319
Knoxville Area Transit LIFT	1-865-215-7850
Knoxville Area Transit City Bus	1-865-637-3000
East Tennessee Human Resource Agency (ETHRA)	1-800-232-1565
Rural Metro	1-865-675-0775

Taxi Cabs – see yellow pages

**For Assisted Living:**

Some Long Term care policies  
\*check your individual insurance policy

## **For Equipment**

Local Churches

Kerbela Temple / Shriners  
Knox County

1-865-573-1082

Scottish Rite  
Knox County

1-865-524-3459

SPARK(Formerly ETTAC)

1-865-219-0130

## **For Medication:**

Cherokee Health

1-866-231-4477

Interfaith Health Clinic

1-865-546-7330

Needy Meds

1-800-503-6897

Partnership for Prescription  
Assistance (PPARX)

[www.pparx.org](http://www.pparx.org)

The Med Program

1-573-778-1118  
[www.themedicineprogram.com](http://www.themedicineprogram.com)

## **For Veterans:**

American Red Cross

1-800-733-2767

US Dept. of Veteran Affairs

1-800-827-1000

VA Medical Center  
Mountain Home, Tennessee

1-423-926-1171

Knoxville Vet Center	1-865-633-0000
Knoxville VA Outpatient Clinic	1-865-545-4592
Veterans Crisis Line	1-800-273-8255 (Press 1)

## **SOCIAL SECURITY ADMINISTRATION**

Knoxville Office: Serves those living in Knox, Blount, Loudon, Sevier, and Union Counties

8530 Kingston Pike  
Knoxville, Tennessee 37919  
1-866-331-9091

Campbell County Office: Serves those living in Campbell and Scott Counties

140 Sharp Perkins Road  
Jacksboro, Tennessee 37757  
1-866-964-7324

Hamblen County Office: Serves those living in Hamblen, Cocke, Grainger, and Jefferson Counties

3112 Millers Point Drive  
Morristown, Tennessee 37813  
1-866-875-6156

Anderson County Office: Serves those living in Anderson, Roane, and Morgan Counties

565 Oak Ridge Turnpike  
Oak Ridge, Tennessee 37830  
1-888-676-2954

Monroe County residents are served in the Athens Office:

921 Congress Parkway  
Athens, Tennessee 37303  
1-866-964-7431

Toll free Number: 1-800-772-1213  
TTY: 1-800-325-0778

## **DEPARTMENT OF HUMAN SERVICES**

Anderson County	182 Frank L. Diggs Drive Suite 200 Clinton, Tennessee 37716 (865) 457-3660
Blount County	303 Home Avenue Maryville, Tennessee 37801 (865) 981-2350
Campbell County	2221 Jacksboro Pike Suite C 19 A – Woodson’s Mall Lafollette, Tennessee 37766 (423) 566-9639
Cocke County	330 Heritage Blvd., Suite A. Newport, Tennessee 37821 (423) 623-1291
Grainger County	8421 Rutledge Pike Suite 101 Rutledge, Tennessee 37861 (865) 828-5251
Hamblen County	2416 W. Andrew Johnson Hwy. Morristown, Tennessee 37814 (423) 585-1444

Jefferson County	1050 South Highway 92 Dandridge, Tennessee 37725 (865) 397-9401
Knox County	2700 Middlebrook Pike Suite 200 Knoxville, Tennessee 37921 (865) 594-6151
Loudon County	485 Pinetop Street Lenoir City, Tennessee 37772 (865) 986-4749
Monroe County	123 Pedigo Road Madisonville, Tennessee 37354 (423) 442-7403
Morgan County	1326 Knoxville Highway Wartburg, Tennessee 37887 (423) 346-6237
Roane County	1086 North Gateway Avenue Rockwood, Tennessee 37854 (865) 354-2419
Scott County	104 Fire Hall Drive Huntsville, Tennessee 37756 (423) 663-2821
Sevier County	815 Dolly Parton Parkway Sevierville, Tennessee 37862 (865) 429-7005
Union County	1403 Main Street Maynardville, Tennessee 37807 (865) 992-5802

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2003 Physician's Desk Reference. Medical Economics Company, Montvale, NJ

**Magazine Publications:**

Brain Injury published by the North American Brain Injury Society

**Websites:**

Brain Injury Association of America

<http://www.biausa.org>

Brain Injury Association of Tennessee

<http://www.braininjurytn.org>

Center on Measures in Brain Injury

<http://www.tbims.org/combi>

Patricia Neal Rehabilitation Center

<http://www.patneal.org>

Patricia Neal Innovative Recreation  
Cooperative

<http://www.patneal.org/pnrc-irc.cfm>