

Brain Injury Education Manual for Patients and Families



You are receiving this education manual because either you or your family member is at Northeast Rehabilitation Hospital due to an acquired brain injury. An acquired brain injury is any injury to the brain that occurs after birth. This may be due to a traumatic event (accident, fall), a brain bleed, a brain illness, tumor, or other cause.



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Thank you for choosing Northeast Rehab

The information in this manual was organized by the physicians of New England Neurological Associates and the Brain Injury staff at Northeast Rehabilitation Hospital. This education manual has been developed to assist you, while your family member is a patient at Northeast Rehabilitation Hospital and as a resource, once they have been discharged from the inpatient Brain Injury Program.

While most people are familiar with general hospitals, this may be your first experience with a rehabilitation hospital such as Northeast. The differences you may observe reflect the specific goals each facility strives to attain. Hospitals are primarily concerned with medical stabilization. They direct their efforts toward providing a high level of continuous medical care.

Rehabilitation centers move a step beyond medical stabilization, utilizing a combination of physical, cognitive, and social therapies to help each patient achieve an optimal level of functioning. In addition to "taking care of "a patient, the rehabilitation plan is designed to satisfy the specific needs of each patient. At Northeast Rehabilitation Hospital, we view the involvement of family and friends as an integral part of the treatment process. You may be invited to participate in various therapies. The entire team is available to meet with you, and in addition, selected team members will meet with you regularly to share information and review treatment progress. Your input is valuable and is always welcomed and encouraged. Feel free to ask any team member your questions and please know that your case manager will be your primary point of contact and information.

You should feel a sense of confidence in knowing your family member is being treated at a CARF (Commission on Accreditation of Rehabilitation Facilities) and Joint Commission accredited hospital. These certifications assure you that the hospital meets the highest national standards established in the rehabilitative healthcare industry.

John F. Prochilo, CEO Administrator



What is Rehabilitation?

Rehabilitation is an educational and therapeutic process. It involves a range of professionals who will work with you and your family to learn how to achieve your personal goals, your highest level of independence safely, and help you participate meaningfully in your community.

You and your family members are central to the rehabilitation process. Together with your rehabilitation team, we will make informed decisions about appropriate rehabilitation services and care for you.

The effects of a brain injury are usually very different for each individual. An injury to the brain may affect the person's abilities to pay attention and remember, to communicate, to undertake everyday tasks, their personality, behavior and mood. And these changes in turn may have implications for the person's abilities to live independently, to communicate effectively with others, drive a vehicle, use public transport, return to work or education, participate in leisure and social activities, perform family roles and maintain personal and family relationships. Some people living with a brain injury may need to acquire new skills and develop strategies to compensate and manage their changed ability.

Your brain injury rehabilitation team provides the expertise necessary to help you achieve the best possible outcomes from your rehabilitation.

Where will my rehabilitation occur?

Your rehabilitation will occur throughout the hospital including your room and designated therapy areas (i.e. therapy gym). Your rehabilitation program may also include activities such as outings in the community and education classes for both you and your family.

What Types of Rehabilitation Services could I receive?

The Brain Injury Inpatient program provides 24-hour, seven-day-a-week medical, rehabilitation and nursing care.

Following your admission to the program, the interdisciplinary team, in partnership with you and your family/caregivers will develop a rehabilitation plan that addresses your identified needs. As part of this process, they will set realistic and achievable rehabilitation goals, so you are able to achieve your best level of functional independence, social participation and community reintegration.

Examples of types of rehabilitation services that may be offered in your program to meet your identified needs and goals could include:

- ✓ Activities of daily living assessment and management
- ✓ Adaptive/assistive technology/equipment assessment and training
- ✓ Audiology (i.e. hearing) screening

- ✓ Behavioral assessment and management
- ✓ Clinical neuropsychological assessment
- ✓ Cognitive assessment and management
- ✓ Communication assessment and management

What is Rehabilitation?

- ✓ Coping and adjustment to disability
- ✓ Discharge planning
- Driving and community transport assessments
- ✓ Dysphagia (i.e. difficulties in swallowing) assessment and management
- ✓ Family/caregiver education, training and counseling
- ✓ Medical assessment and management
- ✓ Mobility assessment and management
- ✓ Nutritional counseling and management
- ✓ Orthopedic assessment
- ✓ Splinting
- ✓ Pastoral and spiritual services

- ✓ Patient advocacy service
- ✓ Patient education, training and counseling
- ✓ Pharmaceutical care and management
- ✓ Podiatry
- ✓ Radiology
- ✓ Rehabilitation nursing
- ✓ Respiratory therapy
- ✓ Safety awareness and training
- ✓ Smoking cessation
- ✓ Urology service
- ✓ Visual assessment and management
- Vocational consultation and guidance as needed

Depending on the type of service and your specific needs, some of the services listed above may occur in individual and/or group training sessions.

Furthermore, please note that not every patient will receive all or the same services listed above. The services you will receive depend on your individual needs and goals.

Rehabilitation is a lifelong process. The ability to carry over the new skills learned in your rehabilitation program into your daily activities both at your home and NRH is central to the success of your program.

Other services we can provide to meet your needs could include:

- ✓ Information and referral about other services
- \checkmark Opportunities for you to meet other people with similar challenges
- ✓ Information and links to community resources and support services



Questions and Answers about Brain Injury Rehabilitation at Northeast Rehab

When can we visit?

Family members and or visitors that will be involved with care of the patient when they are discharged are encouraged to attend as many therapy sessions as possible with the patient. This will facilitate communication between the therapists and the caregivers. This will also allow the caregivers to see what the patient is or is not capable of doing. If a therapist feels that they need some time alone with the patient, they will communicate that. Visiting hours for visitors that will not be involved with the care of the patient are 11:30am to 8:30 pm.

When can phone calls be made and to where?

Patients cannot make or receive phone calls after 10 pm at night unless it is an emergency or if nursing feels it is necessary. Local calls are free from the room but patients will need a calling card for any long distance calls. Nursing will assist the patient if needed.

What volume should the TV or radio be played at?

In order to be considerate of others, they must be played at normal volume. Headphones will be provided if necessary.

What should we bring in from home?

Loose fitting clothing that the patient would be comfortable in when working out in the gym. We also encourage family members to bring in familiar objects/photos from home. You may also be asked to fill out a biographical questionnaire on the patient so that the team may get to know them better.

How do we arrange for the patient to go out on a pass in the community?

Requests for passes when therapy is completed should be identified to the nurse, physician, therapist or case manager several days in advance of the request date with knowledge that special instructions regarding (diet, transfers to and from chair, car, toileting etc.) may need to be given to the family member who will be taking the patient out. Passes can be very therapeutic for the patient but we do ask that they take place when it will not interfere with the therapy schedule.

Can I bring small children onto the unit?

Yes as long as there is one adult who is prepared to supervise and/or remove the child if necessary.

Should we bring in medications from home?

Bringing in medications is not necessary. Occasionally the patient may be on a medication that our pharmacy does not carry, in that case the medication from home should be given to the nurse and they will ensure the correct administration.

Can I walk the patient or transfer them when they are in their room?

Please do not attempt to transfer or walk with a patient unless you have received instruction from our therapists. This will ensure the safety of the patient as well as yourself.

How should I speak to a person after a brain injury?

Speak in your normal tone of voice. , speak slowly and calmly and allow the patient enough time to understand what you are saying and to respond. A lot of how you speak to the person depends on their specific injury. Always feel free to ask the therapist, nurse or any member of the team the best way to approach the patient.

What should I do when the patient is agitated?

Try to identify the cause and redirect the patient's attention. Don't ignore or leave the patient alone, speak in a soothing tone of voice. Ask any member of the team for help when necessary.

How should I treat the person after a brain injury?

Show the person you love and support them. Do not discuss the patient as if they were not there when speaking with others even if you think they cannot understand you. Don't scold them for an incorrect answer, but do praise them for accomplishments. Remember that the person may not have the same energy level or endurance as before. Rest periods are important.

What is a guardian and does the patient need one?

A person may need a temporary guardian when their injury has impacted their ability to make health or financial decisions. If the patient has already designated a health care proxy or power of attorney the guardianship will not be necessary. Anyone who is interested in the welfare of the patient may petition the probate court in their county for temporary guardianship. The doctor, the therapists, and the case manager can help with the decision if a temporary guardian is needed.

Where can I get more Community resources?

The Massachusetts Brain Injury Association and the New Hampshire Brain Injury Association are excellent resources once the patient is back in the community. The case manager can make an appointment for the patient and family with these local agencies prior to discharge.



Team Members

Doctors

Every patient is assigned a primary physician who guides the medical plan of care throughout their stay. The doctors, with the assistance of the rehabilitation team, assess the patients medical status and needs while at Northeast Rehab.

Rehabilitation Nurses

Every patient is assigned a primary nurse and a licensed nursing assistant. The Nursing Team checks patients vitals (temperature, blood pressure, heart and breathing rate), administers medications and helps with daily care such as eating and bathing. They are continuously evaluating the patient's physical, mental and medical response to interventions utilized.

Family and Friends

You provide the emotional support to the patient. Family and friends also provide the health care team with important facts about the patients past history and can help watch for changes. Team members will show you what you can do to help with the recovery process.

Case Managers

They provide emotional support to help the patient and the family adjust to being in the hospital. The case managers coordinate discharge planning, referral to community resources, and answer questions about insurance or disability. They relay information from weekly team meetings and facilitate communication between team members, the patient, and family as needed.

Physical Therapists (PT)

Physical therapists help the patient work toward maximizing their independence and quality of life by focusing on physical mobility training. Treatment may include range of motion/flexibility of the legs, strengthening or muscle re-education, balance, walking/gait training, stair climbing, transfer training, bed mobility training, education and if necessary instruction in the use of equipment such as walkers, canes, or wheelchairs.

Occupational Therapists (OT)

Occupational therapists help the patient work toward maximizing their independence and quality of life by focusing on Activities of Daily Living (ADL), that is, functional activities that the person performs every day. OT activities may include bathing, dressing, grooming, toileting, feeding, sexuality education, functional transfers, functional communication (writing, typing, using the phone etc.) and home management.

Therapeutic Recreation (TR)

Therapeutic recreation assists the patient with the resumption of a satisfactory, healthy lifestyle through the use of leisure activities. The focus of TR is leisure skill development/re-development, education on

adaptive recreation equipment and techniques, and community integration through structured out trips. They also offer peer visitation to assist with the adjustment issues associated with a newly acquired disability.

Speech and Language Pathologists (SLP)

Speech Language Pathologists (SLP) provide evaluation and treatment for patients experiencing communication, cognitive, or swallowing difficulties following a stroke or other neurological dysfunction. Speech Therapy activities may focus on understanding what is said, speaking clearly and meaningfully, assessment and treatment of swallowing difficulties and assessment and treatment of cognitive difficulties, such as memory or concentration

Dieticians

Dieticians assess nutritional needs of the patients. They work with the patient and other team members to help the patients meet their nutritional goals. The dieticians work closely with the patients to educate them about their dietary requirements, not only while in the hospital, but also for when they go home.

Psychologist

The psychologist specializes in evaluating and treating issues involving general coping or adjustment to disability. In addition to offering counseling for problems such as depressed or anxious mood, the psychologist can provide training in self-help techniques to help manage problems such as pain, insomnia, overeating, smoking and substance abuse. Training in relaxation techniques is especially helpful for many of these problems, and can often be learned in just one or two sessions. Lastly, the psychologist can also work closely with other team members to develop a plan to minimize any psychological "obstacles" to your overall progress.

Neuropsychologist

The role of the neuropsychologist is to provide a detailed evaluation of specific mental abilities such as memory, attention or learning. It is sometimes quite important to evaluate these areas, as difficulties could interfere with your ability to process all the information that comes your way in rehab. Neuropsychological difficulties are not uncommon among persons with neurological illness or injury. If deficits are found, there may be treatments available to help improve your functioning in these areas. Furthermore, if your team is aware of any neuropsychological difficulties, they can present new information to you in a way that best matches your areas of mental strength.

Some other team members may include

Respiratory therapy Audiologist Internist Psychiatrist Certified Prosthetist/ Orthotist Chaplain



Understanding How the Brain Works

The human brain is a complex organ. It weighs only three pounds but is estimated to have about 100 billion cells. It controls all of our physical movements and sensations as well as our ability to think, act, feel and communicate.

The brain is divided into several parts, each with very specific functions. Normally, the brain manages to perform routine actions regularly and quickly through constant communication between one part of the brain and the next. When the brain is injured, communication between the different areas of the brain can become disrupted. Certain types of problems are commonly seen with injury to specific parts of the brain. In fact, in some cases the areas of the brain that have been damaged can be identified by changes in the individual's behavior following injury. The best way to understand the deficits associated with brain injury is to understand the function of each area of the brain and its related systems and structures

The brain is an electrical and chemical machine

Let's start looking at the building blocks of the brain – the cells. Most of these cells are called

neurons. A neuron is basically an on/off switch just like the one you use to control the lights in your home. It is either in a resting state (off) or it is shooting an electrical impulse down a wire (on). It has a cell body, a long little wire (the "wire" is called an axon), and at the very end it has a little part that shoots out a chemical. This chemical goes across a gap (synapse) where it triggers another neuron to send a message. There are a lot of these neurons sending messages down a wire (axon). Doctors have learned that measuring this electrical activity can tell how the brain is working. A device that measures electrical activity in the brain is called an EEG



(electroencephalograph). Each of the billions of neurons "spit out" chemicals that trigger other neurons. Different neurons use different types of chemicals. These chemicals are called "transmitters" and are given names like epinephrine, norepinephrine, or dopamine

Getting information in and out of the brain

How does information come into the brain? A lot of information comes in through the spinal cord at the base of the brain. Think of a spinal cord as a thick phone cable with thousands of phone lines. If you cut that spinal cord, you won't be able to move or feel anything in your body. Information goes OUT from the brain to make body parts (arms and legs) do their job. There is also a great deal of INCOMING information (hot, cold, pain, joint sensation, etc.) coming through the spinal cord. Vision and hearing do not go through the spinal cord but go directly into the brain.

Brain anatomy & function

Here are some of the basic structures:



SKULL : The bones that come together to cover and protect the brain.

- **SPINAL CORD:** A delicate structure about ¹/₂" in diameter which starts at the base of the brain and runs down through a tunnel in the backbone. The spinal cord contains a lot of the circuitry that is responsible for posture, patterns of movement and sensation coming from the surface and inside of the body.
- **BRAIN STEM:** A small, but complex structure at the base of the brain, resting against the bottom of the skull. All incoming sensory information and all outgoing information to control movement comes through the brain stem. The center for control of sleep and wakefulness is located at the top center of the structure. Eye movement, swallowing, coordination of the muscles controlling speech, balance and many basic body functions are controlled by the brain stem. Certain postural controls and reflexes come from the brain stem as well.
- **<u>CEREBELLUM:</u>** This structure attaches to the back of the stem. It participates in the control of arm and leg movement, eye movement and balance. The cerebellum, located behind the brain stem, is responsible for muscle coordination and balance.



VENTRICLES: Watery spinal fluid is produced in cavities within the brain. Normally, this fluid flows out of the brain through tiny holes in the brain stem. It then fills the space separating the brain and spinal cord from their hard, bony containers. It is constantly being absorbed by little vessels on the inside of the top of the skull. If anything (for example, blood) blocks usual circulation or absorption of this fluid, then the ventricles tend to expand and may exert pressure on the brain (a condition called hydrocephalus).



CEREBRAL CORTEX:

The cerebral cortex (cerebrum) is what is most commonly thought of as "the brain". It is divided into left and right hemispheres. Generally, each hemisphere directs the opposite side of the body (i.e., the left hemisphere directs the right side of the body and vice versa). Cerebral Cortex (gray matter) consists of a thin sheet of nerve cells that covers the surface of brain. The bulk of the hemispheres consist of the nerve fibers (white matter) connecting these cells.

Left



Each hemisphere is then divided into four lobes that have specific functions:



Frontal Lobes: Are particularly vulnerable to trauma and necessary to higher level thinking, often called "executive" functions. These functions include the ability to focus attention, organize and plan, problem-solve, make good decisions, and show appropriate judgment. Executive functions also play a role in controlling behavior and emotions.

The frontal lobe is the biggest and most advanced part of the brain. (It's called the *frontal* lobe because it's in the front part of brain.) One job of the frontal lobe is **planning**. The frontal lobe is also involved in **organizing**. For a lot of activities, we need to do step A, then step B, then step C. We have to do things in order. That's what the frontal lobes help us do. When the frontal lobe is injured, there is a breakdown in the ability to sequence and organize. A common example is people who cook and leave out a step in the sequence. They forget to add an important ingredient or they don't turn the stove off.

Additionally, the frontal lobes also play a very important role in **controlling emotions**. Deep in the middle of the brain are sections that control emotions. They're very primitive emotions that deal with hunger, aggression, and sexual drive. These areas send messages to other parts of the brain to DO SOMETHING. If you're mad, hit something or someone. If you're hungry, grab something and eat it. The frontal lobes

"manage" emotions. In general, the frontal lobe has a NO or STOP function. If your emotions tell you to punch your boss, it's the frontal lobes that say "STOP or you are going to lose your job".

Occipital Lobes: Responsible for aspects of visual function. (color and form perception)

Temporal Lobes: Regulates memory function, language information (comprehension and expression), aspects of emotional processing, and behavior.

Limbic System (located inside the temporal lobe): The *limbic system* is an area of vital importance to mood and emotional regulation, motivation, attention, and memory. Injury to this system may result in behaviors ranging from

a). flat affect (no expression) to aggressiveness

b). mild distractibility to the inability to pay attention and,

c). slight memory problems to the inability to recall what happened 30 minutes ago.

Parietal Lobes: Important in sensation (touch, pressure, temperature, pain), perception, attention and complex aspects of brain processing. Body sensation, body and space images, visual perception, and reading.

Here is a summary chart of some of the functions each section of the brain controls.

Brain & Behavior Relationships



Understanding How the Brain Works

Movement

The area of the brain that controls movement is in a very narrow strip that goes from near the top of the head right down along where your ear is located. It's called the motor strip. If I have a stroke in the left hemisphere of my brain, the right side of the body will stop working. If I have an injury to my right hemisphere in this area, the left side of my body stops working (remember, we have two brains). This is why one half of the face may droop when a person has had a stroke.



Hearing and language

In the general population, 95 percent of people are right-handed, which means that the left hemisphere is the dominant hemisphere. (For you left-handers, the right hemisphere is dominant.) With right-handed people, the ability to understand and express language is in this left temporal lobe



The right temporal lobe also deals with hearing. However, its job is to process musical information or help in the identification of noises. If this area is damaged, we might not be able to appreciate music or be able to sing. Because we tend to think and express in terms of language, the left temporal lobe is more critical for day-to-day functioning.

What is brain injury and what happens to the brain when it is injured?

Traumatic brain injury (TBI) refers to damage to the brain caused by an external physical force such as a car accident, a gunshot wound to the head, or a fall. A TBI is not caused by something internal such as a stroke or tumor, and does not include damage to the brain due to prolonged lack of oxygen (anoxic brain injuries). It is possible to have a TBI and never lose consciousness. For example, someone with a penetrating gunshot wound to the head may not lose consciousness.

Types of injuries

The brain is about 3–4 pounds of extremely delicate soft tissue floating in fluid within the skull. Under the skull there are three layers of membrane that cover and protect the brain. The brain tissue is soft and therefore can be compressed (squeezed), pulled, and stretched. When there is sudden speeding up and

slowing down, such as in a car crash or fall, the brain can move around violently inside the skull, resulting in injury.

Closed versus open head injury

Closed means the skull and brain contents have not been penetrated (broken into or through), whereas open means the skull and other protective layers are penetrated and exposed to air. A classic example of an open head injury is a gunshot wound to the head. A classic closed head injury is one that occurs as the result of a motor vehicle crash.

In a *closed head injury*, damage occurs because of a blow to the person's head or having the head stop suddenly after moving at high speed. This causes the brain to move forward and back or from side to side, such that it collides with the bony skull around it. This jarring movement bruises brain tissue, damages axons (part of the nerve cell), and tears blood vessels. After a closed head injury, damage can occur in specific brain areas (localized injury) or throughout the brain (diffuse axonal injury).



Damage following *open head injury* tends to be localized and therefore damage tends to be limited to a specific area of the brain. However, such injuries can be as severe as closed head injuries, depending on the destructive path of the bullet or other invasive object within the brain.

Primary versus secondary injuries

Primary injuries occur at the time of injury and there is nothing that physicians can do to reverse those injuries. Instead, the goal of the treatment team in the hospital is to prevent any further, or secondary, injury to the brain. Below are some primary injuries:

- ✓ **Skull fracture** occurs when there is a breaking or denting of the skull. Pieces of bone pressing on the brain can cause injury, often referred to as a depressed skull fracture.
- ✓ **Localized injury** means that a particular area of the brain is injured. Injuries can involve bruising (contusions) or bleeding (hemorrhages) on the surface of or within any layer of the brain.
- ✓ Diffuse axonal Injury (DAI) involves damage throughout the brain and loss of consciousness. DAI is a "stretching" injury to the neurons (the cell bodies of the brain) and axons (fibers that allow for communication from one neuron to another neuron). Everything our brains do for us depends on neurons communicating. When the brain is injured, axons can be pulled, stretched, and torn. If there is too much injury to the axon, the neuron will not survive. In a DAI, this happens to neurons all over the brain. This type of damage is often difficult to detect with brain scans.

Secondary injuries occur after the initial injury, usually within a few days. Secondary injury may be caused by oxygen not reaching the brain, which can be the result of continued low blood pressure or increased intracranial pressure (pressure inside the skull) from brain tissue swelling. Below are some secondary injuries:

- *Increased intracranial pressure (hydrocephalus):* The brain is like any other body tissue when it gets injured: it fills with fluid and swells. Because of the hard skull around it, however, the brain has nowhere to expand as it swells. This swelling increases pressure inside the head (intracranial pressure), which can cause further injury to the brain. Decreasing and controlling intracranial pressure is a major focus of medical treatment early after a TBI. If intracranial pressure remains high, it can prevent blood passage to tissue, which results in further brain injury.
- *Intracranial bleeding*: Bleeding into the brain can cause collections to form called *hematomas*. Further injury can occur to the soft brain tissue from the pressure these collections put on the brain.
- *Neurochemical problems that disrupt functioning:* Our brains operate based on a delicate chemistry. Chemical substances in the brain called neuro-transmitters are necessary for communication between neurons, the specialized cells within our central nervous system. When the brain is functioning normally, chemical signals are sent from neuron to neuron, and groups of neurons work together to perform functions. TBI disturbs the delicate chemistry of the brain so that the neurons cannot function normally. This results in changes in thinking and behavior. It can take weeks and sometimes months for the brain to resolve the chemical imbalance that occurs with TBI. As the chemistry of the brain improves, so can the person's ability to function. This is one reason that someone may make rapid progress in the first few weeks after an injury.

How the injury is measured

"Severity of injury" refers to the degree or extent of brain tissue damage. The degree of damage is estimated by measuring the duration of loss of consciousness, the depth of coma and level of amnesia (memory loss), and through brain scans.

The *Glasgow Coma Scale* (GCS) is used to measure the depth of coma. The GCS rates three aspects of functioning: eye opening, movement and verbal response. Individuals in deep coma score very low on all these aspects of functioning, while those less severely injured or recovering from coma score higher. A GCS score of 3 indicates the deepest level of coma, describing a person who is totally unresponsive. A score of 9 or more indicates that the person is no longer in coma, but is not fully alert. The highest score (15) refers to a person who is fully conscious.

A person's first GCS score is often done at the roadside by the emergency response personnel. In many instances, moderately to severely injured people are intubated (a tube is placed down the throat and into the air passage into the lungs) at the scene of the injury to ensure the person gets enough oxygen. To do the intubation the person must be sedated (given medication that makes the person go to sleep). So, by the time the person arrives at the hospital he/she has already received sedating medications and has a breathing tube in place. Under these conditions it is impossible for a person to talk, so the doctors cannot assess the verbal part of the GCS. People in this situation often receive a "T" after the GCS score, indicating that they were intubated when the examination took place, so you might see a score of 5T, for instance. The GCS is done at intervals in the neurointensive care unit to document a person's recovery.

Post-traumatic amnesia (PTA) is another good estimate for severity of a brain injury. Anytime a person has a major blow to the head he or she will not remember the injury and related events for sometime afterward. People with these injuries might not recall having spoken to someone just a couple of hours ago and may repeat things they have already said. This is the period of post-traumatic amnesia. The longer the duration of amnesia, the more severe the brain injury.

CT or MRI Scan Results

The cranial tomography (CT) scan is a type of X-ray that shows problems in the brain such as bruises, blood clots, and swelling. CT scans are not painful. People with moderate to severe TBI will have several CT scans while in the hospital to keep track of lesions (damaged areas in the brain). In some cases, a magnetic resonance imaging (MRI) scan may also be performed. This also creates a picture of the brain based on magnetic properties of molecules in tissue. Most people with severe TBI will have an abnormality on a CT scan or MRI scan. These scans cannot detect all types of brain injuries, so it is possible to have a severe TBI and be in coma even though the scan results are normal.

Mild Traumatic Brain Injury (Glascow Coma Scale score 13 -1 5):

- ✓ Loss of consciousness is very brief, usually a few seconds or minutes
- ✓ Loss of consciousness does not have to occur—the person may be dazed or confused
- \checkmark Testing or scans of the brain may appear normal
- ✓ A mild traumatic brain injury is diagnosed only when there is a change in the mental status at the time of injury—the person is dazed, confused, or loses consciousness. The change in mental status indicates that the person's brain functioning has been altered, this is called a concussion.

Symptoms of Mild Traumatic Brain Injury:

- ✓ Headache
- ✓ Fatigue
- ✓ Sleep disturbance
- ✓ Irritability
- ✓ Sensitivity to noise or light
- ✓ Balance problems
- \checkmark Decreased concentration and attention span
- ✓ Decreased speed of thinking
- ✓ Memory problems
- ✓ Nausea
- ✓ Depression and anxiety
- ✓ Emotional mood swings

Moderate Traumatic Brain Injury (Glascow Coma Scale score 9 – 12):

- \checkmark A loss of consciousness lasts from a few minutes to a few hours
- ✓ Confusion lasts from days to weeks
- ✓ Physical, cognitive, and/or behavioral impairments last for months or are permanent.

Persons with moderate traumatic brain injury generally can make a good recovery with treatment or successfully learn to compensate for their deficits.

Severe Brain Injury (Glascow Coma Score 8 or less)

Severe brain injury occurs when a prolonged unconscious state or coma lasts days, weeks, or months. Severe brain injury is further categorized into subgroups with separate features:

- ✓ Coma
- ✓ Vegetative State
- ✓ Persistent Vegetative State
- ✓ Minimally Responsive State

Coma is defined as a state of unconsciousness from which the individual cannot be awakened, in which the individual responds minimally or not at all to stimuli, and initiates no voluntary activities.

- Persons in a coma appear to be asleep, but cannot be awakened
- There is no meaningful response to stimulation.

Persons who sustain a severe brain injury can make significant improvements, but are often left with permanent physical, cognitive, or behavioral impairments.

Vegetative State (VS) describes a severe brain injury in which:

- Arousal is present, but the ability to interact with the environment is not.
- Eye opening can be spontaneous or in response to stimulation
- General responses to pain exist, such as increased heart rate, increased respiration, posturing, or sweating
- o Sleep-wakes cycles, respiratory functions, and digestive functions return

There is no test to specifically diagnose Vegetative State; the diagnosis is made only by repetitive neurobehavioral assessments.

Persistent Vegetative State (PVS) is a term used for a Vegetative State that has lasted for more than a month.

Minimally Responsive State (MR) is the term used for a severe traumatic brain injury in which a person is no longer in a coma or a Vegetative State. Persons in a Minimally Responsive State demonstrate:

- Primitive reflexes
- o Inconsistent ability to follow simple commands
- An awareness of environmental stimulation

Rancho Los Amigos Scale

The Rancho Los Amigos Scale is an instrument used to track recovery from brain injury. It is most helpful in assessing the patient in the first weeks or months following the injury, because it does not require the cooperation of the patient. The Rancho Levels are based upon observations of the patient's responses to the world around him. They provide insight into the expected progression during recovery and rehabilitation.

An understanding of the characteristics of each of the ten Rancho Levels is helpful when families must cope with the behaviors demonstrated by their family member following head injury. Rancho Los Amigo Hospital has created a family guide that is helpful.

How the brain heals

Natural plasticity (ability of change) of the brain

The brain is a dynamic organ that has a natural ability to adapt and change with time. Even after it has been injured, the brain changes by setting up new connections between neurons that carry the messages within our brains. We now know the brain can create new neurons in some parts of the brain, although the extent and purpose of this is still uncertain.

Neural plasticity (the ability of the brain/neurons to change) occurs at every stage of development throughout the life cycle. Plasticity is more likely to occur when there is stimulation of the neural system, meaning that the brain must be active to adapt. Changes do not occur without exposure to a stimulating environment that prompts the brain to work. These changes do not occur quickly. That is one of the reasons recovery goes on for months and sometimes years following TBI.

Rehabilitation sets in motion the process of adaptation and change. Keep in mind that formal rehabilitation, such as received in a hospital from professional therapists, is a good initial step, but in most cases this must be followed by outpatient therapies and stimulating activities in the injured person's home.

Brain Injury Facts



Brain Injury Statistics

Traumatic Brain Injury (TBI)

TBI is defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force.

Typical Causes of TBI



Acquired Brain Injury (ABI)

An acquired brain injury is an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth.

Type of Acquired Brain	Estimated Annual
	mendence
Stroke	795,000
Tumor	64,530
Aneurysm	27,000
Viral Encephalitis	20,000
Multiple Sclerosis	10,400
Anoxic/Hypoxic	No National Data Available

Facts about Brain Injury

- 5.3 million Americans live with a long-term disability as a result of TBI.
- Motor vehicle crashes and traffic-related incidences are the cause of 31.8% of TBI deaths.
- Males are more likely than females to sustain a TBI at any age.
- 75% of traumatic brain injuries are classified as "mild."
- The annual cost of TBI to society exceeds \$76.5 billion.
- The estimated cost of stroke in the United States was \$53.9 billion in 2010.
- In 2005, nearly 1.1 million stroke survivors reported difficulty performing basic activities of daily life.

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Rancho Los Amigos Scale – Revised Levels of Cognitive Functioning

Level I - No Response: Total Assistance

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

Level II - Generalized Response: Total Assistance

- Demonstrates generalized reflex response to painful stimuli.
- Responds to repeated auditory stimuli with increased or decreased activity.
- Responds to external stimuli with physiological changes generalized, gross body movement and/or not purposeful vocalization.
- Responses noted above may be same regardless of type and location of stimulation.
- Responses may be significantly delayed.

Level III - Localized Response: Total Assistance

- Demonstrates withdrawal or vocalization to painful stimuli.
- Turns toward or away from auditory stimuli.
- Blinks when strong light crosses visual field.
- Follows moving object passed within visual field.
- Responds to discomfort by pulling tubes or restraints.
- Responds inconsistently to simple commands.
- Responses directly related to type of stimulus.
- May respond to some persons (especially family and friends) but not to others.

Level IV - Confused/Agitated: Maximal Assistance

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

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

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

Level VI - Confused, Appropriate: Moderate Assistance

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

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

- Consistently oriented to person and place, within highly familiar environments. Moderate assistance for orientation to time.
- Able to attend to highly familiar tasks in a non-distraction environment for at least 30 minutes with minimal assist to complete tasks.
- Minimal supervision for new learning.
- Demonstrates carry over of new learning.
- Initiates and carries out steps to complete familiar personal and household routine but has shallow recall of what he/she has been doing.
- Able to monitor accuracy and completeness of each step in routine personal and household ADLs and modify plan with minimal assistance.
- Superficial awareness of his/her condition but unaware of specific impairments and disabilities and the limits they place on his/her ability to safely, accurately and completely carry out his/her household, community, work and leisure ADLs.
- Minimal supervision for safety in routine home and community activities.
- Unrealistic planning for the future.
- Unable to think about consequences of a decision or action.
- Overestimates abilities.
- Unaware of others' needs and feelings.
- Oppositional/uncooperative.
- Unable to recognize inappropriate social interaction behavior.

Level VIII - Purposeful, Appropriate: Stand-By Assistance

- Consistently oriented to person, place and time.
- Independently attends to and completes familiar tasks for 1 hour in distracting environments.
- Able to recall and integrate past and recent events.
- Uses assistive memory devices to recall daily schedule, "to do" lists and record critical information for later use with stand-by assistance.
- Initiates and carries out steps to complete familiar personal, household, community, work and leisure routines with stand-by assistance and can modify the plan when needed with minimal assistance.
- Requires no assistance once new tasks/activities are learned.
- Aware of and acknowledges impairments and disabilities when they interfere with task completion but requires stand-by assistance to take appropriate corrective action.
- Thinks about consequences of a decision or action with minimal assistance.
- Overestimates or underestimates abilities.
- Acknowledges others' needs and feelings and responds appropriately with minimal assistance.
- Depressed.
- Irritable.
- Low frustration tolerance/easily angered.
- Argumentative.
- Self-centered.

- Uncharacteristically dependent/independent.
- Able to recognize and acknowledge inappropriate social interaction behavior while it is occurring and takes corrective action with minimal assistance.

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

- Independently shifts back and forth between tasks and completes them accurately for at least two consecutive hours.
- Uses assistive memory devices to recall daily schedule, "to do" lists and record critical information for later use with assistance when requested.
- Initiates and carries out steps to complete familiar personal, household, work and leisure tasks independently and unfamiliar personal, household, work and leisure tasks with assistance when requested.
- Aware of and acknowledges impairments and disabilities when they interfere with task completion and takes appropriate corrective action but requires stand-by assist to anticipate a problem before it occurs and take action to avoid it.
- Able to think about consequences of decisions or actions with assistance when requested.
- Accurately estimates abilities but requires stand-by assistance to adjust to task demands.
- Acknowledges others' needs and feelings and responds appropriately with stand-by assistance.
- Depression may continue.
- May be easily irritable.
- May have low frustration tolerance.
- Able to self monitor appropriateness of social interaction with stand-by assistance.

Level X - Purposeful, Appropriate: Modified Independent

- Able to handle multiple tasks simultaneously in all environments but may require periodic breaks.
- Able to independently procure, create and maintain own assistive memory devices.
- Independently initiates and carries out steps to complete familiar and unfamiliar personal, household, community, work and leisure tasks but may require more than usual amount of time and/or compensatory strategies to complete them.
- Anticipates impact of impairments and disabilities on ability to complete daily living tasks and takes action to avoid problems before they occur but may require more than usual amount of time and/or compensatory strategies.
- Able to independently think about consequences of decisions or actions but may require more than usual amount of time and/or compensatory strategies to select the appropriate decision or action.
- Accurately estimates abilities and independently adjusts to task demands.
- Able to recognize the needs and feelings of others and automatically respond in appropriate manner.
- Periodic periods of depression may occur.
- Irritability and low frustration tolerance when sick, fatigued and/or under emotional stress.
- Social interaction behavior is consistently appropriate.

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



Healing the Brain

The brain is such an amazing organ, the mysteries of which we are only beginning to unravel. Not so many years ago, the brain's capacity for recovery from serious injury was thought to be very limited. The truth is turning out to be different, much more hopeful and complicated. What happens to the brain very early after an injury is probably very important. The effectiveness with which pressure inside the head is relieved is very important. How carefully blood oxygen levels and brain blood flow are maintained during the days after injury are also key.

If certain critical areas of brain where specialized systems exist are damaged beyond repair, there can be permanent loss of function. Such damage is often very difficult to identify within the first weeks after injury, but often becomes more clear (and evident on imaging studies of brain like MRI) in the months after injury.

By the time a person gets to rehab after a severe brain injury they generally are well past issues with major elevation of pressure inside the head. They have normal blood flow and oxygen levels in the brain. But still there are often many, many nerve cells in the brain that are in a "shock" like state. These cells are not functioning but they are not dead. They are undergoing an "offline" repair process that can take up to a couple of months to complete. There is no clear way to speed up this process. Probably, good nutrition, stable metabolism and decent general health are helpful. But the main factor is the simple passage of time. These neurons *are* destined to return to a functional, connected state and as they do, their 'owner' experiences another step forward in their recovery.

As we interact with others and as we move about and manipulate objects in our environment, our brain physically changes in small ways to make a record (memory) of our experience. As we practice any action, our brain makes it easier for us to do whatever we are practicing in the future. Practice changes all brains – even ones that are injured. This continues for life. Recovery of function after brain injury can span years.



Medical Complications and Brain Injury

Many medical issues may arise during the hospitalization of someone with a brain injury. This briefly discusses some of the most commonly encountered complications. Please check with your health care team for additional information.

Fever and Infection

Infections are very common after a brain injury. Usually the first evidence that a person has an infection is a fever. The most common locations of infections are the lungs (pneumonia) and the bladder. That is why when a patient has a temperature, the physician will often order tests of the urine, known as a urinalysis and culture, as well as an x-ray of the chest. Once the location of the infection is discovered, antibiotics are started to treat the infection.

Conditions other than infections can cause fevers. These include **blood clots** and **heterotopic bone**, which are discussed later. Sometimes the fever can be a result of the brain injury itself and not the result of an infection. This happens when the part of the brain that controls the body's temperature is damaged.

Blood Clots (Deep Venous Thrombosis)

This condition refers to blood clots that form in the legs, **not the brain**, of people. These clots are very common in people with brain injuries; they occur in approximately 40 percent of patients. These clots can break off from the blood vessels of the leg and travel to the lungs where they can cause severe damage or even death. For this reason, your team will be monitoring closely for signs that they have developed. In addition, the person may be given medicine (such as an injection of a "blood thinner") to reduce the risk of their development.

Should the physician suspect that a blood clot has formed, he or she may order a test called **Dopplers** or **blood flows.** If a clot in the lung is suspected, a test called a spiral CT scan may be ordered. If a blood clot is discovered, most likely the person will be started on a strong blood thinner to treat it.

Seizures (Epilepsy)

The risk of seizures depends on the type of injury. In people with a closed head injury, about five percent will develop seizures. In those with a penetrating injury, the percentage can approach 50 percent. A seizure occurs when a part of the brain becomes active on its own. The symptoms of the seizure depend on which area of the brain is involved. For instance, if the area of the brain that controls movement of the arm is affected, the seizure would consist of twitching or shaking of that arm. Not all seizures involve movement.

Medical Complications and Brain Injury

Instead, they can cause an abnormal sensation in the body or changes in mental function. Usually, however, seizure in people with brain injuries can cause a loss of consciousness and shaking of the whole body.

If a person has not had a seizure, the physician may still decide to start an antiseizure (anticonvulsant or anti-epileptic) medicine to help prevent seizures. This decision is based on issues such as the risk of someone having a seizure and the side effects of the medication. When the risk of developing seizures is low, the physician may decide not to start a medicine, unless the patient actually has a seizure. Sometimes, results of a test known as an **EEG test** may be obtained to help make the decision.

If a patient has already had one or more seizures, especially that occurred 24 hours after the injury, the person will be treated with anti-epileptic medicines. Most likely, the person will remain on these medicines for six months to one year, at which time the need for them will be reassessed.

Hydrocephalus

This condition occurs when there is a buildup of fluid in the hollow spaces of the brain known as ventricles. This extra fluid can squeeze the rest of the brain and cause symptoms. The symptoms are not very specific, however. Often, the first signs may be a subtle change in a patient's level of arousal or a slowing of his or her recovery. Of course, many other factors can cause these changes. The physician may order a CT scan if hydrocephalus is suspected.

If the CT scan shows that the patient has hydrocephalus, then a decision will be made in consultation with the neurosurgeon about the type of hydrocephalus and if it would improve with the placement of a **shunt**. Hydrocephalus is thought to occur in about five percent of people with brain injuries. The percentage is higher in those people with severe brain injuries.

Heterotopic Ossification

This refers to formation of extra bone in the body. The extra bone most often forms in the large joints of the body such as the hip or the shoulder. It can cause pain, swelling, inflammation and tightening of the joint. No one knows for certain why people with brain injuries and other conditions are likely to develop heterotopic bone formation. However, approximately 10 to 20 percent of people with brain injuries develop it.

If the physician suspects it, he or she may order tests to help diagnose it. These tests include not only plain **x-rays**, but sometimes a test called a **bone scan**. If a person is diagnosed with heterotopic ossification, the treatment can include range of motion exercises by the therapists, medicines or even surgery.

Fractures and Nerve Injuries

Because most people with brain injuries have been involved in trauma, for instance an automobile collision, they are likely to have other injuries as well. Approximately 30 percent of people with brain injuries have fractures and the same number have injuries to the nerves of the arms and legs. Sometimes, these injuries are not discovered until the person is in rehabilitation. Several reasons exist for this. During the initial hospitalization, the focus is on life threatening conditions. Other more minor issues are not a priority. Also, many fractures and nerve injuries are extremely difficult to diagnose when someone is comatose or minimally conscious because the primary symptoms of these injuries are pain and difficulty moving. As a person becomes more alert, however, the team may order additional tests, such as x-rays or an EMG, (see "Common Tests and Procedures") to diagnose the problem.

High Blood Pressure (Hypertension)

Less than 10 percent of people will have high blood pressure after a brain injury. This is usually because of damage to the part of the brain that controls blood pressure but your physician may run tests to eliminate other possible causes. The patient will also be started on a medicine to help control the blood pressure (it is called an anti-hypertensive).

Spasticity

This is one of the most common problems faced by people with brain injuries. In this situation, certain muscles of the body are tight or hypertonic because they cannot fully relax. For instance, the elbow can be bent almost completely, so that the hand is almost to the shoulder. If one tried to straighten the elbow out, it would be extremely difficult because of the tightness. Spasticity prevents the person from using the body part and can be painful. Besides, even when the person would be unable to use the body part anyway, for instance, because it is paralyzed, the spasticity can interfere with the ability of another to provide care. For example, if the elbow is bent as described earlier, it may be impossible to dress the patient or even clean the crook of the elbow.

Therapies play a crucial role in the treatment of spasticity. In addition, the patient may be started on a medicine to help relax the muscles. Other treatment options are nerve block, botulinum toxin injections and surgery.

Rehabilitation Institute of Chicago-Brain Injury Team, Rehabilitation Institute of Chicago, LIFE CENTER



Seizures

What is a seizure?

A seizure is basically an electrical storm in the brain. An individual with a trauma-related one-sided weakness who has a seizure will often experience some abnormal, involuntary (usually rhythmic) movement on the weak side. They may lose the ability to speak if the seizure starts on the left side of the brain. They may be aware of the fact that something is very wrong, and they may be able to let others know that the movements of limbs on the weak side are involuntary. The episode may go on and end within minutes without any alteration in consciousness. Often there is a period of fatigue afterwards.

Sometimes a seizure is more like an episode of sleep walking (during the day) for which the person has no memory. As they come around, they wonder what's going on and how they got to where they find themselves.

Generalized Convulsions

Occasionally, a seizure will involve abrupt loss of consciousness, without warning, with a general stiffening of the body, often with forceful expiration of air (and a peculiar sound as this air passes through the throat). If the person having the seizure is standing when this happens, there can be a hard fall to ground or floor. This "tonic" phase of the seizure is generally very brief but is responsible for a number of things which often frighten witnesses. Because virtually all skeletal muscles in the body are forcefully contracting at the same time, there may be biting of the tongue, passage of urine, (rarely) defecation or vomiting, and sometimes a change in color to a purplish-blue (due to muscles of respiration being stuck in the tightened state). Then comes the convulsing with violent, rhythmic thrashing of arms and legs, always while the person is unconscious. There is often a build-up and then a decrease in the strength of the movements over the course of one or two minutes.

Thereafter, there is usually a period of deep sleep and deep muscular relaxation. This period is variable in duration but usually less than an hour. During this period, all the muscles that were convulsing are deeply relaxed. If a person in this state is in a position that makes it hard for them to breathe, they may NOT change their own position (see following section). The folklore about people with seizures "swallowing their tongue" actually relates to the airway obstruction which can occur in a person who is on their back with their head flexed forward during the very sleepy period after a major convulsion.

As the sleepiness lightens, a person recovering from a seizure may initially be confused or even hard to engage in conversation beyond a few words. The confusion more often than not passes over minutes, but the desire for a retreat to bed to sleep for a while sometimes lasts for hours. As people awaken from this state, they may appear confused. They may ask what happened. They may look a lot like they looked right after the stroke that everyone thought they made a great recovery from. This is a common and temporary thing. This worsening of neurological status is generally over within 24 to 48 hours after the seizure. Still, the first time it happens, it is completely appropriate to seek emergency attention.

If a generalized convulsion is prolonged (5 minutes or more) or if it is followed by a second seizure before complete recovery (person is awake and interactive), [generally, within minutes], it is time to seek

emergency medical assistance (visit the Emergency Room).

If seizures are a recurrent problem, they tend to be the same each time they happen. IF they do not look the same, this fact needs to be brought to the attention of a physician, preferably a neurologist. Any person experiencing recurrent seizures after a brain injury should have a neurologist in their life.

When seizures recur without any obvious precipitant or cause, then a person may be considered to have epilepsy.

"Focal Fits" - Simple Partial Seizures

Seizures which involve only part of the brain ("partial") without alteration of awareness ("simple") can occur in persons who have had injury to the brain. Most commonly, they involve rhythmic (2-3 twitches per second) twitching of face, hand/arm, and/or leg on the side of the body opposite to the side of brain from which the seizure emanates. Generally, this type of seizure lasts minutes. In some individuals, it forms the prelude to a generalized convulsion. Occasionally, it can go on for a very long time (hours-days). The longer it lasts, the greater the associated fatigue. Extremely prolonged versions of this seizure type can interfere with sleep, cause muscle pain and lead to exhaustion.

If I see someone having a convulsion, what can I do?



First, what NOT to do -

DO NOT TRY TO PUT ANYTHING IN THE PERSONS MOUTH;

This is simple. Never try to put anything in a seizing person's mouth to try to prevent them from biting their tongur. You cannot prevent that from happening. The only time it is appropriate to put something in the mouth of a person with seizure is after the seizure has ended.. During the period when a person is deeply unconscious/relaxed, an oral airway is appropriate and this is what most emergency personnel would use in this scenario.

DO NOT TRY TO RESTRAIN THE CONVULSING LIMBS;

Soften the surface, remove obstacles/furnishings, get the person to a safe spot, cushion head with your hands. DO NOT TRY TO RESTRAIN THE CONVULSIVE MOVEMENTS. LET THEM TAKE THEIR COURSE.

IF A PERSON KNOWN TO HAVE 'CONVULSIVE' EPILEPSY SHOWS A COLOR CHANGE TOWARD BLUE IN FACE, LIPS, NAIL-BEDS AT THE ONSET OF A SEIZURE- COUNT TO 60;

The cyanosis (bluing of lips, nails, skin) that may accompany what in essence is a brief "respiratory arrest" at the beginning of a convulsion is caused by contracted and 'stuck' respiratory muscles. It is not something that can be altered by any bystander/caregiver. It should pass relatively quickly, with improvement in color as the convulsion proceeds.

If the above state lasts beyond a minute, OR if it is followed by relaxation (instead of convulsive movements) with persistent bluish color, it would probably be wise to assume that this IS a respiratory arrest and NOT a seizure. [In which case the proper response would be Basic Life Support].

DO NOT ATTEMPT TO GIVE THE PERSON MEDICATION/FLUIDS UNTIL THEY CAN TALK TO YOU OR OTHERWISE INTERACT;

The person should be talking or demonstrating ability to swallow before any attempt is made to give anything by mouth.

Now, what TO do. (Sometimes the most important things are the simplest) -

Remove anything constricting around the neck – tie, scarf or necklace.

Especially if this is the first seizure you've ever witnessed, or if you don't know anything about the person's medical history, feel for the carotid pulse. Feeling this should provide the necessary reassurance that the individual is not experiencing a cardiac arrest. Hopefully, you can relax enough to remember the following tips -

Create the safest possible environment for the seizure. Position away from objects which threaten injury. Provide a soft surface, if possible. Cushion head with hands to prevent banging of head against the ground/floor.

As the seizure ends and a state of deep relaxation ensues, place the person in the "recovery position". Never



should the individual be left flat on their back - that position invites airway obstruction (by a relaxed/swollen tongue dropping to the back of the throat, blood from a bitten tongue, or vomitus). If, after positioning the person as illustrated there is any sign of ineffective breathing (loud snoring type sound, little/no air moving to/from mouth/nose), ensure that there is nothing in the mouth by sweeping your finger through, removing any debris as you do so [NOTE WELL- The seizure has stopped at this point and the person looks as if deeply asleep]. If there are dentures, this is the time to remove them. If after doing the foregoing there is still a loud snoring sound, try extending the neck a bit more. Other options to help open the airway include use of an oral airway or a performance of a "jaw thrust

maneuver".

Recovery should proceed over minutes, though significant fatigue is likely. If there has not been any injury (eg.- no significant cuts to skin or tongue or concern regarding injurious effects of a fall to ground/floor), the person should be allowed to fulfill their desire to rest.

Seek medical/hospital treatment if their is any concern about significant injury or if this is the individual's first seizure.

A couple of unusual situations-

There are a couple of unusual circumstances that are worth noting, especially because awareness can have a major impact upon outcome in particularly dangerous situations.

<u>Seizure in water (e.g. - swimming).</u> No one should swim alone. Persons known to have epilepsy of any type should not swim without their escort realizing that a seizure in water can be a particularly dangerous thing. During the forced expulsion of air at seizure onset, a seizing person would tend to sink quite rapidly. Then, with onset of the convulsive activity, water would tend to be drawn into the lungs. In non-convulsive seizure disorders, the impairment of awareness or movement control could pose some difficulty to a rescuer, but should not be dangerous as long as the head is kept above the water. Bottom-line? Consider the depth of water used during recreation as well as use of device which add some buoyancy.

Concern about <u>possible neck injury</u> in fall during a seizure. Fortunately, it seems to be remarkably rare for serious injuries to accompany seizures. Still, occasionally the fall at seizure onset is a hard fall to a hard surface. Whenever a person who has had a traumatic fall is unable to report to you how they feel (and particularly how their neck feels), you have to assume that they have a broken neck until an X ray/CT scan proves otherwise. This means applying traction to the head in such a way as to minimize flexion/extension movements, especially after the convulsion ends. There is still a need to move the person into the recovery position, the difference being that someone has to continuously hold the head in such a way as to keep the

spine straight. This can pose a bit of difficulty for one attendant if the person who had the seizure is having difficulty breathing. In this situation, one person should be holding the head straight while another person pulls the lower jaw forward to facilitate breathing.

Again, seizures which are prolonged (going on for more than 5 minutes) or which occur one after another... are a special circumstance. Such seizures can damage the brain.

Emergency medical attention should be sought immediately.

What observations about a seizure (or what I think was a seizure) might be important to my physician?

The observations of a witness are generally key to diagnosing the various forms of seizure and in distinguishing seizures from episodes that can be confused with them (such as faints, various forms of tremor, and a host of unusual causes of episodic behavioral phenomena). While patients can often provide key information (or all the information necessary when there is no interruption of consciousness), a witness/observer is the only one who can provide the information which leads to an accurate diagnosis. Specific observations have particular relevance depending upon the whether this is a person's first seizure, a recurrent seizure or an episode differing from past seizures.

In general, it might be good to write down your observations soon after the episode while memory is fresh, using the following as a guide. [Some questions would best be directed to the person who had the episode, others to a witness].

First Seizure

What was the person doing immediately before the episode?

Did the person seem to have a feeling that something was about to happen before the episode? Was it even more specific than a 'feeling'?

As the seizure began, what did you see first? Was there any color change in skin, lips or nail-beds? Were there movements of eyes to one side? If so, which side? Did one side of the face twitch before the other? Did one limb start jerking before another? [In general, if any movements or postures were seen more on one side than another, it can be helpful to know which side did what.]

In non-convulsive episodes, a description of exactly what the person did/said during and shortly after the episode would be helpful. Note the duration of the spell; between onset and resolution of any confusional period which follows.

- ✓ Was there passage of urine? of stool? Any vomiting?
- ✓ Was there any bleeding in the mouth?
- ✓ How long did the jerking part of the episode last?
- ✓ After the episode, what did the person do?

Recurrent Seizure

- ✓ Did this seizure look the same as prior ones?
- ✓ Was it longer or shorter than average?
- ✓ Have there been any recent medication changes or missed doses of medication?
- ✓ Has there been any recent change in sleep habit (eg.- up all night preceding the day of the seizure)?
- ✓ How much (if any) recent alcohol, caffeine, marijuana, or cocaine has been used? When was it last used in relation to the time the episode/seizure happened?
- ✓ Are there any new medications (prescription or non-prescription) being taken? Any herbal remedies?
- ✓ Have there been any unusually stressful events in life recently?
- ✓ Has there been any major change in weight since the last seizure? [Occasionally, a significant weight change may be associated with a change in blood anticonvulsant level in an individual who had long shown a stable blood level].

Recurrent Seizure, but Different from Previous Seizures

In addition to answers to questions, from the above section ("Recurrent Seizure") please consider the following:

- ✓ Exactly how was the episode different from previous ones?
- ✓ Was there a different 'warning' or "aura"?
- ✓ Did the spell involve a different part or side of the body?
- ✓ Did it start differently?
- ✓ Has there been any recent illness, new symptom of a possible illness?
- ✓ Any recent injury especially blow to the head?

"Should an extra dose of anticonvulsant be given as soon as possible after a seizure?"

In someone who is taking anticonvulsant/anti-epileptic medication, a "breakthrough" seizure may be a sign of a blood anticonvulsant level which has fallen too low. But occasionally (uncommonly) a seizure can be a manifestation of toxicity from too much anticonvulsant in the system. Thus, unless there have been prior directions from a physician covering this contingency, or it is known that a scheduled dose of medication was missed, it is probably most wise to seek direction from your physician/neurologist before giving any extra medication.

"I haven't had a seizure in years but I still take medication to prevent seizures. Am I supposed to take this for the rest of my life?"

It is easier for a physician to provide well-grounded advice regarding starting an anticonvulsant when a seizure disorder has developed or when a person is at unusually high risk for having seizures. Providing advice regarding when to discontinue medication in the absence of seizures is much more difficult. There

needs to be a reasoned weighing of ongoing risk of seizure recurrence against factors such as medication side-effect(s), cost of medications, potential drug interactions, willingness to defer driving during and for a while after the withdrawal of anticonvulsant. These are matters best discussed with your physician/neurologist.

"Is there anything other than medication that can be done to help prevent seizures?"

Seizure activity can be evoked from any brain given the right combination of circumstances. The concept of a "seizure threshold" is based upon the fact that with enough physiological or pharmacologic 'stress', seizures can happen in any mammal (including humans). Individuals differ in what constitutes "enough" of a stress. Some of the factors which influence seizure threshold include genetics (family history), brain trauma (especially "open" or penetrating wounds to brain), a number of medications and drugs (including things not often thought of as "drugs"), body temperature, sleep deprivation and a host of metabolic variables (for example: blood sugar, blood oxygen level, blood minerals, hormones).

There are a number of frequently-overlooked habits which can have a bearing upon seizure risk.

Caffeine (found in coffee, tea, over-the-counter 'stay-awake' pills and many carbonated beverages) lowers seizure threshold. This doesn't mean that all persons with or at risk for seizures should abstain completely from anything with caffeine in it. It just means that moderation is probably wise here, especially if prevention of recurrent seizure is proving difficult.

Alcohol makes it easier to have a seizure. It does so especially as its level falls in the bloodstream. Alcohol also tends to interact with just about every drug used to treat or prevent epilepsy. Because of its complex effects upon metabolism, body water and mineral balance, sugar metabolism and even sleep, alcohol use should probably be avoided in anyone who has had or is at special risk of seizure.

Sleep-deprivation (as in changing from day-shift to night-shift work, or staying up all night to work on a term paper, etc.) probably does much to lower seizure threshold.

Combinations of the above are, more likely than not, additive in there effects.

Additional Resources on Seizures and Epilepsy

Your friendly neighborhood physician/neurologist.

The Epilepsy Foundation of America (Telephone: 1-800-332-1000) - a trove of educational resources, including bibliographic lists, videotapes, brochures and pamphlets.



Frequently Asked Questions

When will he/she be the way they were before the accident?

This is the most common and the most difficult question family members ask. The ability to predict recovery obviously gets easier once a thorough evaluation has taken place and once trends of progress can be seen in therapy. As time goes on and response to various treatments is measured, it often becomes possible to predict recovery of specific functions (for example walking, communication, vision, aspects of thinking). The ultimate outcome as far as things like ability to resume work, school, normal day-to-day life, and self-sufficiency go is often very difficult if not impossible to predict.

Why does a person sometimes talk or act so strangely after a brain injury?

Technically, everything we do or say can be called "Behavior". All behavior represents brain activity. When the brain is injured, the consequences that we observe are changes in behavior. As therapists, we use behavior (what a person says or does) to determine what is going on in the brain (thoughts, visual thinking, sensation and emotion). Different parts of the brain control different aspects of behavior. Changes in ways of talking or acting can provide important clues to what part(s) of the brain have been injured (whether or not there are abnormalities on CAT SCAN or similar tests.)

What is coma? How does a person go into and come out of coma?

Coma is a state of unconsciousness. It is like a dreamlike sleep from which a person cannot be readily awakened. For wakefulness to occur, a very specific center deep in the brain must be functioning. The function of this center can be altered by trauma, drugs, oxygen supply, body chemistry and the electrical activity of other parts of the brain. Emergence from a coma that has been prolonged is a gradual process. There is a tremendous 'in between' range between the deepest coma and full, normal wakefulness. These 'in-between' states are not sharply defined and thus people use cloudy and confusing language to describe them ("light coma", "confused-agitated stage", "hypo-responsive", "under aroused", "partial coma"). During emergence from coma, we pay particular attention to a person's response to different stimuli, an assortment of subtle behaviors associated with sleep and wakefulness, and ultimately (in the "awake" person) to how easily and how long they can focus their mind on an activity.

What is "Behavior Modification"?

Behavior modification is a system of techniques for changing behavior. This system is based on rewarding desired behavior or punishment for undesired behavior. We sometimes borrow techniques from this field when addressing particular problem behaviors if and when they become a regular occurrence. We generally focus on using well-defined rewards for achievable, well-defined positive behavior. The only kind of "punishment" ever used consists of things like issuing a corrective statement or removal of a potential reward after an inappropriate behavior. An example of 'removal of reward' would be the staff placing a patient back in their room briefly after a patient
throws a verbal tantrum in the lounge (rather than rewarding the patient with extra attention and consolation.)

There is no set recipe for dealing with any particular behavior. When we use any behavior modification technique, we do so with primary regard for patient safety, welfare and recovery.

What is a "Seizure disorder"? Is it the same as "Epilepsy"?

A person with a seizure disorder has a tendency toward some kind of episodic electrical disturbance in the brain. Some seizure disorders appear in the form of "convulsion" or "fits" in which a person suddenly loses consciousness, falls to the ground and quakes violently. Others involve alteration of consciousness followed by a brief period of a person looking and acting as if they're on 'auto-pilot' or sleep-walking. Others may only consist of a brief period of 'spacing out' with interruption of memory for whatever happened during the moments just preceding and during the spell. These are all forms of "epilepsy". The one thing that they all have in common is that they represent something like an electrical storm in the brain. Certain types of brain injury create a significant increase in risk of developing a seizure disorder. People who either have had a seizure complicating their brain injury or who are found to be at increased risk of having a seizure may be placed on medication that is meant to prevent the occurrence of seizure/convulsion.

Who makes decisions about patient care and length of stay?

In modern TEAM approaches to rehabilitation, the entire treatment team participates in development and implementation of patient care plans and determination of 'length of stay'. Although leadership guidance is provided by the physician who ultimately shoulders responsibility for team decisions, these decisions almost always represent the consensus of the clinicians treating the patient.

Insurance carriers and government agencies vary widely in the rules they use to determine the nature and duration of coverage they provide. These agencies sometimes attempt to influence decisions regarding treatment and length of stay. When such is the case, the situation will be explained to appropriate family member(s) by the Case Manager.

What is "Cognitive Rehabilitation"?

"Cognition" is "thinking". Brain damage causes disturbance of thinking. Other mental functions (memory, language, perception) may be impaired or relatively well-preserved and there can still be major problems with a persons ability to take in information (ideas, concepts, words, images, numbers), organize the information, and use it to solve a problem or plan and carry out a desired activity based on thought (rather than emotional impulse). Cognitive rehabilitation consists of a set of techniques that therapists use to help the recovery of abilities to take in and process information and to then use the information to guide thought and action. These techniques are based upon research and theory on brain function and recovery of brain function.



Challenges, Changes and Choices

A Brain Injury Guide for Families and Caregivers

Excerpts from: Carolyn A. Rocchio; Family Member of a Person with a Brain Injury; Founder of the Brain Injury Association of Florida

Introduction

According to the Centers for Disease Control and Prevention (CDC), 1.4 million Americans sustain a brain injury each year. Brain injuries may result from falls, motor vehicle-traffic crashes, assaults, and other incidents in which the head is forcefully struck or an object penetrates the skull. For some, the life-threatening nature of the injuries requires immediate hospitalization for extended treatment and rehabilitation. Others seen in emergency departments after sustaining a blow to the head, with or without loss of consciousness, are discharged with little or no information about the life-changing impact the injury may have in the weeks or months to come. Although this booklet is designed to assist families and caregivers of persons with severe brain injury, those whose injuries are categorized as mild may also find some of the tips and information beneficial. Each brain injury is different to some extent, so none of this information will apply to all families: choose the information relevant to your loved one. This booklet is provided by the Brain Injury Association of America to prepare you for the journey toward recovery. In the following pages you will find information about the nature and consequences of brain injury; resource information to help with decision making; and practical suggestions about ways to help your family member, take care of yourself, and enlist the support of others.

The Immediate Aftermath

The early hours, days and weeks after injury can be very confusing. You are immersed in the world of the intensive care unit (ICU) with its unfamiliar lifesaving equipment and techniques as well as different medical professionals. A "good day" of progress may be followed by a "down" day. Setbacks are common and do not necessarily imply a permanent reversal.

Tips for Families and Caregivers

You may find it emotionally devastating when visitation restrictions do not allow your constant bedside vigil. But limiting visitation permits the staff to carry out many necessary procedures. As patients stabilize, they are normally transferred to a patient room within the general hospital population where visitation rules are more lenient.

Family members gathered in a waiting room or the patient's room can put their time to good use by deciding amongst themselves who is most accessible for daily updates from the medical and nursing staff. Start a notebook for this information, collect business cards from the physicians treating your family member, and record questions. This information can then be passed along to other family members and friends. During these first days, ask family and friends to help with chores you are unable to leave the hospital to do i.e., banking, laundry, preparing meals, mowing the lawn, driving the carpool, taking care of small children, taking care of pets

The person with the injury may need help for some time to come—and so may you—so look after yourself. Get enough sleep. Eat properly. Renew yourself in whatever way is meaningful to you. You will need your health and emotional well-being as your family member with the injury moves out of the critical phase and you become more involved in his or her rehabilitation. When you visit your family member, even during an unresponsive stage, talk about current events, friends, family, and details about when, where, and why he or she is hospitalized. Reassure him or her that everything is being done to help. Meanwhile, every member of the immediate and extended family will cope with the event in his or her own way. Some will choose to immerse themselves in the day-to-day struggle. Others may be unable to visit or be an integral part of the family from time to time. Everyone should respect the others' feelings. Given time, each person will develop coping mechanisms that work for him or her. Begin collecting information you will need to manage insurance, determine eligibility for various governmental benefits, and file any recommended litigation. Have available as many of the following items as possible:

- Social Security card (application for Social Security Administration programs should begin at once—check with the social services department of the hospital)
- Insurance card(s) (a copy of all policies in force, if possible)
- Driver's license
- Birth certificate
- School records
- Work records (when filing for Worker's Compensation)
- Tax return for at least the past year
- Information about assets owned by the person with a brain injury
- Information about family assets (important when applying for various governmental funds)
- Accident reports (if applicable)

Later Days in the Hospital

Once the individual is medically stable, the focus of treatment may shift to more rehabilitative efforts.Most medical problems will occur less frequently, but some may still appear (for example, catheters may cause occasional infections requiring antibiotics). The most specialized physicians will no longer be involved in the care of the patient as his/her condition improves. Some of the individual's mannerisms and characteristics will spontaneously begin to re-emerge and therapists will evaluate and work on those functions lost to the injury. Some individuals become agitated during this time. This can be very frightening for family members, but in fact agitation in this early period is a positive sign that the brain is beginning to recover. Similarly, do not be discouraged if physical recovery seems to be proceeding more rapidly than intellectual recovery. It's hard to be patient, but it may be some time yet before cognition can even be evaluated.

Setbacks will become less frequent as your family settles into a routine of visitation and hopefulness. Be prepared to speak with hospital social workers, insurance case managers, rehabilitation evaluators, and representatives from state agencies or trust funds about benefits and payment of claims, eligibility for state-provided programs, legal issues, and discharge options.

Tips for Families and Caregivers

Reach out to the Brain Injury Association of America (BIAA) and the BIA affiliate in your state for information and educational materials. Information will be the key to understanding the consequences of brain injury and the expected course of recovery. You can aid recovery during this stage by asking the physical therapist to demonstrate how to do range-of-motion exercises to augment the therapies provided.

Ask the speech pathologist if you should bring items from home such as family pictures, a battery-operated musical device, or recorded messages from friends. These familiar sounds and visual cues can help stimulate and orient someone emerging from a coma or at a low level of cognitive awareness.

The Rehabilitation Phase

Following acute hospitalization and early rehabilitation, some individuals with brain injuries will be discharged into specialized rehabilitation programs to continue the recovery process. Others who have recovered more significantly may be referred to transitional programs to fine-tune cognitive and vocational skills before returning to the community. Still others may return to the community without follow-up services. During this stage medical issues are no longer the primary concern. More emphasis is placed on cognition (the way a person interacts with his/her environment). The goals are to build skills and prepare for the future. Whether that means returning to school, work, the family home, a care facility, or another setting, the aim is to help the individual enjoy the highest possible quality of life.

Behavior problems may also be the result of late-onset, non-convulsive seizures. You should have the individual evaluated for such "silent seizures" if you notice any of the following behavioral changes:

- ✓ Restless pacing
- ✓ Random, purposeless activity
- ✓ Complaints of foul odors
- ✓ Greater sensitivity to light and sound
- ✓ Hallucinations

Continue to gather information and connect with others to keep current. Join brain injury support groups and other groups for individuals with disabilities.



Attention and Brain Injury

Attention disorders are one of the most common problems associated with brain injury, occurring in almost every case, even after mild brain injury.

What is attention?

Attention is a complex thinking skill that has many different parts. Attention includes the ability to focus on a task or a thought. Attention also lets you come back to a task or thought after doing or thinking about something else. Problems with attention will also affect your ability to remember things if you can't focus long enough to take in new information. Injury to the front of the brain or *frontal lobe* can cause problems with attention.

Attention can be divided into five levels:

- ✓ Focus
- ✓ Sustained
- ✓ Selective
- ✓ Alternating
- ✓ Divided

All five levels of attention can be adversely affected by brain injury.

Focused attention:

The kind of attention used when we are actively attending to something. It is our ability to focus on one thing and exclude everything else. For example when you are studying or driving. After a brain injury, attention may become rigid or inflexible.

Sustained attention:

This is the ability to concentrate on one task for a certain period of time without switching to a different task. After a brain injury, if you need to attend to one thing for some time, you might find you lose your concentration or become distracted quickly.

Selective attention:

This enables a person to avoid distractions, from both external (e.g. noise) and internal (e.g. thoughts) stimuli. For example, after brain injury you may not be able to read a letter when there is a radio playing in the background.

Alternating attention:

This level is the ability to shift the focus of attention and to alter it between tasks. Working on a word search, then pausing to listen for a particular freeway during a traffic report and then returning to the word search without increased error in either task is an example of alternating attention

Divided attention:

This is the ability to respond to multiple tasks at the same time, or to give two or more responses simultaneously. For example, you might be watching television while eating your breakfast. After a brain injury, some people find that they are unable to concentrate on more than one thing at a time.

How is attention affected by brain injury?

The person with the brain injury may not immediately realize that their ability to concentrate is any different to what it was prior to the injury. In addition, there may not be any visible signs to alert other people that a problem exists.

This can often lead to misunderstanding by members of the community who may think that a person who had difficulty maintaining attention is lacking in motivation or intelligence. People who have sustained a brain injury may:

- ✓ Become easily distracted.
- \checkmark Have trouble keeping track of what is being said or done.
- ✓ Experience information overload.
- \checkmark Have difficulty doing more than one task at a time.
- \checkmark Be slower at taking in and making sense of information.

All of these issues can have an impact on people's everyday lives and can:

- \checkmark Affect the ability to learn and remember information.
- \checkmark Cause a feeling of frustration with self and others.
- \checkmark Leave a person feeling overwhelmed and confused.
- ✓ Lead to fatigue, headaches and dizziness.
- ✓ Result in low levels of achievement.
- \checkmark Cause a person to avoid other people and become isolated.

What can make attention problems worse?

- ✓ Fatigue and lack of sleep.
- ✓ Stress or illness.
- ✓ Doing something you are not interested in.
- ✓ Medicine side effects.
- ✓ Depression.

When should I ask for help with attention problems?

- ✓ Your attention problem stops you from being able to complete normal daily activities, including tasks at home, work, or during leisure time.
- ✓ Your attention problem prevents you from caring for yourself or your family.
- \checkmark You have thoughts or feelings that affect your ability to pay attention.
- \checkmark Your attention problems seem to be getting worse.

Attention and concentration strategies

There are a number of strategies that people with brain injury can implement to help improve their attention and concentration. The person with the brain injury should try and identify specific situations where particular strategies may be affective.

Some of the following strategies may be helpful:

- ✓ Reduce all possible distractions in the environment e.g. switch off the television, radio, etc . . .
- ✓ Take regular breaks, have a nap or go for a walk, exercise regularly.
- ✓ Know your own limitations.
- ✓ Develop strategies for physical and mental relaxation e.g. meditation, deep breathing or talking to friends.
- \checkmark Plan how to approach a task with a simple and step-by-step approach.
- \checkmark Write information down using notes and keep them in specific places.
- \checkmark Concentrate on one thing at a time.
- \checkmark Repeat information and clarify it using Dictaphones can help with this.
- ✓ Break important tasks down into small and achievable steps.
- ✓ Schedule demanding tasks when levels of energy and alertness are greatest.
- \checkmark Explain the problems that you have to your family and friends.
- \checkmark Work for short periods only.
- ✓ Eat a healthy diet and sleep well.
- ✓ Wear your hearing aides.
- \checkmark Make sure you have the right prescription for glasses or contacts.
- ✓ Wear your glasses or contacts.
- \checkmark Ask your doctor about medicines that can help you pay attention.

Practice paying attention:

- \checkmark Face the person you are speaking with. Make eye contact.
- \checkmark When talking with another person, summarize or repeat the key ideas back to them.
- ✓ Remind your brain to "focus" as you are doing an activity.

- \checkmark Take notes.
- \checkmark Say the steps of a task out loud while you do the task.
- \checkmark Set aside distracting thoughts when you are trying to focus.
- \checkmark Practice doing the things that are hard for you, in small steps.

Where can I learn more about attention?

Ask a professional:

- ✓ Talk with your doctor or health care provider. Sometimes medicines may be prescribed for attention problems.
- ✓ Talk with your psychologist about ways to improve attention.
- ✓ Talk with a speech and language pathologist or occupational therapist. They can give you ideas on ways to improve your attentions.

How can families help?

- \checkmark Be sure to get the person's attention before you speak.
- \checkmark Face the person and maintain eye contact. This can help the person focus.
- ✓ Stay in one place while speaking. Moving around will distract the person
- \checkmark Help the person get back on the topic if he or she wanders off.
- \checkmark Give polite hints if conversation topics need to be changed.
- ✓ Talk in quiet space without distractions. Turn off the TV or radio and close the door.
- ✓ Try to determine if there is a particular time of day when the person has more energy. Schedule activities or events that require more attention during that time.
- ✓ Help the person pace him- or herself. Taking short breaks during a task or activity may allow someone to complete an activity that otherwise goes unfinished.
- ✓ Reduce the demands on attention by using organizational devices such as written checklists, datebooks, calendars, message boards or stick up note reminders as they are suggested.
- ✓ When speaking, present information in a clear fashion. Do not give too much information too rapidly.

Communication Skills and the Person with a Right Brain Injury

A person with right brain injury has damage to the right side of the brain. This damage may be from a stroke, traumatic brain injury or brain tumor. A person with a right brain injury has problems with thinking skills, but may not be aware of the problems that he or she is having. Common problems include:

- Problems expressing and understanding information:
 - Says a lot, but lacks a main idea or theme.
 - Brings up subjects out of the blue.
 - ► Has a hard time following long instructions.
 - ► Has a hard time understanding indirect requests and humor.
- Changes in interactions with others:
 - ► Loses eye contact.
 - Changes the topic without warning.
 - ► Interrupts.
 - Talks too much or does not talk much at all.
- Flat tone of voice or lack of facial expression.
- Not being aware of objects on the left side may make it hard to:
 - Read or write.
 - ► Look at a person seated to the left.
- Trouble paying attention.

More on next page →

Learn more about your health care.

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- Trouble keeping track of time.
- Trouble learning new information and remembering recent events.
- Forgetting steps in every day activities.
- Unable to see "the whole picture".
- Acting without thinking and with poor judgment.

Helpful tips to improve:

Conversation

- Get rid of distractions:
 - Turn off the TV.
 - Close the door.
 - Face the left side of the person, toward the distraction.
- "Signal" to get attention before talking.
- Use gestures or verbal cues to remind the person to look at you.
- Use spoken reminders to get back to the topic.
- Ask questions that need more than a yes or no answer for the person who does not talk much.
- Use gestures or spoken reminders to signal your turn to talk for the person who talks too much.

Visual Skills

- Help the person find boundaries or edges on the left:
 - ► In the environment
 - During conversation
 - ► When reading
 - When writing
- Use spoken reminders to help find landmarks.
- Encourage looking left to right.

• Use an index card, paper or finger under a line of print to help focus attention on one line at a time.

Orientation

- Use clocks and calendars.
- Keep a daily routine:
 - Plan a schedule.
 - Keep checklists.
- Point out familiar landmarks.
- Remind the person of time, place and situation as needed.

Thinking Skills

- Improve the use of memory:
 - Give extra time to learn new information.
 - Use mental images or associations.
 - Group information.
 - Describe ideas when the person is unable to think of a certain word.
 - Use written reminders.
 - Verbally remind the person.
 - Keep to the same daily routine.
- The person can cue him or herself:
 - Talk through the steps of an activity out loud.
 - Recheck work.
 - Pace oneself.
- Caregivers can give spoken reminders to:
 - Talk the person through the steps in the activity.
 - Remind the person to slow down.
 - Help the person remember.
- Stay calm and relaxed.



Compensation Strategies

The following sections outline common thinking, behavioral, emotional and communication changes that can occur after a brain injury, and ways to help the person with brain injury cope with such changes (compensation strategies). These strategies build on the person's strengths and work around (compensate for) deficits or problems that result from a brain injury.

Compensation strategies work best with a team approach that includes the person with brain injury, family members and other caregivers. Consistent and frequent repetition of these strategies by all caregivers increases the chance of success.

Each person is unique, so a technique that works well for one person may not work for another. Try one strategy for two or three weeks. If it does not work, try another suggested strategy or develop and try your own solution. If, after trying several solutions to a problem, nothing seems to work, ask a member of the health care team to help you develop a different approach.

Behavior Changes After Brain Injury

Brain injury can cause changes in behavior including:

- self control
- self awareness
- response to social situations

The information that follows will help familiarize you with behavior, memory and thinking problems that a person with brain injury may experience. Also included are techniques to help the person participate more effectively and comfortably in the family. Consistent and frequent repetition of these techniques listed will increase the chance of success. Do not hesitate to contact any member of the brain rehabilitation team if you have questions or need assistance and suggestions.

Issue	Symptoms	What You Can Do
Difficulty	\checkmark Acts or speaks without all the	\checkmark Limit the person's choice of
with self	information or without considering	options.
control	the consequences	✓ Suggest alternatives for behavior
	 Impulsiveness or poor judgment 	\checkmark Explain the reasons for tasks.
	\checkmark Lack of inhibition	\checkmark Be fair in your expectations.
	 ✓ Inappropriate comments to or about others 	 Respond immediately to inappropriate ideas but maintain
	 ✓ Gets stuck on one idea or activity (perseveration) 	the original focus of the discussion.
		 ✓ Encourage the person to slow down and think through tasks or responses.

Issue	Symptoms	What You Can Do
		 Provider supportive verbal and non-verbal feedback for reassurance.
		 ✓ If undesired behavior occurs, calmly and confidently discuss the consequences in private.
		 ✓ Praise and reward desired behavior.
Impaired self awareness	 Lack of awareness of deficits and limitations (this is not typically intentional, but rather a common phenomenon following traumatic brain injury) 	 Anticipate lack of insight. Prompt accurate self statements Use feedback generously and supportively.
	 Overestimates abilities; underestimates problems Inaccurate self-image/self- perception 	✓ Give realistic feedback as you observe behavior
Difficulty	\checkmark Acts or speaks without all the	What to do REFORE the event
participating in or begin part of social situations	 Acts of speaks without all the information or without considering the consequences Difficulty taking turns. Impulsiveness Socially inappropriate behavior or comments Not always sensitive to social boundaries Acting out of place in unfamiliar social or public settings 	 Provide clear expectations for desirable behavior in social settings or in special circumstances such as job interviews, attending a funeral or going to church Plan and rehearse social interactions so that they will be familiar, predictable and consistent Establish verbal and non-verbal cues to signal the person to "stop and think"
		What to do DURING the event
		 ✓ Treat the person appropriately, according to age
		 ✓ Encourage the person to slow down and think through responses.
		 Prompt the person to consider consequences of behavior.
		✓ Provide positive feedback for appropriate behavior.

Issue	Symptoms	W	What You Can Do		
		~	Encourage a break in activity when frustration or fatigue are evident.		
		~	Respond immediately to inappropriate ideas but maintain the original focus of the discussion		
		~	If undesired behavior occurs, calmly and confidently address the behavior in private. Be objective and explain that the behavior not the person is inappropriate		
		✓	Reassure and be fair in your expectations.		
		✓	What to do AFTER the event		
		~	Review the behavior, the effectiveness of verbal and nonverbal uses and the overall success of the outing		
		~	Praise appropriate behavior and responses to cues and redirection.		



Disorientation Following Brain Injury by John DeLuca, Ph.D.

What Is Disorientation?

Orientation is defined as the awareness of self relative to one's surroundings. Thus, impaired orientation (or *disorientation*) is the impaired awareness of self relative to the environment. For example, right now a family member with brain injury may not be sure where he or she is, or even who you are. The person may appear confused. Disorientation is the most common symptom following brain injury. Disorientation can last a few seconds following a mild blow to the head, or persist for months after severe brain trauma (for example, after recovering from coma).

When doctors, nurses, and therapists talk about persons who are "disoriented," they are usually referring to three areas of impaired awareness: Disorientation to (1) person, (2) place, and (3) time. *Disorientation to person* refers to persons not knowing who they are themselves. That is, they may not recall their own name or other personal knowledge, such as whether they are married, or their age. They may even "forget" or not recognize members of their own family or close friends. Disorientation to person is not common. If present, it usually gets better (or "clears") quickly.

Disorientation to place is more common than disorientation to person. People with a disorientation to place are not aware of where they are. In some cases, they may even ask, "Where am I?" Often they indicate that they believe they are somewhere other than the place they really are. For instance, while in the hospital, these patients may believe they are at home, or at work. Disorientation to place can persist even after the individual has regained orientation to person.

Disorientation to time is the most common form of disoriented awareness, and lasts longest. Such a disorientation can be observed even if the individual has regained orientation to person and place. Simply put, disorientation to time means that the person is unaware of facts related to time. That is, the person may not know what year it is, or the month, or the day of the week. Less often, the disorientation is related to disorientation to place. For instance, a person may believe the year is 1942, and that he or she is on a ship during World War II.

When the doctor or therapists discuss orientation, you may hear them say (for instance) that your loved one is "disoriented times two" or "times one." This simply reflects how many of the three areas of orientation are impaired. That is, "disoriented times one" means disoriented to time only. "Disoriented times two" refers to both time and place. "Disoriented times three" means that all three areas of orientation are impaired. The more areas that are impaired, the greater is the degree of the person's disorientation.

Recovery from a state of disorientation usually occurs gradually. First the individual regains orientation to person, followed by the return of orientation to place, and finally time. Return of full orientation to time may also be gradual. That is, a sense of broader forms of time (such as what year it is) will return before the everyday concept of time (day of the week, time of day).

Is Thinking Impaired during Disorientation?

During periods of disorientation, the individual usually has difficulty with areas of thinking besides those affecting orientation to person, place, and time. This is particularly true of persons who have been disoriented for weeks or months. Commonly, the individual's memory is impaired as well (for example, the person does not recall that you came to visit the night before). Attention and concentration abilities are usually impaired, too. (For example, it may be obvious that your family member is very restless, or is not listening to your entire conversation.) Other problems with thinking, such as a decreased ability to do even simple arithmetic, or the habit of saying the same thing over and over again, may also be observed in a disoriented person. The person who is disoriented may seem either depressed, restless, or agitated.

Remember that the degree of impairment shown in your family member's thinking and emotions during this period of disorientation may not mean that these will be long-lasting problems. For instance, emotional agitation usually decreases as orientation improves. Thinking or *cognitive* difficulties, which may persist, are evaluated more accurately after full orientation is regained.

Other Aspects of Disorientation

Besides being disoriented to person, place, and time, some people with brain injuries experience other aspects of impaired awareness to themselves or the environment. These awareness problems are usually what contribute most to the confusion you may observe in your relative who is disoriented. An example of this kind of impaired orientation is the decreased ability to know left from right. This is usually referred to as *left/right confusion*. Some patients have difficulty finding their way around the hospital. For example, you may notice that your family member cannot find the way back to the hospital room from the hall. This type of difficulty is called *topographical disorientation*, or *spatial disorientation*.

What Should the Family Do?

Perhaps the most important advice for you, the family member or friend, is not to take things personally during the disorientation stage of recovery. Your loved one is in the initial stages of recovery from brain injury. The brain is starting to try to make sense of the environment—and it will often be wrong. This is simply the natural recovery pattern. So, when your loved one does not recall your name, or "forgets" that a baby was just born in the family, or is agitated, seems depressed, or can't concentrate on seemingly important things, do not take it personally.

Second, try to understand what your loved one is going through. This disorientation phase is the brain's attempt to make sense of the world after a traumatic event. Improvement in orientation is a sign that the brain is getting better.

Remaining calm will help both you and your family member. If the person with brain injury is having difficulty making sense of the environment, don't add another piece to the puzzle. Express your love and caring feelings, but try not to express feelings of frustration, anger, or depression that you may also have. You may wonder whether you should try to correct your family member's orientation, or just leave things alone. You may wonder how many times you should repeat yourself when trying to give your family member certain information. It is fine to remind your loved one who you are, or where you are, or what day of the week it is. However, do not become a therapist. The best thing you can do for your loved one is just to be the family member or friend you always have been. Try to engage in positive conversation. If it ends abruptly, that is fine. Try not to exclude your loved one by carrying on conversations with other visitors in the room. This can be done elsewhere. Besides, too much noise and confusion will not help your loved one. If you have specific questions about what you should or should not say or do, feel free to ask the doctor or therapists. They often have a treatment plan, and you should have access to it.

Conclusions

Recognize that your loved one is taking one of the first steps on the road to recovery. Watching your loved one during this stage can be disturbing. But know that this is a necessary step in recovery from a brain injury. By understanding what is going on during this phase, you and your loved one will find it easier to tackle the recovery and rehabilitation challenges that lie ahead.



Driving After a Brain Injury

People who have sustained a brain injury sometimes find that their driving skills are no longer the same. Family, friends, and caregivers may also be worried about whether a person with a brain injury can drive safely. This section reviews the skills required to drive well, the research into driving after brain injury, and the basics on driving evaluations, legal issues, transportation alternatives and more.

How Can Brain Injury Affect Driving Ability?

Because we take our driving skills for granted, it is easy to forget that driving is the most dangerous thing we do in our everyday lives. We might even think of it as the ultimate multi-talking experience. Brain injury can affect the many physical, cognitive, and behavioral skills needed to drive well, depending on the individual and the extent of the injury. Areas of driving that may be affected include:

- ✓ Ability to maintain a constant position in a lane.
- ✓ Having accurate vision
- ✓ Maintaining concentration over long periods of time.
- ✓ Memory functioning, such as recalling directions.
- ✓ Figuring out solutions to problems.
- ✓ Hand-eye coordination.
- ✓ Reaction time.
- ✓ Safety awareness and judgment.
- ✓ Studies also indicate that even mild thinking difficulties, which may not be recognized by the injured person, may add to increased risks while driving.

Warning signs of unsafe driving

- ✓ Driving too fast/slow.
- ✓ Not observing signs or signals.
- ✓ Judging distance inaccurately when stopping or turning.
- \checkmark Slow to make decisions.
- ✓ Becoming easily frustrated or confused.
- ✓ Having accidents or near misses.
- ✓ Drifting across lane markings into other lanes.
- ✓ Getting lost easily, even in familiar areas.

How often do individuals with TBI return to driving?

Between 40 to 60 percent of people with moderate to severe brain injuries return to driving after their injury. To lessen the risk of crashes people with TBI may place limitations on their driving habits. They may drive less frequently than they did before the injury or drive only at certain times (such as daylight), on familiar routes, or when there is less traffic. Having experienced a seizure after the TBI may be a barrier to driving. States often require that a person be free of seizures for a period of time, such as 6 months before resuming driving.

Driving evaluations and training

A driving evaluation is a crucial step in determining a person's ability to drive following recovery from a brain injury. Research studies indicate that most TBI survivors are not thoroughly evaluated for driving skills before they begin driving after the injury, and this may put TBI survivors at risk for a crash. Often, it is up to the individual, family members or other caregivers to ask for a driving evaluation referral. Should the medical professionals attending to the person with the brain injury do not suggest an evaluation, it should not be assumed that the person is safe to drive independently.

While there is no standardized assessment test or process, a typical driving evaluation has two parts:

- ✓ Pre-Screen Evaluation: An assessment of vision, visual perceptual and visual spatial skills, cognitive abilities including reasoning, judgment, problem solving, mental flexibility and divided attention, neuromuscular status, and reaction time.
- ✓ On-the-Road Evaluation: A test of the mechanical operation of a vehicle driving on the roadway in the presence of an evaluator. This evaluation is used to assess safe driving skills in various traffic environments, as well as basic driving skills while a client uses the appropriate adaptive driving equipment.

Current research indicates that many individuals with TBI can become competent, safe drivers with the proper training. Training can be designed to improve specific driving skills, and often takes place with an evaluator.

Vehicle Modifications

If an individual with TBI has physical disabilities but has well-preserved cognitive functions, the individual may be able to resume driving with adaptive equipment and/or other modifications.

Recommendations for adaptive equipment and modifications could include:

- \checkmark Hand controls for gas and brake systems.
- ✓ Spinner knobs for steering.
- ✓ Left foot accelerator
- \checkmark Cross over signal bars.
- \checkmark Lifts for entering and exiting the vehicle.

Legal and insurance considerations

A person who wishes to resume driving must have a valid driver's license. Each state establishes its own rules and regulations on driving after a medical event such as a brain injury. Some states require physicians

Driving After A Brain Injury

to report to the authorized state licensing agency if they have a patient for whom driving may no longer be safe. Other states require licensed drivers to report any change in medical status before they resume driving.

Individuals and families should also be familiar with their insurance policies. Some policies may limit liability if certain requirements are not met following a vehicular crash involving injury.

Other transportation options

In the event that an individual is no longer able to operate a vehicle safely, it is important to locate other transportation options. This can be accomplished by reaching out to family, friends and colleagues. Buses, trains, and subway systems may also be an option. Some communities provide public transportation specifically for disabled riders. States have agencies that are responsible for making sure that people with disabilities have transportation options. If you are unable to locate community transportation options through your local transit company, contact the Brain Injury Association affiliate or Center for Independent Living in your state for further assistance.

Conclusion

The course of recovery after brain injury can be very unpredictable. It is often difficult to plan for the future and remain realistic about just how much independence a person can regain. You can determine whether you are safe to resume driving by:

- ✓ Discuss your ability to drive with your doctor and/or health professionals, family members.
- ✓ Get a professional evaluation to determine your driving ability.
- ✓ Based on your evaluation you may be allowed to drive, need training or vehicle modification before returning to driving, or will need to use other transportation options.



Dysphagia by Brad Hutchins, M.A., and Cynthia Hildner, M.S.

What Is Dysphagia?

Swallowing is a complex function that involves skilled coordination of many muscles in the mouth, neck, and esophagus (the tube leading from the throat to the stomach). Sometimes disease, stroke, or injury (such as a traumatic brain injury) disrupts a person's ability to control food or liquids in the mouth, or to swallow. This swallowing disorder is called *dysphagia* (dis-fayja). Dysphagia can lead to poor food or liquid intake, choking, or the deposit of food bits into the lungs *(aspiration)*, which can cause pneumonia. Dysphagia can also contribute to malnutrition and dehydration.

Dysphagia in individuals with brain injury is fairly common. One study found that one of every four individuals with brain injury had some degree of dysphagia.

What Are the Symptoms of Dysphagia?

Symptoms of dysphagia include:

- coughing during or shortly after eating
- a wet, gurgly voice during or after eating or drinking
- complaints of food sticking in the throat
- food drooling out of one side of the mouth
- food remaining in the mouth after a meal (usually in the space between the cheek and side teeth)
- difficulty swallowing water and/or taking medications by mouth
- general lack of awareness of food in the mouth
- refusal to eat foods of certain textures and types that were previously enjoyed
- recurrent lung/bronchial infections

What Tests Are Used to Detect a Swallowing Disorder?

If symptoms of dysphagia are present, the physician will often refer the person to a speech-language pathologist (SLP) for evaluation.

Clinical swallow evaluation. The speech-language pathologist will first examine the muscles used for swallowing. Then the SLP will observe the person eating foods and liquids of various consistencies. It is important to consider this variety because some foods may be more difficult for the individual to swallow than others.

Videofluoroscopic swallow evaluation. Without specialized tests, it is impossible to accurately detect whether food or liquid is passing normally through the throat to the stomach, or abnormally entering the

breathing passages or lungs. A common test used to evaluate dysphagia is an x-ray procedure called *videofluoroscopy*. This kind of x-ray image is shown on a television monitor and recorded on videotape. The purpose of this test is to determine precisely which foods are safe to swallow and which foods are to be avoided because they are aspirated (taken into the lungs) or could lead to aspiration or choking. This test is also used to learn if certain therapy techniques can help the person swallow difficult foods safely.

The clinical evaluation and the videofluoroscopic evaluation will lead to a diagnosis of the type and severity of the dysphagia.

Types of Dysphagia

There are four major classifications or types of dysphagia: oral preparatory dysphagia, oral phase dysphagia, pharyngeal phase dysphagia, and esophageal phase dysphagia.

- Oral preparatory dysphagia describes difficulty with eating and with chewing food into small pieces and mixing it with saliva before swallowing.
- Oral phase dysphagia describes difficulty with controlling food and moving it to the back of the mouth for swallowing.
- *Pharyngeal phase dysphagia* describes difficulty with the actual swallow, where food may remain in the throat after a swallow, *or* food may enter the airway to the lungs during the swallow process (aspiration).
- *Esophageal phase dysphagia* refers to swallowing problems that arise when the food does not easily pass through the esophagus (passage from the throat area to the stomach).

What Treatments Are Available?

Based on the test results, the speech-language pathologist, physician, and other team members will develop a specific treatment plan. Food and liquids that are difficult to swallow or that may be aspirated may be restricted. At the same time, changes are recommended for the way that the food is eaten. The person with dysphagia may learn to take smaller bites, or to slow down when eating. The person may learn to change body positioning during swallowing by turning the head to one side or tucking the chin, for example. An exercise plan also may be developed to strengthen weak muscles. In addition to the swallowing treatment plan, the physician and dietician will develop a plan to assure intake of the recommended allowance of nutrients and liquids. It is important that the patient follow all such dietary and swallowing guidelines carefully.

At times, when dysphagia is so severe that the individual is not able to take adequate nutrition by mouth safely, an alternate feeding method may be necessary. There are three common alternate feeding methods:

- 1. a tube passed through the nose and throat to the stomach (*NG tube*)
- 2. a tube surgically inserted into the stomach or small intestine through the abdominal wall (gastrostomy)
- 3. an *intravenous (IV) drip* with nutrients passed directly into a vein

It is usually possible to provide dysphagia therapy even when alternate feedings are used for nutrition.

Other Considerations

Individuals with brain injuries often have impairments in physical abilities, behavior, judgment, and reasoning. These impairments may increase the severity of the swallowing disorder. For example, the individual may use poor judgment when eating: He or she may select foods that are not safe to swallow, or eat too rapidly. The individual may be very lethargic or in a semi-comatose state, with decreased awareness that food is in the mouth. Either case could cause choking or aspiration.

Can People Recover from Dysphagia?

Yes, people can recover from dysphagia, but no two people recover in the same way or at the same rate. Often a great deal of progress is made during the first several months after the brain injury. Recovery can take from six months to two years. The dysphagia team will look for many indicators that point to a good recovery from dysphagia. These indicators may include:

- good comprehension and understanding of the swallowing disorder by the individual
- ability to self-monitor and self-correct during swallowing therapy and eating
- ability to cough when food enters the airway passage to the lungs
- active family involvement in the therapy plan and follow-through of the dysphagia program

How Can Families Help?

Helping a loved one eat is a common way to show care; however, following a brain injury it is very important to follow the advice of the dysphagia team regarding what to offer, and when and how to feed. Dysphagia can be life-threatening. When food is swallowed improperly, it could block or enter the airway. For that reason, it is important that careful monitoring and follow-through of the dysphagia treatment program occur at all times. Even with close monitoring, however, a life-threatening situation may arise.

Some things you can do to help are:

- While your loved one is in a medical setting, know the facility's emergency procedure for calling for help.
- Learn about, and be able to perform, the Heimlich maneuver.
- Learn how to administer cardiopulmonary resuscitation (CPR) from your local Red Cross chapter, hospital, or adult continuing education program.
- Think now of what needs to be done in an emergency situation, and find out what types of emergency services are available in your area.

Dysphagia Terminology

aspiration. Entrance of food, liquid, saliva, or other material into the passageway to the lungs.

dysphagia. A swallowing disorder; a disruption in the normal transfer of food from the mouth through the throat and into the stomach.

esophagus. The passageway through which food goes from the throat to the stomach.

gastrostomy. An alternate method of feeding. Food and liquids are introduced through the abdominal wall and into the stomach through a surgical opening (sometimes referred to as a *g-tube*).

nasogastric tube. A temporary feeding tube inserted through the nose and passed down the throat into the stomach; sometimes referred to as an *NG tube*.

NPO. A medical abbreviation that means that the individual may have nothing by mouth, including medication, food, or liquids.

oral-preparatory stage. The beginning stage of the swallow process in which the food is chewed, mixed with saliva, and formed into a cohesive mass.

oral stage. The stage of swallowing in which the mass of food is moved to the back of the mouth in preparation for the swallow.

pharyngeal stage. The stage of swallowing that begins at the back of the mouth and ends when the food enters the esophagus.

pharynx. The throat.

videofluoroscopy. A special type of x-ray that produces moving x-ray pictures that are shown on a television screen. This x-ray can be recorded on videotape for later viewing and an in-depth examination of swallowing.

Dysphagia

Dysphagia (a swallowing disorder) refers to a set of circumstances that affect how well you swallow. It is a problem in the normal transfer of food or liquid from the mouth to the stomach. Dysphagia can be caused by problems with movement, feeling, thinking or physical difficulties.



What Is Normal Swallowing?

Every person swallows in a slightly different way. Many events must happen for normal swallowing to occur. There are 4 main stages in the swallowing process:

Stage I Oral Preparation:

Stage II Oral Transit:

The food is chewed, mixed with saliva, and formed into a food ball (bolus).

The food is moved to the back of the mouth by a squeezing action mostly by the tongue.





Stage III Pharyngeal Phase:

- The food enters the upper throat area, above the voice box, and the soft palate or back roof of your mouth pulls up.
- Small flap closes at the top of the voice box (epiglottis) closes off the opening to the trachea (windpipe).
- The tongue moves backwards and the throat walls move forward.
- These actions help force the food or liquid down toward the esophagus.

What Is A Swallowing Disorder?

Persons may have problems during any of the 4 stages of swallowing. Swallowing problems may lead to poor nutrition and increased time needed to eat a meal. Abnormal movement of food or liquid into the trachea (aspiration) or the inability to eat food or liquid safely may also result from swallowing problems.

Stage IV Esophageal Phase:

The food ball or liquid enters the esophagus and is moved to the stomach by a squeezing action.

- The most common causes of swallowing problems include:
 - Head and neck cancer
 Brain disorders
 - Multiple medical problems
 Head trauma
 - ▶ Tracheostomy or being on a ventilator ▶ Stroke
- Swallowing disorders may be identified if you have:
 - Mouth or face weakness
 Poor he
 - Weak cough or weak voice
 - Gurgly voice during or after eating
 - Coughing or choking when eating
 - Avoiding some or all food or liquids

What Happens If I Have A Swallowing Disorder?

- If your doctor suspects that you may have a swallowing disorder, you will be seen by a Speech-Language Pathologist (SLP). A SLP is a professional who specializes in diagnosing and treating swallowing disorders and communication problems. The Speech-Language Pathologist will complete a Bedside Swallowing Evaluation (BSE). You will be asked questions about your medical history and ability to swallow. The SLP will examine your mouth and may ask you to eat different foods or liquids to find out what type of swallowing problem(s) you may have.
- If a swallowing disorder is identified, the SLP may try certain treatment techniques or may refer you for a special swallowing test. The SLP will discuss the test results with your doctor. Recommendations will be made about your ability to swallow safely, the types of foods you can safely swallow and what special actions you can take to swallow safely. Additional testing is sometimes necessary.
- The SLP will review the test results and recommendations with you. You will be given an individual swallowing plan and any special materials you may need for your swallowing problems.

If you would like more written information, please call the Library for Health Information at (614)293-3707. You can also make the request by e-mail: health-info@osu.edu.

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- Poor head control
- Drooling
- Recent weight loss
- Slow eating

Upon request all patient education handouts are available in other formats for people with special hearing, vision and language needs, call (614) 293-3191.



Dysarthria

by Marilyn Certner Smith, M.A., CCC-SLP

What Is Dysarthria?

Speech can sound different when the muscles that control speech are affected by a traumatic brain injury. *Dysarthria* is the clinical term for this speech impairment. Some of the more common symptoms of dysarthria include:

- slurred-sounding pronunciation
- volume that is too soft or too loud
- a change in voice quality, which may sound
 - hoarse harsh
 - nasal (coming through the nose) strained
 - breathy
- impaired speech rhythm—flat, choppy, or rushed
- changed speech rate—too fast or too slow

All individuals with dysarthria have some of these symptoms.

Speech recovery depends upon several factors. As a person recovers from dysarthria, improvements occur in both the naturalness and intelligibility of speech. A person's potential for improving the quality of his or her speech production depends upon:

- the severity of the speech symptoms
- the ability to strengthen and control the muscles for speech
- the ability to learn different ways to produce speech (compensate for problems)
- the ability to know how and when to use these compensatory strategies

Speech recovery is greatest in the early months after the injury. Improvements that occur after that are more gradual.

The natural impulse when speaking is to think about *what* you will say, not *how* you will say it. Someone who has developed dysarthria after traumatic brain injury, however, must learn to do both. This is not as simple as it sounds. Cognitive (thinking) impairments make it harder to think quickly. In addition, compensation for dysarthric speech requires the ability to use divided attention. *Divided attention* means that you juggle your attention between two or more different activities. In the case of dysarthria, the task is to think about what you will say and at the same time evaluate and change how it sounds. It is a difficult skill to master. Nevertheless, many people with dysarthria do, and they improve.

What Is Treatment for Dysarthria Like?

The speech-language pathologist (SLP) specializes in treating people who have dysarthric speech. Each treatment plan is tailored to meet a person's individual speech and cognitive needs. However, most treatment programs include:

- exercises for those muscles that need to become stronger or more coordinated
- practice in voice changes that will improve speech quality
- efforts to increase the person's self-awareness of the most desirable speech production techniques
- efforts to increase consistent use of the most desired speech production techniques

In speech therapy, some treatment approaches may include:

- practice performing lip, tongue, or breathing muscle exercises in front of a mirror
- practice repeating words, sentences, and conversation with the SLP
- similar speech practice using biofeedback machines, which are computers with visual displays; this equipment lets one compare desired to actual speech production
- conversational practice in a group, where the treatment focus is on monitoring (obtaining and maintaining best speech production)
- use of a palatal lift (a device that attaches to the teeth and raises part of the roof of the mouth), which lessens nasal voice quality

How Can the Family Help?

As your family member learns which strategies help improve speech most, you can help, too. Be a sensitive listener, and offer practical suggestions tactfully. For example, statements such as, "Please speak more slowly," "Please speak louder," "Please repeat the last few words," are helpful. Some other considerations are:

- converse in quiet areas away from noise (that is, avoid other loud conversations, or loud music)
- save lengthy conversations for times when energy and alertness are best
- in cases where dysarthria is severe, encourage use of other ways of communicating as well, such as by gesture, or by pointing to words or pictures

Summary

Dysarthria is a speech disorder that changes the way speech sounds. Through various exercise programs and focused speech practice, people with dysarthria aim to increase speech quality, naturalness, and intelligibility. Given enough time, many can succeed.



Fatigue and Brain Injury

What is Fatigue?

Fatigue is an overwhelming lack of energy. Fatigue can be mental or physical tiredness. It can make it hard to do even basic activities in your life. You may also feel like you cannot think clearly. Fatigue may change the way you do things or limit the things you can do each day. Fatigue usually improves as a person heals from a brain injury, but often does not completely go away.

Why does a brain injury affect fatigue?

You may have fatigue because your brain is working harder than it did before your injury. You may also be recovering from related problems, which can also take energy to heal. Your brain is trying to heal itself and do its best to help you function. It needs more energy than usual. Brain injury can also disrupt sleep. If you often felt tired before your injury, you are at a higher risk for having fatigue problems after your injury.

What happens when you have fatigue?

When you get fatigued, it may be because you have done more than your mind or body can manage. Sometimes fatigue happens for no obvious reason. When you are fatigued, you may feel exhausted without much warning, and you may not have the energy to do even a small task that you can usually do well.

What makes fatigue worse?

- \checkmark Doing too many things.
- \checkmark Not taking breaks during the day.
- ✓ Stress or illness.
- ✓ Chronic pain.
- ✓ Too little exercise.
- ✓ Poor nutrition, such as eating junk food.
- ✓ Feeling depressed or anxious.
- ✓ Poor sleep.

When should I ask for help with my fatigue?

Talk with your health care provider if:

- \checkmark You are too tired to get out of bed during the day.
- ✓ Your fatigue is getting worse.
- \checkmark You have cut back on doing things you love to do.
- ✓ You are not sleeping well at night.
- \checkmark Your fatigue seems to be related to your emotions or pain.

- ✓ Your thinking is often affected by fatigue.
- ✓ You are having trouble taking care of yourself or your family.

What can I do about fatigue?

Take care of yourself:

- \checkmark Exercise regularly.
- ✓ Eat a well-balanced diet.
- ✓ Avoid alcohol and too much caffeine, especially at night.
- ✓ Get a full night's sleep. Wake up at the same time every day.
- \checkmark Avoid napping if possible, or take one brief nap per day for less than an hour.
- ✓ Take your medicines as prescribed.
- ✓ Limit the amount of stress in your life.
- \checkmark Do relaxing activities during the day.
- \checkmark Make sure you do at least one enjoyable activity each day.

Save your energy:

- \checkmark Be realistic about how much you can do in a day.
- ✓ Build your stamina slowly, and be patient with yourself.
- ✓ Take small breaks throughout the day instead of trying to do as much as you can and then "crashing" for the rest of the day.
- \checkmark Alternate hard tasks with easy tasks.
- \checkmark Do not do tasks that do not need to be done.
- ✓ Plan ahead and organize your work.
- \checkmark Sit during tasks (such as cooking), when possible.
- ✓ Use lightweight or electric utensils and tools. Let gravity help you do the work.
- \checkmark When possible, ask friends or family to help you do things that use the most energy.

Set priorities:

- \checkmark Prioritize things you want to do in the day, so you have the energy for the most important things.
- ✓ Do activities that make you tired at the times of day when you have the most energy. Many people find the morning is the best time to do big tasks.

Pace yourself:

Do a little bit at a time. Break down tasks and do each part separately, with rest periods in between. For example, instead of vacuuming the whole house at one time, take a break between vacuuming each room.

Talk to your occupational therapist, physical therapist, or speech and language pathologist, as they can give you additional ideas for conserving energy and overcoming fatigue.



Hearing Loss and Brain Injury

An excerpt of an article titled "How Traumatic Brain Injury Affects Hearing" by Lynn Fugaro

Hearing problems are quite common after a traumatic brain injury (TBI) because the inner ear is directly connected to the central nervous system. Ringing in the ear (tinnitus) and hearing loss are two of the most widely reported side effects of a TBI. Some other hearing problems that may occur include hyperacusis (normal situations seem very loud); difficulty filtering one set of sounds from background noise; and auditory agnosia (also called pure word deafness). Auditory agnosia is a condition in which a person is unable to recognize the meanings of certain sounds.

Following a TBI, hearing problems can occur for a number of reasons, both mechanical and neurological, particularly when the middle ear, inner ear and/or temporal lobes have been damaged. External bleeding in the ear canal, middle ear damage, cochlear injury and/or temporal lobe lesions can all cause auditory dysfunction.

The inner ear is made up of a series of delicate membranes, which can easily rupture during a head trauma. The cochlea can be damaged by a strong blow to the head causing hearing damage. Other types of membrane damage may cause hearing loss as well as dizziness or vertigo and nausea. Sometimes surgery can correct middle ear damage, e.g., disarticulation of the ossicles, and possibly can correct damage to the inner ear.

Because hearing loss limits or takes away one of the primary means of communication, hearing loss has the potential to complicate many of the other side effects of brain damage, mainly cognitive and social issues.

Fortunately, for some TBI patients, hearing problems may disappear a few weeks after the accident that led to the patient's brain damage, but other hearing problems will last indefinitely. Since many hearing problems cannot even be detected by the patient him/herself, it is recommended that anyone suffering from a TBI be evaluated by an audiologist, even if nothing appears to be wrong with his/her hearing.



Memory and Brain Injury

What is memory?

Depictions of persons with head injury in movies and television almost always show that person experiencing some type of amnesia, or memory loss. Indeed, memory loss is the most common cognitive side effect of a severe traumatic brain injury. In patients with a mild TBI, memory loss is still one of the most common symptoms. And the more severe the patient's memory loss is, the more severe the brain damage is likely to be. Memory is the brain's ability to take in, keep, recall and use information. A brain injury can affect any of these areas of memory. A brain injury may also make it difficult to learn and remember things.

Why does a brain injury affect memory?

A brain injury often damages parts of the brain that are responsible for taking in, storing, and retrieving information. A brain injury may make memory problems that existed before the brain injury, worse.

Some traumatic brain injury-related amnesia is temporary. These patients are usually unable to recall what happened directly before, during and after their accidents. This is often caused by edema, or a swelling of the brain in response to the damage it sustained. Because the brain is pressed against the skull, parts that were not injured are still not able to function properly. As the swelling goes down, the patient's memory returns, often slowly over a period of weeks, months or even years. Temporary memory loss may also be an emotional response to the stress of the event that caused the TBI.

Memory is stored in the temporal lobe of the brain. The hippocampus is the part of the brain that stores and recalls our memories. If there is damage to one or both of these parts of the brain, problems with memory may be seen.

Memory problems after brain injury are often long lasting. Learning to deal with memory loss is a key part of rehabilitation. It can be a challenge and may cause frustration for the person as they try to learn new tasks and get back to work and life in their community.

Types of Memory

There are different types of memory:

Short-term memory is being able to remember recent information. Remembering a new phone number of the name of a person you just met are examples of this type of memory. You must first take information into your short-term memory before it can be placed in your long-term memory. People with a stroke or brain injury are more likely to show short-term memory loss.

Long-term memory is being able to remember information for days, weeks or years. Knowing your address, your spouse's birthday, or how many day's there are in a year are examples of things stored in long-term memory loss.

Episodic memory is being able to recall your personal experiences. Errands you ran or appointments you need to keep during the day are this type of memory.

Memory and Brain Injury

Procedural memory is being able to remember steps for a task. Knowing how to play a card game or how to run a load of laundry may be part of this type of memory.

Post Traumatic Amnesia is memory loss for events around the time of an injury. This can include a loss of events from a certain time before the injury. It may also be a loss of memory of certain things that happened since the brain injury.

Confabulation: Some people who have lost much of their memory confabulate or make up information. It is thought that the person is trying to make up for his or her poor memory skills. This person may give false or strange answers when asked questions about events of the recent past.

Ways to help with memory problems

- ✓ Ask for information to be repeated. Hearing it more than once may help you remember.
- ✓ Repeat to yourself information you need or want to remember.
- ✓ Write information in one place, such as in a journal or calendar. Little sticky notes can get lost easily.
- \checkmark Make a journal or photo album to help remember things that have happened in the past.
- \checkmark Make a daily log of the things you have done each day.
- \checkmark If you live with other people, label items that are yours so you can find them more easily.
- ✓ Keep a "cheat sheet" of important information in your wallet.
- \checkmark Use signs, labels, or cue cards to remind you where objects are located.
- ✓ Use a checklist to remind you of the steps of a task, or a list of items, such as what you need to take when you leave the house.
- \checkmark Use checklists to help you remember what you have done.
- \checkmark Focus on one thing at a time.
- ✓ Buy appliances that shut off automatically.
- ✓ Use a pill organizer to organize your medicines.
- ✓ Write down key words or main points of conversation to help jog your memory later.
- ✓ Post messages in places where you will easily see them. Have a message board in the kitchen or post notes on the bathroom mirror.
- \checkmark Keep a list of important phone numbers by each phone.
- ✓ Make a shopping list with like items grouped together.

Set a routine:

- ✓ Have a plan for each day and each week so you remember important things like taking your pills and going grocery shopping.
- \checkmark Have one place for each thing in your house and always put it there.
- \checkmark Use a calendar and post it where you will see it often. Check it every night before you go to bed so

you know what you are doing the next day.

 \checkmark At the end of the day, check off the day on your calendar to help you remember what the date is.

Let someone else remember:

- ✓ Ask your bank to automatically pay your bills or get a protective payee to help handle your money.
- ✓ Use different kinds of signals throughout the day to remind you of appointments or other activities. For example, use a TV or light timer, program an electronic organizer or cell phone, or use a beeping watch.
- \checkmark Have a family member take notes during meetings with your doctor or health care provider.

Learn more effectively:

- ✓ Break down new information into small parts. Learn the small parts instead of trying to learn everything at one time.
- \checkmark Think of ways to connect new and old information.

You can learn more about memory by speaking to your doctor or health care provider, your psychologist, an occupational therapist or a speech and language pathologist. They can give you ideas on ways to make the most of your memory.



Muscle Tone After a Brain Injury

Spastic hypertonia, or increased muscle tone often occurs after a traumatic brain injury (TBI) as a result of damage to the brain stem, cerebellum or mid-brain. The damage affects the reflex centers in the brain, interrupting the flow of messages along various nerve pathways. This disruption of signals can cause changes in muscle tone, movement, sensation and reflex. The location of the brain injury can affect which areas of the body are affected and what the specific motor deficit may be.

Shortly after a brain injury, individuals often go through a period of increased muscle tone where their body posture becomes very rigid. A common position is elbows held rigidly at their sides, wrists and fingers bent and fists clenched. The legs are usually extended at the hips and knees with ankles and toes flexed. When the elbows are bent it is referred to as decorticate posture. If the elbows are extended it is called decerebrate posture.

As the individual recovers, nerve signals that control motor movement may change. Some signals may not reach the reflex centers of the brain. In other cases, the brain may send too many signals, and the muscles cannot respond properly. As motor movement begins to return, the movement is usually unconscious and reactive rather than planned and purposeful. There may be spasms or other large uncontrolled movements. During the first six months, there will be changes in patterns and movement as the individual recovers. Muscle tone can develop and change dramatically over the first year following injury.

Understanding muscle tone

Many different mechanical and chemical factors affect how your muscles move. Muscle tone is most important. (Tone is the amount of tension or resistance to movement in a muscle). Unlike a normal muscle, when stretched, a spastic muscle does not easily relax. Instead, the muscle remains stiff or perhaps non-moveable. Muscles with too much or too little tone cannot function at their best. Muscles lacking tone are flaccid or soft and cannot offer resistance when stretched. A muscle with high tone is rigid or hypertonic. This makes it difficult for a person to perform normal tasks (walking, picking up objects, dressing). For example, muscle tone must change for you to pick up a cup. The muscles must be able to contract to grasp the cup and then relax at the proper time to let go of the cup.

Treatment

Proper positioning is the primary treatment goal for an individual with TBI who has abnormal posturing caused by spastic hypertonia. The individual should be properly positioned when laying and sitting. Therapists often work on preventing contractures (a permanent shortening of a muscle or tendon due to continued spasticity) or further tightening of the muscles that may develop due to abnormally high tone and improper positioning of the limbs. Abnormal posture can also lead to pressure sores, a decrease in blood flow to the extremities or a decrease in blood pressure.

Spastic hypertonia is not necessarily a medical problem unless the extreme muscle tone interferes with normal range of motion or regular daily activity. For example, stiffened muscles or contracted muscles may keep individuals from doing their own self-care, or it may also make it difficult for the caregiver to assist with basic tasks.

Possible advantages of spastic hypertonia

- ✓ Maintains muscle tone and mass
- \checkmark Reduces bone loss and decreases the risk for osteoporosis.
- ✓ Increases metabolic requirements such as promoting blood circulation and improving breathing.
- ✓ Helps in performance of daily self-care routines such as assisting in pressure reliefs to prevent pressure sores.
- ✓ Helps in performing daily functions such as picking up items, transferring or walking with braces.
- \checkmark Warns when there is a problem in areas where the body has no feeling.

Possible disadvantages of spastic hypertonia

- ✓ Limits range of motion.
- \checkmark Causes pain due to stress put on joints and muscles.
- ✓ Interferes with daily functions from dressing and eating to driving, walking and participating in other activities.
- ✓ Interferes with other activities such as sexual function, sleeping, changing position, sitting or transferring.
- ✓ Affects posture and ability to sit comfortably, maintain balance or change positions.
- \checkmark Causes rubbing and friction to the skin and increases the risk for pressure sores.
- \checkmark Adds to the cost of medications and attendant care.

Rehabilitation

Daily range of motion and regular stretching can promote relaxation of rigid or spastic muscles. All stretching and exercises should be prescribed by a physical or occupational therapist. Sometimes dynamic splints, static splints, standing devices or standing frames can be utilized for helpful treatment.

Medications

Medications are the most widely used option for treating muscle tone. Some medications are taken by mouth (oral) or by feeding tube (enteral feeding). These are common medications used to manage muscle tone:

- ✓ Benzodiazepines [Diazepam (Valium[®]), Clonazepam (Klonopin[®] or Rivotril[®]) act on the central nervous system and result in a decrease in overactive muscles and fewer painful spasms. These drugs are sedative/hypnotics and are used mainly for nighttime spasms and sleep disturbances. Common side effects are dizziness, drowsiness, impaired memory and attention, and loss of strength. These medications can be addictive for some individuals, so a sudden stop in use may cause symptoms of withdrawal. This is not the first drug of choice in a new head injury because of cognitive side effects that can slow recovery.
- ✓ Baclofen (Lioresal®) is another medications that works through the central nervous system. It helps to improve passive range of motion and reduces muscle spasms, pain and tightness. Daily

functioning and activities of daily living may not improve with baclofen use. Some individuals reported side effects such as dizziness, drowsiness, weakness, fatigue, nausea, urinary retention or incontinence, bowel constipation or incontinence and sexual dysfunction.

- ✓ Dantrolene sodium (Dantrium[®]) is a medication that works differently than benzodiazepines and baclofen. It acts at the muscle, rather than on the central nervous system, where it interferes with muscle contraction. Dantrolene improves passive movement, decreases muscle tone and reduces muscle spasms, tightness and pain. Its use has been limited in individuals with TBI because it is not selective for spastic muscles. Dantrolene can cause generalized weakness to all muscles, including the respiratory muscles. This drug is metabolized in the liver and requires a blood test to monitor liver enzymes. The most common side effects are dizziness, drowsiness, diarrhea, fatigue and weakness.
- ✓ Tizanidine (Zanaflex®) is a medication that reduces muscle tone by acting on the central nervous system. It does not reduce the strength of muscles as much as other types of oral or transdermal medications (skin patch). It is a short acting drug and should be taken during daily activities when the relief of muscle tone is most important. Some individuals may experience side effects such as sedation, dizziness, and low blood pressure. There are other oral medications that are currently being studied to determine their effectiveness on muscle tone. A medical doctor experienced in working with individuals with TBI will be able to help you with this.

Motor point blocks

Chemodenervation is the use of chemicals injected directly into the muscle to interrupt the flow of nerve impulses to the spastic muscles. Some of these chemicals include Botulinum Toxin Type A (BOTOX® and Dysport®), Botulinum Toxin B (Myobloc®), and Phenol and Alcohol. They work by reducing muscle contractions and allowing a more normal position or function of the involved limb.

The advantage to using these drugs is that they only work for several weeks. If you do not like the side effects, you can stop treatment with no permanent effect on motor nerve communication. The disadvantage is that the overall effect is temporary and localized muscle weakening will clear up. Each chemical has advantages and disadvantages, so you should talk to your doctor about any possible risks or side effects of the treatment.

Intrathecal

Intrathecal medication is a fast growing treatment option. First, an Intrathecal Pump (IP) is surgically implanted into the abdomen. The difference between the IP and other surgical options is that the IP surgery is reversible. Second, the IP has a reservoir of medicine (usually the same baclofen used as an oral medication). The medicine is pumped through a small tube directly to the fluid surrounding the spinal cord.

Advantages of the intrathecal pump

- \checkmark Medicine is sent directly to the nerve cells where it is needed.
- ✓ Medicine dosage can be adjusted as needed.
- ✓ Much less medication is needed than if it were taken orally, which reduces side effects, especially sedation.
- ✓ Reservoir is easily refilled by injection when needed.
- \checkmark Surgery is reversible.
Disadvantages of the Intrathecal Pump

- ✓ Requires surgery to implant the pump.
- ✓ Expensive.
- ✓ Tubing can come disconnected or kinked.
- Risks include infection, baclofen overdose, pump dysfunction, and developing symptoms of withdrawal.

Surgical options

Before surgery can be successful, the muscle tone must first be controlled or reduced. Otherwise the contracture is bound to return despite splinting and positioning. Individuals who choose surgery as an option should also understand that most of these procedures are nonreversible. Orthopedic surgery is done to correct or counterbalance the effects of muscle tone through various procedures to muscles, tendons or bones. Four common types of these orthopedic surgeries are:

- ✓ Contracture release either partially or completely cuts a tendon to release a contracture of the tendon or muscle. A contracture is an abnormal joint posture due to persistent muscle shortening. When muscles are not stretched regularly, the tendons shorten and tighten, which limits the muscle's full range of motion.
- ✓ Tendon transfer moves the attachment point of a spastic muscle. This means that the muscle can no longer pull the joint into a deformed position.
- \checkmark Osteotomy is removing a small wedge from a bone to allow it to be repositioned or reshaped.
- \checkmark Arthrodesis is the fusing together of bones that normally move independently.



Visual/Perceptual Changes after Brain Injury

After a brain injury, visual changes may occur. These changes can vary from mild to severe impairments depending on the type and location of the injury. The ability to perform daily activities can be affected in various ways.

Typical problems may be with:

- ✓ Ocular-motor (eye) control.
- ✓ Visual acuity (clarity)
- \checkmark Visual attention
- ✓ Visual perception. (how the brain interprets visual information)

Ocular-motor control

Ocular-motor difficulties result in problems coordinating eye muscles. Examples include:

- \checkmark Difficulty tracking or following object movements in space with the eyes.
- ✓ Problems with scanning, the ability to move eyes in an organized pattern and be aware of one's surroundings.
- ✓ Lack of ability to converge for both eyes to come in towards the nose and move back to the center of eye orbit.
- ✓ Impaired depth perception
- ✓ Double vision
- ✓ Difficulty reading

The ability to control eye movement can play a major role in how well a person can participate in daily activities.

Visual Acuity

Visual acuity is simply how clearly you see – whether it is near vision, as needed for reading, or distant vision, as needed for driving. Typical changes following an injury include:

- ✓ Need for corrective lenses or modification of current prescription glasses.
- ✓ Altered contrast sensitivity (seeing objects distinct from the background environment, for example, seeing a white sock on white carpet). This may require training in special compensatory strategies.

Visual attention

Visual attention is the ability to focus on objects and environments, to note specific characteristics and know their relationship to each other. It requires being able to focus and to shift focus between objects. It is a necessary function of the eyes to assess other visual and perceptual functions.

Visual perception

Visual perception refers to how the brain processes and interprets visual information. After brain injury, visual perception can be altered in several ways.

- \checkmark Visual field deficits loss of vision in a part/side of one or both eyes.
- ✓ Reduced visual attention limited focus or awareness sometimes on one side of the body. When this occurs on one side of the body it is called unilateral neglect. This could result in someone shaving only one half of his face, by putting on only one pant leg or eating only from one side of the plate.
- ✓ Impaired spatial relations decreased ability to see objects in relation to their environment or other objects.
- ✓ Difficulty with functional mobility tasks and navigating around environmental obstacles.
- \checkmark Apraxia inability to use an object or do familiar tasks.

Compensatory strategies

Below is a list of some of the visual perceptual issues, common symptoms one may see, and ways to compensate or help the individual experiencing these deficits.

Issue	Symptoms	What you can do
Unilateral	\checkmark Bumps into objects on the affected side.	\checkmark Ask visitors to stand on the affected
Neglect	\checkmark Turns head toward the unaffected side.	side to encourage the person to look toward that side.
	✓ Ignores food on the side of the plate on $f(x) = \frac{1}{2} \int_{-\infty}^{\infty} \frac{1}{2} \int_{-\infty}^{\infty$	\checkmark Position bed and chair to encourage
	the affected side.	looking toward the affected side.
	 ✓ Fails to dress the affected side of the body 	\checkmark Position bright objects on the affected
		side. This "visual cueing" should be
	Forgets to bathe or attend to other hygiene tasks on the affected side	done only when the person is alert and not tired
	\checkmark Applies makeup to only one side of the	not thed.
	face.	
	✓ Jabs the eye on the affected side when putting on glasses.	

Issue	Symptoms	What you can do			
Visual Field Cut	 Suddenly notices objects that seem to appear or disappear. Bumps into objects on the affected side 	 Remind the person to look around the environment, especially on the affected side. 			
	 Bumps into objects on the affected side. Turns head toward the affected side. Cannot see food on the side of the plate on the affected side. Loses track of the last location on a page where the person was reading or writing. When reading, cuts words in half and they cannot be understood. 	 Mark "on" and "off" switches of frequently used items, such as televisions and kitchen appliances, with bright pieces of tape so the person can easily know when equipment is on or off. Position bright objects or favorite things to the affected side and ask the person to turn his or her head until they spot the objects. 			
		 ✓ Draw a straight, brightly colored line down one side of a book or notebook as a cue indicating the edge of the page. Do this on the right side of the page if the right side is affected, and on the left side if the left side is affected. 			
Apraxia	 ✓ Uses objects incorrectly; for example, might use a toothbrush to comb hair or a fork to eat soup. ✓ Fails to follow spoken directions due to an inability to understand or do what is asked; for example, may not give the "thumbs up" sign when asked. ✓ Puts clothes on backwards, upside down or inside out. 	 Stop the person from continuing a task the wrong way. Show the person what to do by demonstrating the position or movement. Place your hand over the person's hand and move it through the correct motions to perform a task. Re-direct the person to put on clothing in correct order, one step at a time. Develop a daily routine for hygiene and dressing. 			

Issue	Symptoms	What you can do		
Spatial Relations	 ✓ Mistakes the location of a chair when sitting down. 	 ✓ Limit clutter; keep the home and drawers organized and neat. 		
	 ✓ Has difficulty finding items in a cluttered room. 	 ✓ Keep items used often in the same location. 		
	 ✓ Has trouble using a fork or spoon to pick up food from a plate. 	 ✓ Provide cues with words and pictures. Place brightly colored tape across the 		
	✓ Misjudges distance; for example, misses the cup when pouring coffee.	 edge of each step on stairways. ✓ Remind that handrails should be used when sucilable. 		
	 ✓ Misjudges space between steps when going up or down stairs. ✓ Reaches too far or not far enough to get objects. ✓ Stands too close or too far away from 	 ✓ Encourage using both hands to feel for objects 		
		 Provide gentle reminders and ask the person to move when standing too 		
	 ✓ Requests eye appointments often, because of perception that vision is affected. 	 Wait for six months after brain injury or the time recommended by your physician, to schedule an eye appointment. It is unlikely that the problem with perception is the result of a new problem with the eyes. 		

A person with TBI experiencing difficulties with their vision should consult their doctor, nurse or therapist as it may be appropriate to be referred to an occupational therapist and/or neuro-optometrist. These specialists may help correct visual deficits, and teach adaptation or use of compensatory strategies that improve abilities to perform daily activities.

What is a Neuro-Optometrist?

Neuro-optometrists assess the way the brain processes information sent by the eyes. They often work in tandem with an occupational or physical therapist to coordinate vision functions with the rest of body. They are specialists in the diagnosis and rehabilitation of visual disorders caused by neurologic events including TBI, stroke and MS. Neurogenic visual disorders treated include loss of visual acuity, blurred vision, loss of depth perception, double vision and decreased peripheral vision.



Vocational Rehabilitation and Brain Injury

Vocational rehab: http://www.nh.gov/disability/about/documents/vocrehab.pdf

New Hampshire-

What is vocational rehab-the vocational rehabilitation (VR) program is one of the nation's oldest federal programs established by the Rehabilitation Act of 1973 (the Act). The VR program is also a full partner in the NH Works one-stop service delivery system.

The mission of the VR is to help people with disabilities prepare for, find and keep suitable employment. You will make "informed choices" during the VR process. VR will give you the information, assistance, and support you need to understand how to make informed choices. The VR choices you make at each step should be based on your informed choice and Vocational Rehabilitation requires your active involvement. **Resource:** <u>http://www.nh.gov/disability/about/documents/vocrehab.pdf</u>

Massachusetts-

Vocational Rehabilitation Services Overview

MRC's Vocational Rehabilitation Program assists individuals with disabilities to obtain and maintain employment. The Vocational Rehabilitation Program helps individuals with physical, psychiatric and/or learning disabilities face the challenges of the modern workplace. This may include identifying job goals based on individual interests and aptitudes, providing funds for college and vocational training, assessing worksite accommodations, educating an employer about the Americans with Disabilities Act, or assisting an individual returning to work after adjusting to a new disabling condition. Vocational rehabilitation services can often reduce or remove barriers to employment. Priority is given to those individuals who have the most severe disabilities in areas such as communication, mobility, work tolerance and work skills.

The Vocational Rehabilitation Program is mandated and regulated by the federal government while being administered through state government. Find out more information about the VR Program's federal parent agency, the Rehabilitation Services Administration.

To be eligible for VR services from a State VR agency, a person must have a physical or mental impairment that is a substantial impediment to employment; be able to benefit from VR services in terms of employment; and require VR services to prepare for, enter, engage in, or retain employment.

The State VR agencies assist persons with disabilities to locate employment by developing and maintaining close relationships with local businesses. Furthermore, they assist persons served to become tax paying citizens and to reduce their reliance on entitlement programs.

- MRC VR staff will outline available vocational rehabilitation services when you attend a group orientation or schedule an individual appointment. To inquire about an orientation at the VR office nearest you.
- If you are interested in receiving services, a professional vocational rehabilitation (VR) counselor will be assigned to meet with you and assist you in obtaining a job.
- During the initial interview, you and your VR counselor will have the opportunity to discuss your employment interests, concerns and vocational goals.

Eligibility **Information** is gathered from:

- Physicians
- Therapists
- Hospital and other medical records
- Self report
- Social Security Administration

Eligibility **Determination** is made by:

- Identifying substantial barriers to employment caused by a disability.
- Establishing a reasonable expectation that a positive employment outcome will occur as a result of VR services.

Resource: <u>http://www.mass.gov/eohhs/consumer/disability-services/vocational-rehab/</u>



Behavior Definitions and Brain Injury

Agitation

A heightened state of (typically purposeless) excessive activity in which an individual is responding primarily to his or her own internal confusion. External input is often of brief or little help. May include confused, aggressive, hostile or bizarre behavior such as in the Rancho Level IV "confused-agitated" state. Confusion often precedes and is a part of agitation, and individuals typically refuse to cooperate or let people help them.

Confusion/Disorientation

Involves reduced awareness of the environment, typically in the context of impaired attention, resulting in generalized cognitive impairment, either increased or decreased motor activity, and a disturbed sleep/wake cycle. People are typically unaware of the day/date, their location, the purpose of an interaction, or the reason for their hospitalization. Symptoms of confusion can fluctuate in severity over the course of a day.

Decreased willingness/low motivation

Motivation is the desire or internal drive to do things or achieve certain goals. It can be triggered by internal or external incentives. Low motivation is a decreased desire or drive to engage in an activity or to work toward a goal. In severe cases, a person may demonstrate apathy, or the inability to generate and sustain purposeful action. The neurologically based inability to initiate or complete activities due to decreased or absent drive is called abulia.

Discriminatory comments

Negative or derogatory comments or behavior related to race, gender (sexist), sexual orientation, age, or ethnicity whether intentional or not. The behavior is typically experiences as demeaning or rejecting simply on the basis of one's race, gender, or other attribute.

Elopement Risk

Elopement risk refers to a patient who may try to leave the hospital by either wandering or for the purpose of running away. Elopement can be the result of confusion or a deliberate desire to escape an undesirable situation.

Impaired safety awareness

This term refers to a specific deficit in a patient's ability to appreciate safety concerns and considerations related to their behavior and/or situations. As a result, they may engage in behavior or get into situations that have an elevated risk of danger or harm.

Impulsive

Initiating or performing an activity too quickly or without proper planning (including safety precautions). Impulsive behavior is a problem with self-regulation, and can adversely affect a person's ability to perform daily activities safely or accurately. It is often associated with problems with attention (e.g., distractibility). Sometimes impulsive behavior will result in a patient doing things that are embarrassing to them and/or others.

Mood Symptoms (lability, anxiety, bipolar, depression, irritability)

Mood refers to a person's emotional functioning and well-being. It is a prevailing and sustained subjective emotional state or experience as reported by the person. (This is in contrast to emotional or "affective" expression which is the emotional tone experienced by an observer.) Patients may report that their mood includes depression, anxiety, irritability (i.e., an excessive or heightened response to any internal or external stimuli, on edge, reactive), mixed or up-and-down feelings/emotions (lability), or true bipolar symptoms (that include periods of depression and mania or hypomania).

Perseverative behavior

Persistence or repetition of the same behavior or response, even when it is shown to be inappropriate, problematic or unsuccessful. Perseveration may involve motor acts, speech or ideas; it can involve repetition of the same word, phrase, or idea in response to different questions.

Physical Assault (hitting, punching, kicking)

Any behavior that involves deliberate, aggressive physical contact, such as hitting, punching, slapping, kicking, that is intended to cause harm or protect oneself from a real or perceived threat.

Poor awareness of deficits

Awareness of deficits is complex. It involves an ability to understand the physical, cognitive, emotional, social-behavioral and/or functional problems that are the result of an injury or disorder. It represents the level of insight that a patient has in understanding the nature of their deficits, the impact of their deficits on their current functioning, and/or their need for treatment.

Poor awareness means that the patient fails to understand or only partially understands and appreciates the changes in ability their illness or injury has caused. From a clinical perspective, staff might observe cases of patients with paralysis, hemiparesis, visual field deficits, aphasia, or memory problems who deny their deficit, over-estimate their abilities, claim that they are moving their impaired limb and do not differ from other people, or partially admit their difficulties but attribute them to other causes (like medication effects, fatigue, not wanting to try). Such patients will persist in their beliefs despite contrary objective evidence and feedback by staff and family members. As a result, they reject treatment or compensatory supports, and over-estimate their ability to complete a task successfully or safely.

Property Destruction (breaking items)

Any behavior that includes the deliberate and aggressive breaking of property or items. This most often includes throwing objects against a wall or to the ground or hitting furniture, objects, or wall-hangings or walls, resulting in their breakage.

Psychosis (hallucinations, delusions)

Hallucinations involve seeing false visions or hearing false voices. A patient may seem to see, hear or experience things that are not present. Sometimes a patient will be seen talking to people who are not there or will describe seeing things not seen by others, or behave as if she/he is seeing things not seen by others (people, animals, lights, etc). While less frequent, a patient might also report smelling odors not smelled by others, describe feeling things on his/her skin or appear to be feeling things crawling on or touching her/him, or describe tastes that are without a known cause (e.g., there's nothing in the person's mouth). Delusions are when a patient has beliefs that you know are not true (such as insisting that people are trying to harm him/her or steal from him/her), and they are convinced that these things are happening to him/her. They are often distressing and disruptive.

Refusing to participate in care

Refusal is lack of agreement or cooperation to perform a particular course of action, such as engage in a care routine or therapy. A refusal can be indicated by a verbal or nonverbal rejection of care/treatment.

Refusing to participate in therapy/activities

Refusal is lack of agreement or cooperation to perform a particular course of action, such as engage in a care routine or therapy. A refusal can be indicated by a verbal or nonverbal rejection of care/treatment. Restlessness

An inability to achieve relaxation; a continuous feeling of physical and/or mental discomfort or distress. Restlessness is frequently an early, subtle sign of agitation or deterioration. It often includes purposeless movement or hyperactivity.

Self injury

The deliberate infliction of damage to one's own body; it includes cutting, burning, and other forms of injury, and is often repetitive, particularly during periods of stress. It typically does not represent a suicide attempt. Importantly, it may be related to a trauma history.

Sexual comments or behaviors

Speech that includes uninvited comments, conduct, or behavior regarding sex, genitals or sexual orientation. Sexual comments may include explicit propositions to provide or receive sexual acts, or about a person's physical attributes in a manner that is sexualized. Sexual behaviors include unwanted and inappropriate touching of another person, or openly touching their genitalia in a sexual way, such as in masturbation.

Sleep Disturbance

Is any disruption in the normal pattern of sleep and wakefulness. This can include insomnia (difficulty falling asleep, waking up easily/often during the night and difficulty falling back asleep, waking up early, feeling tired on awakening) or excessive sleep, including daytime sleep or sleepiness or laying in bed during daytime hours. Most people require a minimum of 7 hours of continuous sleep a night; anything less than 5 hours/night is very low.

Sleep disturbance is NOT getting up once or twice a night to go to the bathroom and falling back to sleep in a short period of time.

Suicidal Thoughts

Thoughts related to ending one's life; ideas that include an intent to die or desire to kill oneself. Suicidal thoughts may include an intention or plan to kill oneself by some particular method. Feelings/thoughts of hopelessness, worthlessness (including being a burden on others) and pessimism about one's future are commonly associated with suicidal thoughts.

More passive thoughts about death or wanting to be dead, particularly when worries about being a burden to others or about how one can make a new life are *not* by themselves suicidal. In many cases, such thoughts point to an effort a person is making in trying to find a solution for how to live given their current circumstances. Such thoughts, however, may be an indication of depression and anxiety.

Verbally abusive

Speech that is aggressive, mean, critical and/or hostile, and which leaves a person feeling demeaned or emotionally hurt. It can be intentional or not intentional, such as when a person says things when upset without regard for the feelings of those around them.

Wandering

Involves moving away from an area one is expected to be in, often for the purposes of maintaining safety. It is typically aimless or purposeless, and can accompany confusion, restlessness and the early stages of agitation.



Factors Affecting Behavior and Cognition

Domain	Factor	Clinical Impact		
Background	Education &	• Understand a patient's educational history and level (i.e., last		
Factors	Work History	grade completed, performance, history of learning problems		
		and/or AD/HD).		
		• Patients with low levels of education (< 12 yrs) <i>may</i> learn		
		more slowly, need more repetition/practice, and more		
		concrete, task or situational supports to master rehab routines		
		and new self-care, safety and health habits.		
		• Patients with low levels of education may be more prone to		
		confusion or misunderstanding, leading to frustration,		
		reduced effort, or behavioral problems.		
	Psychiatric &	• A past history of depression, anxiety, or AD/HD may be		
	Substance Use	made worse by the acquired brain injury directly (by further		
	History	hurting parts of the brain that were already compromised) or		
		indirectly by the coping challenges created by the brain		
		injury (e.g., speech or movement disorders, physical		
		limitations).		
		• Sometimes it's not the acquired brain injury that's creating		
		challenges, but the person's ongoing mental health problem		
		(such as depression, anxiety, worry, proneness to panic,		
Biological/	Medical	While neurological problems such as acquired brain injury		
Comfort	Conditions	• While heurological problems such as acquired brain injury may be the primary reason for a patient's rebabilitation		
Needs	Conditions	various medical problems also have an important impact on		
iteus		cognition & behavior		
		 Be knowledgeable about a patient's neurological AND 		
		medical conditions.		
	Sleep	• Sleep quality has a very important impact on cognition &		
	1	behavior.		
		• Poor sleep is associated with reduced arousal, orientation,		
		processing speed, attention/concentration, working memory,		
		learning & memory, executive functions/problem-solving,		
		thus interfering with carryover.		
		Poor sleep lowers frustration tolerance, and increases		
		irritability, agitation, and the likelihood of		
		aggression/outbursts.		
		• Daytime drowsiness impairs participation in rehabilitation,		
		and nighttime wakefulness increases risk of falls and		
		behavioral disturbances.		
		Monitor sleep quality closely.		
	Pain	• Pain has a negative influence on cognition, especially		
		attention/concentration—it is distracting and reduces a		

		 person's attention resources and working memory. It is often important to address pain pain-related fear and activity avoidance, fears and misconceptions about medication addiction and abuse, and the distinction between pain as a sensation and sign of tissue damage.
	Body Temperature Regulation	• Ensure that room temperatures are appropriate for the patient, as the body's ability to adjust to external temperatures is often reduced in aging and after brain injury.
		• Discomfort associated with poor temperature regulation (too hot or too cold) can contribute to discomfort or irritability and interfere with participation in rehabilitation.
	Bladder/Bowel Control	• Worry/fear about incontinence (including reduced self- esteem, embarrassment, and social withdrawal) is common, and may reduce participation in rehabilitation.
	Swallowing Difficulties (fluid or food)	 Dysphagia (swallowing difficulties) affects 10-30% of patients, and negatively impact caloric intake/nutrition. Living with swallowing difficulties can be very challenging for some patients, and can contribute to anxiety, depression/irritability, and quality of life. Dysphagia may contribute to changes in behavior, mood, and interactions with family, friends, and staff.
Psychological	Mood/ Anxiety & Substance Use	 A left hemisphere stroke is most likely to produce depression, while a right hemisphere stroke can result in emotional "flatness" or indifference/apathy. Depression and worry (generalized anxiety) are associated with higher rates of irritability and overt (especially) verbal abuse/aggression after acquired brain injury (48-64%).
	Substance Use	 Many acquired brain injury patients are at high risk of returning to pre-injury usage levels within 3 years (≥75%). Increases in alcohol use post-injury may be related to self-medication to alleviate pain, depression, and/or anxiety.
	Health Beliefs, Attitudes & Motivation	 Patient's perception of their problems, their cause and the value of treatments and health behaviors will influence their cooperation with rehabilitation and care routines. Motivation and treatment adherence are increased by staff's autonomy-supportive behaviors (e.g., opportunities for choice/options, respect for & acknowledgement of patient questions, opinions, and feelings, and providing a meaningful rationale for the treatment or recommendations).
	Cognitive Status	 The kinds of cognitive problems that follow stroke, brain tumors or infections vary from patient to patient, and depend on where in the brain the injury occurred and its size. Location and amount of brain damage matter; in general, the greater the damage, the greater and more persistent the deficits. Confusional states include fluctuations in arousal (between

			hypo- and hyper-arousal) that may be rapid or prolonged, and influenced by medical and environmental factors.
		•	Neglect is an attention disorder, and most often occurs after a
			right hemisphere stroke or injury that results in a failure to
			pay attention or orient to the left side of the patient's body and space. Neglect negatively impacts ADLs, rehabilitation
			success, length of hospitalization, and functional outcome. It
			also poses significant safety concerns (e.g., harm/burns to an
			affected limb, falls due to neglect of surrounding space).
		•	Language problems and aphasia are most likely to occur with damage to the dominant (usually left) hemisphere: strokes
			result in aphasia in about 1 in 3 adults.
		•	In terms of memory, recognition is almost always better than
			are responsible. Remote (past) memory is always better than
			new, recent memory.
	Reduced Self-	•	In general, neurological patients tend to underestimate the
	Awareness		severity and meaning of their cognitive and behavioral
			In most cases the underlying cause is neurological and NOT
			psychological.
	Behavioral	•	Wandering is associated with problematic social behavior,
	(wanaering)		loss) resistance to care, independence in locomotion/
			ambulation, and dependence in ADLs, especially hygiene.
		•	Other reasons for wandering include boredom, physical
Social/	Social &		exercise, self-stimulation, and akathesia.
Environmental	Environmental	•	busy areas, too much noise, velling
	Factors that Trigger	•	Too many restrictions. lack of space, lack of choice, lack of
	Agitation/Aggression		freedom, locked doors
		•	Negative interactions with staff: staff have an inflexible
			negative communication style (critical, hostile, talking down
			to a patient), inappropriate interaction with staff,
			inexperienced staff, too much staff rotation/lack of continuity of staff, lack of staff expertise
		•	Negative interactions with other patients: conflicts, theft of
			tood or belongings, invasion of privacy/space, disruptive behavior
		•	Negative interactions with family members: conflicts/fights,
			negative interactions personally, high expressed emotion
			(especially criticism or hostility), and patients being treated
			like children.
		•	Pinpointing specific environmental triggers to agitation, and

		•	modifying them can resolve the agitated behavior, reduce the need for unnecessary medications, and delay nursing home placement (in the case of individuals with dementias). Remove or modify identified triggers.
I A	Environmental & Communication- Interaction Approaches	•	Provide a structured environment and consistent routines in which adaptive behavior, especially social behavior, is reinforced.Face the patient and make eye contact when providing information or talking with patients.Allow extra time for the patient to respond to questions & directions.



Emotional Changes and Brain Injury

Most people with brain injury have some changes in emotional behavior. They may have "emotional lability" or a "flat affect." A person's "affect" can be thought of as the way he/she expresses his emotions. Emotional lability occurs when a person may **laugh** or **cry** in response to minor events. The response is out of proportion or opposite to what would normally be expected, and the mood may change suddenly. The person's expression does not necessarily reflect his/her internal feelings.

For example, when being told of the death of a friend, the person may laugh out loud. The person may start crying when someone visits and says, "Good morning."

"Flat affect" on the other hand is a lack of emotional response. The person may show limited or no emotion to anything. There may be a general lack of smiling, laughing, or crying in any type of interaction during the day.

Problems with affect can occur as a result of the brain injury. Certain parts of the brain control normal emotional expression and response. In addition, the brain controls the ability to respond "correctly" in an emotional situation such as when sad news is talked about or a funny joke is told. The doctor may prescribe certain medicines to help with better control emotions. Some of these medicines work on a chemical in the brain called serotonin. Serotonin is thought to help improve mood as well as decrease feelings of despair and hopelessness. Common brand names include: Prozac, Zoloft, Paxil, Lexapro, Celexa and Effexor.

Ways To Help

- ✓ Don't take it personally when lability or flat affect is present
 Be aware that these responses are part of the brain injury and are not being done on purpose
- \checkmark Encourage rest periods as suggested by the therapy team
- ✓ Tell other friends and family members of the affect problems so they do not become upset with the person
- ✓ Encourage a non-emotional distraction when a person becomes labile. For example, ask the person about the weather.
- ✓ Help the person be aware of affect by saying "You look happy/sad. How do you feel?"

Depression and Anxiety

Depression and anxiety are common problem that may be experienced after a brain injury. A person may feel uneasy or apprehensive and/or sad, discouraged or helpless. Depression and anxiety can be problems in daily life because it may interfere with a person's ability to take on new challenges, learn new things, and/or participate fully in therapeutic activities.

A person may act very upset or overwhelmed when learning new tasks or when there is a change in the daily schedule. Frequent or unnecessary questions may be asked or there may be a general resistance to trying new things. The person may even be afraid to be alone or simply isolated from others. Tearfulness and irritability are also common.

Ways To Help

- ✓ Encourage rest periods and quiet time
- ✓ Tell the person what is going to happen during an activity in order to prepare him/her so anxiety will be minimized
- \checkmark Orient the person to day, place, task or whatever the situation may be
- ✓ Maintain as much structure/routine in the daily schedule as possible. Introduce unanticipated changes slowly and calmly.
- ✓ Keep "familiar" items nearby such as photographs, toys & special clothing when leaving usual surroundings
- ✓ Start with small challenges and gradually progress as tolerated
- ✓ Inform the doctor if anxiety and/or depression are interfering with daily activities, including active therapy participation.
- ✓ Praise and encourage <u>often</u> and <u>immediately</u> after an accomplishment

Emotional Stages of Recovery from Brain Injury

There are a number of very common emotional stages that people with brain injury go through. The first phase that people go through is a *confusion/agitation phase*. This can last minutes or it can last for months. Someone who is very meek and mild, for example, can become physically aggressive. Generally, this *confusion/agitation phase* goes away. It may take a while, but people eventually come out of it.

The next stage is *denial*. *Denial* can be very difficult for both family members and for the medical staff. The person in denial says there's nothing wrong, even when directly confronted by family members with the contrary. When someone is in denial, you must give consistent feedback that everything is not "okay". Generally, direct feedback is necessary. However, some people get really angry when facing the feedback. Distractions, such as changing the topic of conversation, is better than getting into long winded arguments. Denial is very common, but eventually it breaks down. As the challenges continue they will lead to the next stage of *depression/anger*.

When you realize you are different and can't do things like you used to, you may become *angry or depressed*. Some of the anger is due to the brain injury. You may notice that the anger comes extremely quickly and also goes away just as quickly. This is directly related to the brain injury. The sections of the brain that control those emotions have been injured. Virtually all people who through a serious illness or injury will have some anger and depression. This pattern of becoming anxious about abilities or changes in abilities and the subsequent depression about those changes can become cyclical. This cycling pattern can go back and forth and some people may never move on the next stage without medical intervention.

The next stage almost always follows after a period of recovery and improvement in thinking abilities. When people eventually realize they are improving they go through the *testing phase*. Basically, they test themselves to see their limits. For example, many people with a brain injury have a fatigue disorder. They know they get tired easily. But during this testing phase, they "forget" and may act contrary to what they know they should do. They may not truly "face" any changes until they go through this stage of testing their limits.

The next stage is *uneasy acceptance*. This is when you learn what your limits are. You have learned after many attempts in the testing phase what you can or cannot do at this point. Generally, people are not happy

about but they do learn to accept it. This is when people are able to say, "I have to deal with this brain injury".



Sexuality and Brain Injury

It is possible for a person to go through an entire period of hospitalization for brain injury, return home thereafter and be fully capable of resuming sexual relationships as before their injury. Very rarely would there be any medical restriction upon sexual activity. If there is a piece of skull bone missing, sexual activity should probably be somewhat gentle. If there is any doubt or concern, it is always best to ask your physician.

If there are sexual changes after brain injury, the most common change is decreased interest in sexual activity. There can be hormonal changes directly related to the brain injury. If so, certain blood tests can help identify the problem. Sometimes supplying a missing hormone can remedy the issue.

Depressed mood is usually accompanied by loss of interest in sex. When the depression ends, interest returns.

Many medications are known to alter sexual function in males. If the offending drug is removed or changed, the problem may end.

Occasionally there is sexual disinhibition after brain injury but this is relatively rare. This kind of problem is most common after injury to the orbitofrontal cerebral cortex. When this is an issue, the unaffected partner has to be the one who sets the limits upon whatever interaction takes place because the fundamental issue is that the injured person is unable to set their own limits.

A person who is recovering from injury to the brain – even concussive injury – may be experiencing a great deal of uncertainty and self-doubt. Their self-image may be significantly affected. They may feel ugly or unattractive. This can have a major impact upon sexuality. Good communication can sometimes overcome an issue like this. Sometimes the right counselor can be helpful.

If a sexual matter is affecting your life, you really should bring it to the attention of a trusted MD or nurse. Sexual issues can and should be raised with a rehab physician, primary care MD and/or OB-GYN.



Prevention and Brain Injury

There are many ways to reduce the chances of sustaining a traumatic brain injury, including:

- 1. Buckling your child in the car using a <u>child safety seat</u>, <u>booster seat</u>, <u>or seat belt</u> (according to the child's height, weight, and age).
- 3. Wearing a seat belt every time you drive or ride in a motor vehicle.
- 4. Never driving while under the influence of alcohol or drugs.
- 5. Wearing a helmet and making sure your children wear helmets when:
 - a. Riding a bike, motorcycle, snowmobile, scooter, or all-terrain vehicle
 - b. Playing a contact sport, such as football, ice hockey, or boxing
 - c. Using in-line skates or riding a skateboard
 - d. Batting and running bases in baseball or softball
 - e. Riding a horse
 - f. Skiing or snowboarding
- 6. Making living areas safer for seniors, by:
 - a. Removing tripping hazards such as throw rugs and clutter in walkways;
 - b. Using nonslip mats in the bathtub and on shower floors; Installing grab bars next to the toilet and in the tub or shower;
 - c. Installing handrails on both sides of stairways;
 - d. Improving lighting throughout the home; and
 - e. Maintaining a regular physical activity program, if your doctor agrees, to improve lower body strength and balance.^{1,2,3}
- 7. Making living areas safer for children, by:
 - a. Installing window guards to keep young children from falling out of open windows; and
 - b. Using safety gates at the top and bottom of stairs when young children are around.
- 8. Making sure the surface on your child's playground is made of shock-absorbing material, such as hardwood mulch or sand.⁴

Resource: http://www.biausa.org/



Safety Issues

Once a person has a brain injury, he or she is 3 times more likely to have a second brain injury. After the second brain injury, the chances of having a third brain injury increases by 8 times.

There may be problems with judgment, decision-making, motor control and impulsivity. Because of this, it is essential that personal safety is always on the forefront.



Individuals with a brain injury may have problems with judgment, decisionmaking, motor control, and impulsivity. For this reason, personal safety should be a concern to prevent any further injuries.

Hospital Safety: While you are in the hospital, we will be keeping a close eye on you. It is extremely important that you do not try to get up on your own. Wait and press your call-light and wait for help. We also ask that your family does not get you up, unless they have had teaching with your therapist. Teaching for transfers can be scheduled through the in-patient physical therapy department.

Other safety concerns may include placing a bed or chair alarm on your bed and chair. This is to help to remind you to wait for assistance before getting out of the chair or bed. We also may utilize a "wanderguard" bracelet that alerts the staff when you leave the nursing unit. We ask you do not leave the nursing unit unless family or our staff accompanies you.



Home Safety: An important aspect to discharge is making sure the environment is safe. Most accidents occur in the kitchen and bathroom. These are places where people spend most of their time. Always be aware of the surroundings. Keep an eye out for wet floor surfaces as they can become slippery. In the kitchen be aware of hot surfaces. Cooking at home should only be done once approved by the Occupational Therapist. Make sure any spills are cleaned up to prevent falls. Remove knives and store them in a locked

area. Keep a fire extinguisher close by. If necessary, lock up appliances that could be potentially dangerous, including the toaster, coffeemaker, and blender.

Remember to keep heavy traffic areas free of clutter and remove small rugs and runners to prevent falls. Make sure any throw rugs are secured in place with a rubber backing. Remove any extension or phone cords from walkways to prevent tripping.

HOME SAFETY CHECKLIST

OUTSIDE THE HOME:

✓ Entryways are well-lit Remove/secure rugs at entryway.

- ✓ Railings/steps are secure and safe
- \checkmark Have keys handy.
- ✓ Always have railings be aware of ice/slush.
- \checkmark Avoid shoveling snow.

INSIDE THE HOME:

- ✓ Secure all electrical cords / avoid using extension cords
- ✓ Make sure all rooms are well lit.
- ✓ Use night-light.
- ✓ Remove all obstacles from pathways.
- ✓ Remove/secure all rugs.
- \checkmark Use a portable phone.
- ✓ Use a TV with remote control
- ✓ Secure railings; Install grab bars;
- ✓ Do not sit on rocking chairs
- ✓ Place all necessary items in reach. Avoid reaching (especially in kitchen).
- \checkmark Don't use a step stool.
- \checkmark Secure bed, not on wheels
- ✓ Place light and phone within reach of bed. You might also want to have a flashlight nearby in the case of a power failure.
- ✓ Use top drawers of dresser, do not bend.
- ✓ Wear short gown/robe to avoid tripping
- ✓ Wear sturdy shoes/slippers
- ✓ Properly store medications
- ✓ Properly store hazardous materials
- ✓ Make sure that hot and cold water faucets are properly marked; Make sure hot water is less than 110 degrees F.
- ✓ Lock up all medicines and poisons such as household cleaners, pesticides, gasoline, anti-freeze and bleach.

Place a list of emergency names and numbers near the phone. Never rush to answer the phone.

Personal Safety: Encourage rest periods with enough time for sleep at night. Consider wearing a medic alert bracelet. Avoid events that are noisy and crowded. Consider limiting the number of visitors and length of visits. Long visits and busy days may result in feeling more tired.

DO NOT DRIVE UNLESS YOU HAVE BEEN APPROVED BY YOUR PHYSICIAN. For this reason, we usually ask family members to keep the car keys out of reach.

Medications should be locked up taken under supervision to ensure the correct medication and dosage. See



the special section on Medications for further information. Keep an up to date list of all your current medications as well as the reason for each medication. (See additional information under the "Medication" section.)

If you have any questions about safety do not hesitate to ask. We ask that your family and friends become active participants in keeping you safe.

What's on your plate?





Before you eat, think about what and how much food goes on your plate or in your cup or bowl. Over the day, include foods from all food groups: vegetables, fruits, whole grains, low-fat dairy products, and lean protein foods.



Make half your plate fruits and vegetables.



Make at least half your grains whole.



Switch to skim or 1% milk.



Vary your protein food choices.

Vegetables	Fruits	Grains	Dairy	Protein Foods			
Eat more red, orange, and dark-green veg- gies like tomatoes, sweet potatoes, and broccoli in main dishes. Add beans or peas to salads (kidney or chickpeas), soups (split peas or lentils), and side dishes (pinto or baked beans), or serve as a main dish. Fresh, frozen, and canned vegetables all count. Choose "reduced sodium" or "no-salt-added" canned veggies.	Use fruits as snacks, salads, and desserts. At breakfast, top your cereal with bananas or strawberries; add blueberries to pancakes. Buy fruits that are dried, frozen, and canned (in water or 100% juice), as well as fresh fruits. Select 100% fruit juice when choosing juices.	Substitute whole- grain choices for refined-grain breads, bagels, rolls, break- fast cereals, crackers, rice, and pasta. Check the ingredients list on product labels for the words "whole" or "whole grain" before the grain ingredient name. Choose products that name a whole grain first on the ingredi- ents list.	Choose skim (fat- free) or 1% (low-fat) milk. They have the same amount of calcium and other essential nutrients as whole milk, but less fat and calories. Top fruit salads and baked potatoes with low-fat yogurt. If you are lactose intolerant, try lactose-free milk or fortified soymilk (soy beverage).	Eat a variety of foods from the protein food group each week, such as seafood, beans and peas, and nuts as well as lean meats, poultry, and eggs. Twice a week, make seafood the protein on your plate. Choose lean meats and ground beef that are at least 90% lean. Trim or drain fat from meat and remove skin from poultry to cut fat and calories.			
For a 2,000-calorie daily food plan, you need the amounts below from each food group. To find amounts personalized for you, go to Choose MyPlate .gov.							
Eat 2½ cups every day	Eat 2 cups every day	Eat 6 ounces every day	Get 3 cups every day	Eat 5½ ounces every day			
What counts as a cup? 1 cup of raw or cooked vegetables or vegetable juice; 2 cups of leafy salad greens	What counts as a cup? 1 cup of raw or cooked fruit or 100% fruit juice; ½ cup dried fruit	What counts as an ounce? 1 slice of bread; ½ cup of cooked rice, cereal, or pasta; 1 ounce of ready-to- eat cereal	What counts as a cup? 1 cup of milk, yogurt, or fortified soymilk; 1½ ounces natural or 2 ounces processed cheese	What counts as an ounce? 1 ounce of lean meat, poultry, or fish; 1 egg; 1 Tbsp peanut butter; ½ ounce nuts or seeds; ¼ cup beans or peas			





Look out for salt (sodium) in foods you buy. Compare sodium in foods and choose those with a lower number.

Drink water instead of sugary drinks. Eat sugary desserts less often.

Make foods that are high in solid fats—such as cakes, cookies, ice cream, pizza, cheese, sausages, and hot dogs—occasional choices, not every day foods.

Limit empty calories to less than 260 per day, based on a 2,000 calorie diet.

Be physically active your way

Pick activities you like and do each for at least 10 minutes at a time. Every bit adds up, and health benefits increase as you spend more time being active.

Children and adolescents: get 60 minutes or more a day.

Adults: get 2 hours and 30 minutes or more a week of activity that requires moderate effort, such as brisk walking.



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General Exercise

Regular physical activity provides important health benefits for everyone, including people with disabilities. Getting active can help you: strengthen your heart, build strong muscles and bones, improve coordination, relieve stress, improve your mood, and help you feel better about yourself.

Before you begin...

- Talk to your doctor about starting an exercise program. If you are taking medicine, be sure to find out how it will affect your physical activity.
- It's also a good idea to talk to a trained exercise professional. Find a fitness center near you that is comfortable and accessible. Ask if they have experience working with people with similar disabilities.

Aim for 2 hours and 30 minutes a week of moderate aerobic activity.

- This includes walking fast or pushing yourself in a wheelchair, raking leaves, or other activities that make your heart beat faster.
- Start slowly. Be active for at least 10 minutes at a time.
- Do strengthening activities 2 days a week.
- This includes sit-ups, push-ups, or lifting weights.
- Try working on the muscles that you use less often because of your disability.
- Find support and stick with it.
- Bring along a friend, especially if you are trying out a new activity.
- If you don't meet your exercise goal, don't give up. Start again tomorrow.



Smoking Cessation

Smoking Cessation:

Quitting smoking is one of the most important things you can do for your health. The sooner you quit, the sooner your body can begin to heal. You will feel better and have more energy to be active with your family and friends. Smoking is the most preventable cause of death and disease in the United States. Smoking causes:

- Lung cancer
- Many other types of cancer
- Heart disease
- Stroke
- Chronic obstructive pulmonary disease (COPD)
- Pregnancy problems
- Sudden infant death syndrome (SIDS)
- Lung disorders
- Gum disease
- Vision problems (cataracts)

How can I quit smoking?

Quitting smoking is hard, but it can be done. Start by thinking about why you want to quit. If you've tried to quit before, think about what worked and what didn't. This will help you find the right quitting strategies. Here are some things you can try to help you quit:

- Make a quit plan.
- Change your routine. For example, go for a walk instead of having a cigarette.
- Eat healthy snacks instead of smoking.
- Get medicine from your doctor or pharmacy
- Get support from family, friends, and coworkers.

Nicotine – the drug found in tobacco – is just as addictive as heroin or cocaine. It's the nicotine in cigarettes that causes the strong feeling (craving) that you want to smoke. Remember, quitting isn't easy, but it is possible!

Smoking Cessation

Your body begins to heal as soon as you quit smoking. Here are some ways you will feel better:

- You will breathe more easily.
- Your senses of taste and smell will get better.
- You will have more energy.
- Your lungs will become stronger, making it easier for you to be active.
- You will cough and wheeze (struggle to breathe) less.

Quitting smoking will help you live a longer, healthier life. After you quit smoking:

- Your chances of having a heart attack or stroke goes down.
- Your lungs can fight off infection better.
- Your chance of dying from cancer goes down.
- Your blood pressure goes down.
- Your pulse and blood oxygen level return to normal.
- If you have kids, they will be healthier. Kids whose parents smoke around them are at higher risk for lung and ear infections.

To help control your weight as you quit smoking:

- Be active- Aim for 2 hours and 30 minutes a week of moderate aerobic activity, like walking fast or dancing.
- Eat healthy snacks, like vegetables or fruit.
- Talk with your doctor about ways to control your weight.



Substance Abuse and Brain Injury

SUBSTANCE ABUSE AND BRAIN INJURY

Judith Falconer, Ph.D.

Research documents that many individuals who sustain head injuries have histories of recreational drug and alcohol abuse and, in many cases, consumed such substances immediately prior to their accidents. Although this paper focuses primarily on abuse of recreational drugs and alcohol, it is critical to keep in mind the possible role of other substances in complicating and confounding the total picture in head injury

- Misuse, abuse or mixing of non-prescription (OTC) drugs may also interfere with recovery following a head injury, and/or may complicate long term adjustment to residual deficits.
- Survivors may also abuse more common substances such as tobacco, caffeine and vitamins.
- Survivors and their families may utilize megavitamin therapy in the belief such a practice will speed recovery. The effect of such a practice is unknown but vitamins are powerful chemical substances which can disrupt metabolism and, in large doses, may be toxic.

The Chronology of Substance Abuse in Head Injury

Pre-injury substance abuse: In addition to the social, psychological and behavioral problems involved in substance abuse, pathological changes, some of which are irreversible, have been demonstrated within the brain and central nervous system. The absolute amount of brain damage depends upon the drug(s) utilized, their purity and the frequency/duration of abuse.

Acute care: Differential diagnosis is more difficult when a head injury is accompanied by moderate to high levels of blood alcohol or drugs: the behaviors noted following acute intoxication and overdose are similar to those following head injury (lethargy or agitation, confusion, disorientation, respiratory depression, etc.). Patients may be discharged from the emergency room with a diagnosis of intoxication when they have also sustained an undiagnosed head injury.

Acute rehabilitation: By the time the individual enters rehabilitation, physiological withdrawal from recreational drugs or alcohol has usually been completed. Unfortunately, psychological dependency has not usually been addressed so the problem continues to pose an underground threat. Patients and family members are not likely to voluntarily admit to substance abuse in fear of making the patient appear a poorer candidate for rehabilitation; accompanying medical records may not include this information. In rehabilitation the patient interacts with others who may have histories of drug and alcohol abuse. The relative social freedom of many rehabilitation settings allows drugs and alcohol to be introduced or re-introduced. Home passes may begin and peers may visit, some of whom may be chemical users.

A number of myths exist about the positive effects of drugs, especially marijuana, on post-injury medical problems such spasticity, ataxia, and dysarthria. As a consequence, even the individual who has no history of drug use may experiment with such substances in an attempt to relieve troublesome symptoms.

Community Care: Once discharged into the community, opportunities to resume previous relationships and behavior patterns surface. With the structure of the rehabilitation setting withdrawn, the individual has

Substance Abuse and Brain Injury

significantly more free time and fewer activities with which to fill that time. In many cases, former friends rarely visit. Family members return to their own lives out of economic and social necessity.

Physical, cognitive, emotional and behavioral limitations frequently preclude many favored pre-injury activities. Since the cognitive and physical requirements for successful drug and alcohol abuse are minimal, such behaviors are readily accessible to even severely injured individuals and may well provide both a link with the past and an entrée into peer groups. Individuals who previously refused marijuana, alcohol or other drugs may now accept such substances in an attempt to be "one of the guys".

Within the non-adapted home and community, the full impact of various deficits may be experienced for the first time. Rather than deal with the emotional consequences of such awareness (e.g., depression, frustration and boredom) the individual may seek refuge in the bottle, especially if such a pattern existed in the past. In sharp contrast to the rejection experienced in other social situations, members of the drug culture extend a warm and friendly welcome and cognitive and physical limitations are readily accepted.

Family members may be uncomfortable denying alcohol to an adult who was previously allowed to drink: "everything else has been taken away; I can't take away that one remaining pleasure." Which is understandable but ignores the fact that tolerance for alcohol is decreased following a head injury and even in small amounts further decreases cognitive and physical functioning. In this framework, it may be easier for the caregiver to refuse alcohol.

Those individuals with less severe disabilities may well be able to obtain drugs and alcohol independently but with limited financial resources, they may purchase such items at the expense of more essential resources. They may also fall easy prey to unscrupulous drug dealers and pushers who sell oregano as marijuana.

The deficits which commonly follow head injury are such that the affected individual may well be questioned and/or arrested by local authorities as drunk or high: slurred speech, unsteady gait, poor memory, and altered moods can quite easily be misinterpreted. Survivors may then feel "I got the name, I might as well have the game."

Detecting Substance Abuse

Given the memory deficits experienced by many survivors, expectation of accurate self-reporting of substance abuse may be unrealistic. The individual may truly not recall having consumed inappropriate chemical substances or may underestimate amounts consumed. At the same time, however, cognitive and behavioral limitations make it less likely that the abusing individual will be able to successfully hide patterns of substance abuse. For those involved in providing supervision, detection may be quite difficult: substance abuse behaviors are similar to those frequently seen after head injury: unsteady gait, decreased memory, uninhibited behavior, euphoria, sleep disturbance, altered appetite, visual disturbances, etc. But drug or alcohol effects are superimposed upon the injured individual's *typical* post-injury cognitive, physical, emotional and behavioral patterns. Detection becomes a process of noting decreases in functional abilities which are not explainable on any other basis and which coincide with time periods where alcohol or drugs might have been consumed. It is critical, however, to ensure that such functional decreases are not explainable in terms of acute illnesses (e.g. respiratory infections, hydrocephalus, and development of seizures) or newly instituted medications.

Preventing Substance Abuse

Given the difficulty altering patterns of substance abuse in individuals who have not sustained head injuries, it is not surprising that the same problem is experienced when working with survivors. Since many survivors are unable to obtain employment, the threat of job loss is an empty one. And given social norms which exert strong pressure on family members to take care of individuals who are ill, threats to remove family support are rarely credible. Repeated attempts to "persuade" the injured individual to avoid chemical substances are usually unsuccessful. This is largely attributable to the kinds of cognitive and behavioral deficits typically found after head injury: decreased judgment and reasoning; impaired abstraction; decreased generalization ability; and impaired memory. The individual with moderate to severe head deficits may vehemently deny the existence of any disabilities and feel attempts to change pre-injury behavior are unnecessary and inappropriate.

Probably the best way to prevent substance abuse following head injury is to ensure sufficient meaningful relationships and activities to maximize quality of life: if there are no voids, there will usually be no attempts to fill them with chemicals. While it is impossible to force others to interact with survivors, using appropriate behavior management techniques can maximize the social behavior of the survivor. Exploration of community services such as support groups, YMCA/YWCA, UCP, adapted recreational services, and community colleges, may aid in the search for appropriate social opportunities.

Wherever possible, survivors should be involved in active rehabilitation to remediate deficits and to ensure maximal recovery. Once the individual's medical status is stable, continued reliance on the medical model may encourage dependency upon medical approaches to deficit remediation, including use of chemicals for behavior control. At that point in the recovery process, cognitive and behavioral rehabilitation approaches are more likely to be successful in preventing substance abuse since they require injured individuals to accept responsibility for their own behavior, provide consistent objective feedback on performance, and more directly address the long term deficits which lead to substance abuse.

Caregivers who are aware of substance abuse problems need to ensure that cues to engage in such activity are withdrawn from the environment. Alcohol may need to be removed from the house or stored in locations which are inaccessible to the survivor. This may also include denying opportunities for social relationships with pre-injury friends who are known to abuse chemicals. Obviously, the caregiver becomes the "heavy" when such tactics are required but there is no reasonable alternative. Reasonable limitations on access to funds may be necessary to prevent purchase of chemical substances.

Conclusion

Substance abuse can frequently be prevented, even when it was present prior to the injury. While many individuals with a history of substance abuse may benefit from formal drug and alcohol rehabilitation programs, such programs are not usually designed to address the physical and cognitive limitations of those who have sustained head injuries. Should enrollment in such a program be considered, it is essential that program personnel be fully apprised of the medical problems of the survivor to ensure that medical needs are met. Family members must be aware that some individuals who sustain head injuries will continue with or develop patterns of substance abuse which are intractable. While this is unfortunate, feelings of guilt and failure are not justified if reasonable attempts, including enlisting professional assistance if necessary, have been made. It is unrealistic to expect all individuals who have sustained head injuries to avoid substance abuse when it is so prevalent in our society.

References:

J. S. Kreutzer, et.al. A prospective longitudinal multicenter analysis of alcohol use patterns among persons with traumatic brain injury. J. Head Trauma Rehabil. 1996:11(5): 58-69.

J. D. Corrigan, E. Rust, and G. Lamb-Hart. The nature and extent of substance abuse problems in persons with traumatic brain injury. J. Head Trauma Rehabil 1995:10(3): 29-46.

1.1 Who Is at Risk for Developing a Substance Abuse Problem After TBI?

Many people who incur a traumatic brain injury have a substance abuse problem prior to their injury. As a result, it is not surprising that a number of people after they have had traumatic brain injury also have a substance abuse problem. Adolescents and adults who are hospitalized for traumatic brain injury are much heavier drinkers than their peers who have not incurred a TBI. However, for traumatic brain injury as well as for other injuries, there is often a "honeymoon" after the injury when the amount of drinking stops or reduces (Bombardier, Temkin, Machamer & Dikmen, 2003; Corrigan, Lamb-Hart & Rust, 1995; Kreuzer, Doherty, Harris & Zasler, 1990; Krueutzer, Witol, Sander, Cifu, Marwitz & Delmonico, 1996).

A few studies of persons with traumatic brain injury have found that alcohol use gets worse in the period 2 to 5 years after the injury and that unless something is preventing them, many resume their prior levels of alcohol and other drug use (Corrigan, Rust et al., 1995; Kreutzer, Witol et al., 1996; Kreutzer, Witol et al., 1996; Corrigan, Smith-Knapp et al., 1998). Situations that limit resuming use include having to live in an institutional setting where alcohol and other drugs may be less available, or living under closer supervision of family members who help the individual consume less. Of course, use may reduce or stop if the individual is provided information about the effects of alcohol and other drugs after traumatic brain injury or, for people with actual substance abuse problems, being provided treatment.

In addition to the large number of individuals who had a substance use disorder before their injury and return to those levels after, some studies have indicated that between 10% and 20% of persons with traumatic brain injury develop a substance use problem for the first time after their injury (Corrigan et al., 1995; Kreutzer et al., 1996). Thus, taken together, it is a very high proportion of individuals who have been hospitalized for traumatic brain injury who will be at risk for developing a problem after their injury — either because they had one before or because of the vulnerabilities created by the injury itself.

"Substance abuse is a risk factor for having a traumatic brain injury and traumatic brain injury is a risk factor for developing a substance abuse problem." –John Corrigan

1.3 How common is a history of substance abuse before the injury?

Corrigan (1995) reviewed published literature on persons with TBI who were intoxicated at time of injury and those who had a prior history of substance use disorders, whether or not they were intoxicated. Based on articles reporting these variables, having a prior history of substance abuse was more common than being intoxicated at the time of injury. Additionally, clinicians and researchers who used screening tools during the hospital stays found significantly higher rates than those who relied on later medical record review. This result suggests that more people will be identified if a systematic method of inquiring is used; rather than counting on patients to volunteer information or relying on reports of intoxication at injury. Since that review, there are several additional sources of data on the frequency of prior substance use disorders in adolescents and adults treated in acute rehabilitation. Results from the following articles are graphed below:

- TBI Model Systems National Database (n=1,262; Corrigan et al., 2003): 43% problem alcohol use or worse, 29% illicit drug use, 48% history of either;
- OSU Suboptimal Outcomes Study (n=356 consecutive admits to acute rehab): 54% alcohol abuse or worse, 34% other drug abuse or worse, 58% history of either;
- University of Washington (n=142 consecutive admits to acute rehab, Bombardier, Rimmele & Zintel, 2003): 58% at-risk alcohol use or worse, 39% recent illicit drug use, 61% history of either.

For adolescents and adults who require inpatient rehabilitation-as many as 60% may have a prior history of substance use disorder.

1.4 How common is TBI among persons receiving substance abuse treatment?

While there has not been a definitive, population-based study of how many individuals receiving treatment for substance abuse problems have incurred traumatic brain injuries, a collection of studies in the last 20 years suggests that it may be as high as 50%. The studies are summarized below and their results are graphed in the accompanying figure. The lowest rate observed was 38% of persons in treatment, the highest was 63%. Visual inspection of the graph supports an estimate of 50%, if not more.

2.1 How does substance abuse affect a person who has had a traumatic brain injury?

There are multiple reasons why alcohol and other drug use after traumatic brain injury is not recommended. The substance abuse education series "User's Manual for Faster, More Reliable Operation of a Brain after Injury" (Ohio Valley Center, 1994) enumerates eight reasons:

- 1. People who use alcohol or other drugs after they have a brain injury don't recover as much
- 2. Brain injuries cause problems in balance, walking or talking that get worse when a person uses alcohol or other drugs.
- 3. People who have had a brain injury often say or do things without thinking first, a problem that is made worse by using alcohol and other drugs.
- 4. Brain injuries cause problems with thinking, like concentration or memory, and using alcohol or other drugs makes these problems worse.
- 5. After brain injury, alcohol and other drugs have a more powerful effect.
- 6. People who have had a brain injury are more likely to have times that they feel low or depressed and drinking alcohol and getting high on other drugs makes this worse.
- 7. After a brain injury, drinking alcohol or using other drugs can cause a seizure.
- 8. People who drink alcohol or use other drugs after a brain injury are more likely to have another brain injury.

2.2 How is the brain affected?

There is mounting evidence about the adverse effects of alcohol and other drug use after traumatic brain injury. Several studies have observed an association between use and such unwanted outcomes as unemployment, living alone and feeling isolated, criminal activity and lower life satisfaction (Sherer et al., 1999; Corrigan et al., 1997; Kreutzer et al., 1996; Kreutzer et al., 1991; Corrigan et al., 2003). While these studies have observed associations, the causal links or processes have not been fully explained.

There are also studies suggesting an "additive effect" on brain structure and function for substance abuse and traumatic brain injury (Barker et al., 1999; Baguley et al., 1997; Bigler et al., 1996). One example is the study by Ian Baguley and colleagues from Australia (see graph below). Their 1997 study of event-related evoked potentials (an indication of how fast the brain detects new stimuli) showed a clear additive effect of heavy social drinking and traumatic brain injury requiring hospitalization. Those subjects who had either of these conditions were slower responding then people with neither; and those with both were slower still.

3.1 Are there treatment approaches that have been proven effective for people with traumatic brain injury?

Clinicians and researchers have repeatedly observed that cognitive and emotional impairments caused by brain injury present unique problems when addressing co-existing substance use disorders (Langley, 1991; Center for Substance Abuse Treatment, 1998; Corrigan, Bogner et al., 1999). While several models of how substance abuse treatment can be adapted to traumatic brain injury rehabilitation were proposed in the past (Blackerby & Baumgartnen, 1990; Langley, 1991), most presumed protracted inpatient or residential treatment that is no longer available to most persons with traumatic brain injury. Bombardier and colleagues have recommended brief interventions based on motivational interviewing techniques for use during acute rehabilitation (Bombardier, Ehde & Kilmer, 1997; Bombardier & Rimmele. 1999). Cox, Heinemann, et al. (2003) found some support for Structured Motivational Counseling in a study using a non-random comparison group.

A community-based model for treatment of substance abuse and traumatic brain injury was proposed by Corrigan and colleagues (Corrigan, Lamb-Hart & Rust, 1995; Bogner, Corrigan, Spafford & Lamb-Hart, 1997; Heinemann, Corrigan & Moore, 2004). The model uses consumer and professional education, intensive case management, and inter-professional consultation to address substance use disorders in adults with traumatic brain injury. Program evaluation data suggest significant differences in outcomes depending on whether discharge occurred before an eligible client could be engaged in treatment (eligible but untreated), after initiation of treatment but before treatment goals were met (premature termination) or upon mutual agreement with staff that goals had been met (treated). The Network's three programmatic outcomes (abstinence, return to work or school, and subjective well-being) assessed three months post-discharge are shown below. The median length of stay for those discharged successfully is 2 years. As might be expected, drop-out is a significant problem in this model. Retrospective analysis of 1,000 consecutive referrals indicated that 66% of those eligible for treatment either are not engaged initially or drop out prematurely.

Resource: http://www.brain-train.com/articles/substanc.htm



Leisure and Recreation and Brain Injury

Participation in meaningful leisure experiences is essential to the recovery of the person with a brain injury. Most people naturally select certain activities that they enjoy and help them meet some basic needs.

People with brain injuries may face barriers to experiencing this kind of fulfillment, including:

- Attitude (some people may not realize the importance of leisure activities)
- Physical disability (they may no longer be able to enjoy the activities they once did)
- Lack of cognitive skills (skills needed to participate in some activities attention,
- concentration, initiation, planning, problem solving may be impaired)
- Interruption of social and/or language skills
- Lack of knowledge (some may not know how to engage in certain leisure activities
- or how to adapt them so they can participate)

Family members can help by:

- Helping the person identify leisure interests
- Assisting with structuring time and daily schedules so that leisure
- balances with necessary tasks and activities
- Planning ahead for recreation to keep life interesting
- Investigating community resources (city parks/recreation departments,
- libraries, churches, and other avenues for leisure options)
- Through leisure, basic human needs are met, including:
- Feeling good about ourselves
- Being part of a group
- Competing with ourselves and with others
- Experiencing success
- Laughing and having fun (reducing stress)
- Developing useful skills
- Developing friendships
- Strengthening social relationships

Source: Understanding Brain Injury, A Guide for the Family, Mayo Clinic

A General Guide for Taking Medicines

This information will help you when taking any medicine. In addition to these guidelines, you need to have specific information about each medicine you are taking. Your doctor, pharmacist or nurse can give you that information.

Before Taking Your Medicine:

Before you take any new medicine, tell your doctor if:

- You have ever had an allergic or unusual reaction to any medicine, herbal product, food or other substance. Ask your doctor or pharmacist if you have questions.
- You are on a low salt, low sugar or any other special diet. A special diet can change how a medicine works.
- You are pregnant or if you plan to become pregnant. The use of any medicine during pregnancy must be carefully considered. Your obstetrician or pharmacist will be able to tell you of the safety of any medicines you take during pregnancy.
- You are breastfeeding. Some medicines pass into the breast milk and can cause undesirable side effects in your baby.
- You have taken any prescription, over the counter medicines, herbal products or dietary supplements in the past few weeks. Medicines can change how other medicines work.

More on next page **→**

Learn more about your health care.

© Copyright, (11/7/2007) Department of Pharmacy, Ohio State University Medical Center - Upon request all patient education handouts are available in other formats for people with special hearing, vision and language needs, call (614) 293-3191.



What You Should Know About Your Medicines:

- Please ask questions about medicines you are taking. Write down your questions and take them with you to your doctor's visit. Your pharmacist also can answer questions about the medicine when the prescription is filled.
- Learn both the generic and brand names.
 - ▶ Generic medicines:

In most cases, generic medicines are the same as brand name medicines. There are some exceptions. Your pharmacist will be able to tell you which medicines can be substituted with a generic and which should not.

- Make a list of your all your medicines and keep it with you. Your medicine list should include:
 - Prescription medicines
 - Over the counter medicines
 - Vitamins and herbals
 - Dietary supplements
 - Sample medicines
 - ▶ Skin patches, eye drops, inhalers, creams and ointments
- Find out the following information about all your medicines and write it down so you can refer to it as needed:
 - ▶ Why am I taking the medicine?
 - What does the drug do?
 - What is the strength of my medicine?
 - ▶ How much do I take?
 - ▶ What time should I take it?
 - ▶ Should I take this medicine with food?
- ▶ What food, drink or activities should I avoid while taking it?
- ▶ What are the usual side effects and what do I do if they occur?
- ▶ What do I do when I forget to take my medicine?
- ▶ What do I do in case of an accidental overdose?
- ▶ How long do I take it?

Proper Use of Your Medicine:

- Take your prescribed medicines at the right time and for the full length of time. If any unusual side effects occur, call your doctor.
- If you take medicine each day, ask for a refill several days before your supply is gone.
- Take over the counter medicines as directed on the label. Talk with your pharmacist before you choose an over the counter medicine. If the medicine does not work within the time it claims, call your doctor.
- It is important to take your medicine(s) exactly the way it is prescribed, even if you feel better. In some cases, the medicine may need to be given for years or the rest of your life to control a disease or problem.
- Do not stop taking your medicines without checking with your doctor.
- Always read the label before taking any medicine. Check the date on the bottle and throw out those medicines that have expired.
- Child proof caps are required by law. This law has reduced the number of accidental poisonings. If there are no children in your home, ask your pharmacist for an easy to open cap. You may need to sign a release form to get the easy to open caps.

How to Store Your Medicine:

• Keep your medicines tightly capped in the original bottle. Never put different medicines in one bottle to store for a long time. If you use a pill reminder box to help you to take the medicine, put in only enough medicine for the day or week you use this item.

- Keep a list of each medicine you put into the pill reminder.
- Store your medicines away from heat and direct sunlight. Do not put medicines in bathroom cabinet, because heat and moisture may cause them to change. Store medicine in a kitchen cabinet, away from heat, but where children cannot get to them. Do not store medicines in the refrigerator or freezer unless you are told to do so.
- Outdated medicines or any prescription medicine not used for more than one year should be thrown out. Check with your pharmacist about how to get rid of them safely. Do not throw old medicines in the trash can.
- If you have chemotherapy medicines, ask your pharmacist how to safely handle and dispose of these.

Precautions:

- Do not give your prescription medicine to other people. This can be very dangerous and it is against the law. The medicine is for your problem and may not be the correct treatment for another person.
- Before you have surgery or emergency treatment, tell your doctor or dentist about medicines you are taking. Be sure to include any vitamins, herbals or other over the counter medicines.
- If you take more medicine than prescribed, call the poison control center, your doctor or pharmacist right away. Keep local telephone numbers close to the telephone.
- Use only one pharmacy so the pharmacist has a record of all of your medicines. This allows for checks that your medicines can be taken together safely.
- Talk to your doctor or others on your health care team if you have questions. You may request more written information from the Library for Health Information at (614) 293-3707 or email: healthinfo@osu.edu.



Medications

Medications are an important part of your recovery. Some of the types of medications you may be placed on during your recovery include the following:



- ✓ Anticonvulsants or Anti-Seizure Medications: These medications may be prescribed to treat and prevent seizures. It may also be used to treat certain types of pain, to decrease agitation and aggression, or to treat other conditions as determined by your doctor.
 - **Precautions:** Do not stop taking the medication without talking to your doctor first. Abrupt stopping of this type of medication could cause serious side effects. You might also consider wearing a Medic Alert bracelet informing emergency personnel that you are on this medication if you are taking it for seizure control. Check with you doctor before adding over the counter or other prescription medications to your current regimen.
- ✓ Stimulants: This type of medication is used to stimulate the brain and keep you alert as well as help attention, concentration, and initiation. It may also be used to decrease aggression, agitation, fatigue and impulsiveness.
- ✓ Antidepressants: These types of medications are used to treat depression or other conditions as determined by your doctor, such as to increase arousal or attention.
- ✓ Anti-spastic agents: These are medications that help to relax skeletal muscles, the muscles that move the skeleton (also called striated muscle). It is used for treating spasms of the skeletal muscles that cause muscle clonus, and rigidity.
- ✓ Anticoagulants: These medications help to prevent and treat blood clots in blood vessels. They may also be used to treat and prevent certain types of acute heart attacks. The names of some anticoagulants you might be receiving include: Coumadin, Arixtra, Heparin, Lovenox and Aspirin.
 - Some of these medications might require lab testing to ensure the proper dosage. Check with you physician and nurse regarding which medication requires this.
 - **Precautions:** While you are on anticoagulants, take extra care to report any unusual bleeding or bruising to your physician right away. It is highly recommended that you wear a medical alert bracelet.
 - Diet: Some of these medications require special considerations for your diet including eating vegetables with Vitamin K. Check with your nurse or dietician to ensure you are on the proper diet.
- ✓ Anti-Anxiety Medications: These medications may be prescribed for you to help you decrease your anxiety as you continue to recover. If you find yourself increasingly fatigued, please speak to your physician regarding the effects of this type of medication.
- ✓ Sleep Aids: During your course of your recovery, you may find yourself having trouble sleeping,

This is not uncommon. Your physician may order medications to assist you with your sleep pattern. Make sure you only take the medication as directed. The goal is for you to have a good night sleep so that you may be better able to participate in your recovery.

FOR ALL MEDICATIONS: Make a list of the current medications and any over the counter medications you take regularly <u>and</u> bring it with you to <u>ALL</u> your doctor appointments. It is extremely important that all

of your doctors know what medications you are on. There are some medications that might interact with other medications you are currently taking, Also, make sure you ask for information on all the medications you are taking, including actions, side-effects, precautions etc. Be sure you read how to store the medication as well.

If you miss a dose for any of the above medications, call your doctor of pharmacist for instructions. Check also with your doctor before adding any over the counter or other prescription medications to your current regimen. Store this type of medication at room temperature in a tightly sealed container away from heat, light and away from children. Store it away from moisture (not in the bathroom).



AND FINALLY, If you have any questions regarding your medications, please do not hesitate to ask. We are here for your health.



What Happens After Acute Care

What Happens After Acute Care in New Hampshire?

Many patients need additional care or therapy after discharge from the acute care hospital. Members of the health care team will discuss their recommendations for continued care with you. They will also talk with you about possible ways to pay for rehabilitation. Funding sources will depend on the specific situation of your family member.

Rehabilitation includes services and therapies such as medical, psychological, physical, occupational, cognitive, speech and recreation. The amount and frequency of therapies are based on the patient's needs and what the facility or program is licensed to provide. The following are some options that may be available.

Discharge to a Rehabilitation Facility

Acute Inpatient Rehabilitation: This may be provided at either a hospital or freestanding rehabilitation facility that offers 24-hour nursing care. After acute rehabilitation, patients may be transferred to sub-acute rehabilitation or discharged home.

Sub-acute Rehabilitation: Sub-acute care is provided in an inpatient setting, such as a nursing home, with 24-hour nursing care. Some patients may transfer from this setting to acute inpatient rehabilitation if appropriate, or discharged home.

Skilled Nursing Facility: These facilities are more focused on medical needs and have 24-hour nursing care. Therapies are provided as appropriate to meet medical needs.

Discharge to Home

The health care team and family will assess the home setting to ensure patient safety and determine equipment needs. The patient may need therapy or other care. Some options are:

Outpatient Rehabilitation: The outpatient program might consist of one or several kinds of therapy, depending on what the patient needs. Therapy is provided in a variety of settings.

Home Care: Rehabilitation services may also be provided in the home setting. Skilled nursing care and home health aides can also be part of home care.

Community Based Programs: These programs provide services and training to help people adapt, find employment, and be active in their communities. In some programs, the services are provided while the person is living in their own home. In others, the individual lives in housing provided by the program.

What is a Community Care Waiver?

It is a waiver from the federal government to provide Medicaid funding for community-based services for persons with brain injuries who need an extensive level of care and services, in lieu of having the services provided in a skilled nursing or long-term rehabilitation facility. The focus of the Waivers is to improve the quality of life for eligible consumers while providing a more cost effective use of existing Medicaid funds. There are three community care waivers for brain injured individuals.

For eligibility information and to apply for the Acquired Brain Disorder Waiver and the Developmentally Disabled Waiver, please contact your local Area Agency (contact information listed in the following resource section).

For information on the Elderly and Chronically Ill Waiver, contact your District Office of Human Services (contact information listed in the following resource section).

We're Home... Now What?

It may be a relief to be back home, but it may also be a little scary. Often families have many questions as they try to establish routines and help their loved one work towards more independence. A list of resources that may be helpful is provided in the following pages.

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Questions to Consider Before Discharge

There are many things to think about and learn as you or your loved one returns home. The following questions may serve as a guide for issues to consider and discuss with the healthcare team prior to discharge. The list is not intended to be comprehensive and some questions may not apply to your situation.

Medical

- ✓ Does my loved one need medical follow-up and outpatient therapy? Have the appointments been scheduled? Will my insurance cover the cost?
- ✓ Are home care services required? Will my insurance cover the cost? What agency is supplying the services? Have they been scheduled?
- ✓ Do I have prescriptions for outpatient therapies, home care services and equipment?
- ✓ What are some things I can do to assist with personal care and rehabilitation?
- ✓ What medication will my loved one be taking? What is the medication schedule? Will I be given an adequate supply with refills, or do I need additional prescriptions? Is this a standard drug or will the pharmacy need to special order it?
- ✓ Will my loved one need to follow a special diet?
- \checkmark Do I know how to contact the doctors who have been caring for my loved one?
- ✓ Who do I contact in an emergency?
- ✓ Have I prepared a plan in the event of an emergency? For example, who will accompany the patient and who will watch the children?
- ✓ Have I gathered all pertinent medical records?
- ✓ Is my loved one safe to be left alone? What type of supervision is required?

Equipment and Home Modification

- ✓ Will my loved one require special equipment? Will my insurance cover the costs? What company is supplying the equipment? Has it been ordered?
- ✓ Do I know how to use the special equipment?
- ✓ How do I properly assist with transfers from the wheelchair, bed, commode or car?
- ✓ Do I need to consider special modifications for my home, such as wheelchair ramps, or accessible bedroom and bathroom?
- ✓ Do I have comfortable, functional clothing for my loved one to wear?

Education and Work

- ✓ Have I contacted my loved one's school or place of employment to inform them of injury?
- ✓ What therapy and education services must the school system provide for my child? Do I have prescriptions from the doctor for these therapies?

Finances, Support and Community Resources

- ✓ Have I explored financial resources, for example, disability insurance, Social Security and Medicaid?
- ✓ What transportation resources are available?
- ✓ What is respite care? Is it available to me? How do I apply for it?
- ✓ Have I been made aware of available community resources, and do I have them in written form?
- ✓ Do I have a spiritual support system, a church, synagogue or temple that could provide emotional and pastoral support?
- ✓ Who are the people available and willing to provide ongoing support, for example, professionals, clergy, family, friends and neighbors?
- ✓ Do I have the phone number of the Brain Injury Association for my state?

Source: The Brain Injury Association of NH

Community Onnections linics



Brain Injury and Stroke

NH Residents Brain Injury, Stroke and Neurological Survivors/Families

Salem, NH: 2nd & 4th Wednesday of Every Month 3:00 PM – 5:15 PM

Portsmouth, NH and Nashua, NH: One time a month by Case Manager Referral

- Ongoing community case management
- Support services from NH Brain Injury Association
- Assistance with application for community resources
- Financial services linkages



MA Residents Brain Injury, Stroke and Neurological Survivors/Families

Appointments by request

- Support services from MA Brain Injury Association
- Assistance with application for community resources



MA Residents

(Brain Injury and Statewide Specialized Community Services) **Traumatic Brain Injury Survivors** Appointments by request

- Ongoing community case management
- Support services
- Financial services linkages



Location of clinics will be posted prior to event. Please call Case Management with any questions.

Making the Most of Visits with Your Doctor

Talking with a doctor or other health care professional is stressful for most people. It is a good idea to organize your information and questions before your visit. Here are some suggestions that will help you make the most of any medical care visit.

Preparing for the Visit

- Write down questions before you plan to see your doctor. Underline or highlight the major problems you want to talk about. Keep this information organized in a folder or notebook.
- Try to be specific when describing your symptoms or problems. Notes may help you. For example, if you have headaches, tell the doctor when you get them, how long they last, if you get dizzy, etc.
- Bring along information and dates about your personal health history. This could include procedures, tests, surgeries, medicines and health conditions.
- Come ready to talk about all remedies you use for your health or to control an illness. Your health care professionals need to know about all treatments you use. Here are examples of remedies that should be discussed:
 - ▶ Vitamins, supplements
 - Special nutrition

More on next page →

Learn more about your health care.

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- Herbal remedies
- Massage or touch therapy
- Movement or dance
- Meditation, guided imagery
- Biofeedback, hypnosis
- Counseling, psychotherapy
- Non prescription medicines
- Any other self help therapies
- Most doctor visits are 10 to 15 minutes long. This means you will need to be organized to ask questions that you want to know.
- Bring a friend or family member to help listen and take notes. It is easy to forget much of what is talked about during an office visit. This is often true if information is given that was not expected.
- Bring something along to do during waiting time. Make a plan for your absence from work or home in case you have an unexpected delay.
- Bring all the medicines you are taking (prescription and over the counter) in their original containers.
- Ask for copies of recent scans and reports you have had, and bring them along.

During the Visit

- Let the doctor know how much or how little you want to know. If you don't want or need pictures and detailed explanations, say so.
- If you want to know the details, tell the doctor you want as much information as you can find. Ask for references on the subject and check the library for information. Write or call local offices of organizations related to your illness for information. You might call or visit OSU Medical Center's Library for Health Information (see note below.)

- Ask questions such as:
 - ▶ What signs should I watch for?
 - ▶ How can I help myself?
 - ▶ What are the side effects of this treatment?
 - ▶ What may I expect in the future?
 - ▶ How might this affect my ability to ...?
- Repeat anything important that has been said to help you remember.
- Make certain that you:
 - Understand what you are to do at home. Get written instructions if needed.
 - Know what medicines you need to take, and how and when to take them.
 - Remember to ask the doctor to give you prescriptions for your medicines.
 - Ask about changes in your diet that you should follow.
 - Find out if there are changes in activity or exercise that you should do.
- Be assertive, not aggressive, about asking questions. If the discussion gets off the topic, bring it back to your concerns. If the doctor is called out of the room while you are talking, remind him or her of what you were talking about. For example, "Just before the interruption, we were talking about a problem I am having with . . ."

Points to Consider

• Remember that there are some questions that your doctor cannot answer. There are unknowns.

• As a patient, you have choices. You may get a second opinion. You may ask about changing the treatment plan. If you and the doctor cannot communicate well, you may change to a different doctor.

Related Materials: Ask for "Information for my Doctor or Health Care Provider"

 Talk to your doctor or others on your health care team if you have questions. You may request more written information from the Library for Health Information at (614) 293-3707 or email: health-info@osu.edu.



Respite Care and Brain Injury

New Hampshire

Eligibility-Respite Care and Supplemental Services

Grants for temporary respite and supplemental services are available through the NH Family Caregiver Support Program for eligible full time family caregivers who are personally providing unpaid care, full-time care to a frail individual who is 60 years of age or older.

Eligibility requirements:

In order to be eligible the family caregiver must be personally providing assistance to the care recipient with at least two of the following activities of daily living:

- Bathing The family caregiver is helping the individual they are caring for with bathing, including helping with washing, shampooing, getting in or out of the tub or shower brushing teeth, and other aspects of personal grooming.
- Dressing The family caregiver is helping the individual they are caring for with dressing including helping the individual to put on or take off clothing and footwear.
- Toileting The family caregiver is helping the individual they are caring for with transferring to get on or off the toilet, commode or bedpan, and to clean self, or the individual is incontinent.
- Transferring The family caregiver is helping the individual get to and from a bed or chair.
- Walking/Mobility Includes helping the individual move from one stationary point to another by removing obstacles, opening doors, and assisting with canes, wheelchairs or other assistive devices.
- Eating / Feeding The individual the family caregiver is caring for has difficulty chewing or swallowing without assistance or needs partial or total help with eating.

And/Or:

The person the family caregiver is caring for has been diagnosed with a cognitive or other mental impairment (such as Alzheimer's disease or other type of irreversible dementia) and it is no longer safe for them to be left alone.

The person the family caregiver is caring for has a serious health condition (such as COPD, Parkinson's disease, or mental illness) requiring around the clock supervision and it is no longer safe for them to be left alone.

The purpose of this program is to help prevent caregiver burnout, and delay or prevent nursing home placement.

Examples of NH Respite Care:

The Service Link Aging and Disability Resource Center (866) 634-9412.

The NH Family Caregiver Support Program

Information about community programs and local resources:

New Hampshire:

NH Family Care Guide: Alzheimer's Disease and Related Disorders

http://www.dhhs.nh.gov/dcbcs/beas/familycaregivers.htm

Massachusetts: http://massfamilyvoices.org/Respite%20Brochure.pdf

Self-Advocacy



Advocacy Defined. Advocacy is a type of problem solving designed to protect personal, and legal rights, and to insure a dignified existence. There are many types of advocacy. For example, system advocacy, is useful for changing "the system;" additionally, it is used to promote causes. Legal advocacy is what lawyers are paid to do, and legislative advocacy is designed to change laws. Self-advocacy, involves advocating for oneself; while individual advocacy involves advocating for another. While there are many types of advocacy, the focus of this section will be self-advocacy.

Well practiced advocacy skills will increase your chances of getting what you want; when you want it. Effective advocacy is built on a broad based analytical approach to problem solving.

Why Self-Advocacy? Self-advocacy skills can help you avoid or solve problems with family and loved ones, doctors and lawyers, employers, associates, and friends. Self-advocacy skills can help you obtain reasonable and necessary accommodations in both public and private settings. They can be useful in matters of public entitlements, such as education, housing, employment, transportation and taxation.

Empowerment Through Advocacy. Well practiced self-advocacy skills can give you important advantages in most situations. Sometimes you will be subjected to information that is incorrect or inaccurate. Other times, you will face situations that require you to make choices about things that are inappropriate, immoral or unethical. Then, there are times when your rights to humane treatment and dignified existence will have been ignored or denied. Self-advocacy skills can help you identify, analyze, and make informed decisions concerning such choices. The regular exercise of self-advocacy skills will empower you to gain more control over your life.

Problem Definition. Advocacy takes time and effort. Developing a clear and specific definition of the problem helps minimize frustration and waste. Additionally, defining the problem requires you to distinguish major issues from incidental details. It means getting to the heart of the issue and, if possible figuring out what is causing it. In some cases, defining the problem also leads to ideas for its solution. Advocacy skills will give you essential maps and tools for defining and resolving problems.

Getting Started. If you have had a head injury you will be confronted with the advice of many professionals in the fields of medicine, education, and/or rehabilitation.

You might become confused by all the different opinions you receive about your care, or you might not agree with a particular professional's advice or plan of care. The challenge then becomes how to advocate effectively for your needs without alienating those whose help you need?

Building Expertise. Educate yourself about your condition. Where head injury is involved, you might want to become expert in matters of Post Concussion Syndrome. There are many ways that you can become expert about your condition. Increasingly, public and university libraries hold a wealth of knowledge about head injury as well as many other medical conditions and disabilities.

If you become familiar with the <u>medical terms</u>, possible prognosis and treatment choices for your condition, you will gain the respect of professionals. Increased confidence will come with your growing medical expertise. The application of the self-advocacy skills in this section will give you the power to achieve your objectives.

Keep Good Records. Keep written records of all meetings, telephone calls, and written communications about your condition. You are entitled to copies of your medical and rehabilitation records, so be sure to ask for copies from each professional. It is also helpful to have a friend or family member to go with you.

Keep good notes of items covered and action plans. At the end of each contact or visit confirm the accuracy of your notes and impressions. Ask for opinions in writing, ask the professional you are working with to sum up the results of any conclusions or action plans in a letter or memorandum to you. That way, you will know right away whether you have a clear understanding of any agreements that have been reached.

Problem Solving. If you do not agree with a recommended treatment or plan of action, you have options. First, you can present your concerns in writing to the professional you are working with. A written document is often more clear and convincing than a conversation that can become emotional on such issues.

Next, you can get a second or third opinion. When your well-being is at stake, it is important to compare the advice from several professionals and choose the option that is best for you. If you feel there is a need, you can take your problems up the chain of command. Sometimes patients are reluctant to "go over a professionals head" in an organization, but that is why there are levels of authority. You may find that your problems are easily solved at the second or third level above the one where you started.

Importance of Attitude. Finally, you are the last word on your treatment. You do not have to agree to any plan that you do not feel is in your best interest. Trust yourself, you may not have lots of degrees, titles or letters after your name, but you are the expert and ultimate authority when it comes to your needs. You can get the best care for yourself being friendly - yet firm, assertive - not angry, and persistent - not pushy.

<u>A positive attitude</u> about your advocacy efforts is critical to your success. As a society we hold many different cultural values. Some of these values make it hard to feel good about yourself when you advocate; however, other values can make you feel good about your advocacy efforts.

Persistence Pays Off. Effective advocacy requires follow through. You must follow up to ensure that agreements reached are carried out and that promises made are promises kept.

Thank those who helped you. Each one of us has worked with truly dedicated professionals and individuals who have become special friends and allies. Thank these special people in little ways -- flowers from your garden..., a special card, a note of praise to the firm, agency, or individual. Everybody likes to feel appreciated. Sometimes little kindness' can improve a previously "problem" relationship.

The Brain Injury Association of NH 603-225-8400 or 1-800-773-8400 www.bianh.org

Brain Injury Resource Library

Family Issues

The following are available to be borrowed.

Videos

- **Building Friendships:** when students have special needs. Teachers discuss methods for inclusion. Lash & Associates
- Care giving Series: Volume 9, A Tips And Solutions On Caregiver Wellness
- The Effects of Head Injury on the Family, National Resource Center For Traumatic Brain Injury. 6/88. This videotape describes common problems encountered by families and effective strategies for incorporating them into the treatment team.
- Making Life Work After a Brain Injury, Brain Injury Ass. Of Florida : Part 1 of 3 part series " Coming Home" Families and survivors describe how their lives have been effected by brain injury. Discussions ensue about the initial recovery process when one re-enters into the community/home after injury.
- Making Life Work After a Brain Injury; Brain Injury Ass. Of Florida: Part 2 of 3 part series: "Coping Strategies". Families describe the coping strategies they have usd to live with a loved one who has sustained a brain injury. Introduces living with a brain injury for both survivor and family.
- Making Life Work After a Brain Injury; Brain Injury Ass. Of Florida, Part 3 of 3 part series; "Living Skills": Families describe social re-intergration skills for involving the survivor in leisure activities.
- The Journey Back; Surviving Coma: A mother talks about her daughters journey to become independent after injury.
- Self Determination: The Sean Tease Story, Brain Injury Ass. Of America 2001: Story of a families struggle to create the optimal environment for quality of life for their son after injury.

Books

- Finding Meaning with Charles
- In an Instant- Lee & Bob Woodruff
- Fighting for David
- In Harm's Way Help for the wives of military men, police, EMT's and Firefighters
- The Get Well Soon Balloon by Vicki Sue Parker
- Into the Future, planning care today for a secure life tommorrow by Comprehensive Rehab
- Family Rehabilitation Activity Manual by Messenger & Ziarnek
- Brain Heal Thyself by Madonna Siles
- Brain Injury it is a Journey by Hammond & Guerrier
- Your mother has suffered a slight stroke. Bosworth, Kathleen, America House Book.
- Being with Rachel, Brennan, Karen
- Head Injuries, Aaseng, Nathan & Jay

- Stroke and the Family a new guide. Stein, Joel, MD
- The Stroke Book, Biermann, June & Toohey, Barbara
- **Building Friendships:** when students have special needs. Teachers discuss methods for inclusion. Lash & Associates
- Brain Injury: Causes & Consequences for students. Lash & Associates
- Family Article about TBI, Communication Skill Builders
- Brain Injury: A Guide for Families. DeBoskey, Dana S. HDI Publishers, Inc. 1996 F1003b
- Coming Home: A Discharge Manual for Families of Persons with BI. DeBoskey, Dana S. HDI Publishers, Inc. 1996 FI004b
- Understanding and Coping with Your Child's Brain Tumor. Dragone, Mary Alice MS,RNC,PNP The Severyn Group 1997 FI005b
- Burnout in Families: The Systemic Costs of Caring. Figley, Charles Ph.D. CRC Press 1998 FI006b
- Brain Injury Rehab: The Role of the Family in TBI Rehabilitation. Guth, Mark HDI Publishers, Inc. 1996 FI007b
- Head Injury: A Booklet for Families. Hutchison, Ruth M.S. et al Texas Head Injury Found. 1983 FI008b
- When Your Child is Technology Assisted: A Home Care Guide. Kahn, Paul Rsch. & Trg. Ctr. NE Med. 1997 FI009b
- When a Parent Has a Brain Injury.Lash, Marilyn MA BIA Association 1993 FI010b
- A Manual for Families of Children with Acquired Brain Injuries. Lash, Marilyn et al NE Medical Center 1996 FI011b
- When Your Child is Seriously Injured: The Emotional Impact on Family.Lash, Marilyn M.S.W. Exceptional Parent 1991 FI012b
- **39 Family Supports for Families with a Disabled Member.** Lipsky, Dorothy Kerzner World Rehab. Fund, Inc. 1987 FI013b
- A Family Guidebook for Children/Adolescents with Serious Emotional Disability. Malloy, Joanne M. AMI of NH 1997 FI014b
- Head Injury and the Family.Orto, Arthur E. Dell & Paul W.Power PMD Publishers Group 1994 FI015b
- Treating Families of Brain Injury Survivors. Sachs, Paul R. Ph.D. Springer Pub. Co. 1991 FI016b
- Living with Head Injury: A Guide for Families. Senelick, Richard C. & Cathy E. Ryan Rehab Hosp. Srvcs. Corp. 1991 FI017b
- Living with Head Injury: A Guide for Families. Senelick, Richard C. & Cathy E. Ryan Healthsouth Press 1998 FI018b
- Keys To Parenting A Child With Cerebral Palsy.Faulkner-Leonard, Jane et al Barron's Educational Series 1997 FI019b
- Children With Cerebral Palsy: A Parents Guide.Geralis, Elaine editor Woodbine House 1998 FI020b
- When Young Children are Injured: Families as Caregivers. Lash, Marilyn & Jane Haltiwanger Exceptional Parent 1994 FI021b
- Rough Crossings: Family Caregiver's Odysseys through Health Care.Levine, Carol United Hospital Fund of NY 1998 FI022b
- Journey Through Brain Trauma. Morningstar, Louisa et al Taylor Publishing Company 1997 FI023b

- The Humpty Dumpty Syndrome. Warrington, Janette Moffat Light and Life Press 1981 FI024b
- Living with Brain Injury: A Guide for Families and Caregivers. Acorn, Sonia & Penny Offer Univ. of Toronto Press 1998 FI025b
- Head Injury: Info & Answers to Commonly Asked Questions. Sturm, Christopher D. Et al Quality Medical Pub., Inc. 1998 FI026b
- Brain Injury and the Family: A Life and Living Perspective.Orto, Arthur E. Dell & Paul W.Power CRC Press 2000 FI027b
- Where Is The Mango Princess? Crimmins, Cathy Alfred A. Knopf 2000 FI028b
- Head Injury: The Facts.Gronwall, D. et al Oxford University Press 1998 FI029b
- The BI Sourcebook: Answers to Questions Most Often Asked. by Fam. Gourley, Gene, Jeff Kreutzer et al Virginia Commonwealth Univ. 2000 FI030b
- Getting Better and Better After BI: A Guide for Families, Friends & Care. Kreutzer, Jeff et al Virginia Commonwealth Univ. 1999 FI031b
- Family Advocacy Skills. Training Hood, Donald R. et al HRSA: Maternal & Child Health 2001 FI032b
- Living with Brain Injury: A Guide for Families. Senelick, Richard & Karla Dougherty HealthSouth Press 2001 FI033b
- To Wherever Oceans Go. Bryant, Beverly Wings 1996 FP001b
- Through this Window: Views on Traumatic Brain Injury.Felton, Patricia I., editor EBTS, Inc. 1992 FP002b

Brain Injury Resource Library

Articles

Copies of the following articles are available. If you find something of interest, you may either stop by our office or request a copy through e-mail or by calling us. We prefer that you stop by our office to receive the materials to cut down on our shipping costs.

Family Issues

- Basic Family Rights as They Relate to Head Injury
- Critical care
- Relationship and family breakdown following TBI
- A family testifies before Health and Human Services
- Changes in relationships for families and caregivers
- Access Support Services
- Better Cope with a family member's disability
- Survive the bumpy road to inclusion
- Recognize and acknowledge family strengths
- Learn about laws that impact your Family's life
- Use group parent power to make things happen
- Family News & Views Articles (Information & Preparation After BI, Support Groups Help Families, Unexpected Medical Problems After BI)
- Family Adjustment to Head Injury
- Coping With Losses
- Families as Case Managers

- Head Injuries Happen to Families
- Family Involvement through Mentoring
- Psychological Implications of TBI for the Patient's Family
- Brain Damage is a Family Affair
- Training Families to work with the Head Injured
- Relating to Your Head Injured Family Member
- Coping with Survival
- Living with a Characterologically Altered Brain Injured Patient
- The Mother Who Would Not Give Up
- Brothers and Sisters: Brain Injury is a Family Affair
- The Silent Epidemic: Rehab of People with TBI
- Head Injury: A Family Matter
- Families With Head Injured Members: A Personal Account
- Family Expectations for the New Millenium
- Where Do We Go From Here?
- The Role of the Family in Delivering Case Management Services
- A Stranger in the House: Cathy Crimmins Info
- TBI and Family Adjustment
- Meeting the Needs of Siblings & Children of TBI Survivors
- Loving a Perfect Stranger
- Parents with TBI
- The Sleeping Beauty Fantasy
- Family Guide to Rehab
- Children's Issues
- Deal With the News that Your Baby Needs Special Care
- Better Cope With a Family Member's Disability
- Some Disturbing Thoughts About the Loss of a Mind
- Emotional Problems Experienced by Families
- Family Expectations for the New Millenium
- When a Parent Has a Brain Injury
- A Study of Married Couples
- Relating to the Brain Injured Person
- Head Injury: A Guide for Families
- Returning Home After Brain Injury
- Strategies for /Families and Caregivers
- Spouses: Overlooked Victims
- Meeting the Challenge: Recognizing and Dealing with the Impact of Having a Disabled Child
- What Changes for Women After Traumatic Brain Injury
- Book: Why Did It Happen on a School Day?
- Publications & Resources
- Reading ListsDeveloping a low cost Brain Injury Rehab Program: Guidelines for Family Members.
- Head Injuries Happen to Families
- Stress Management following Brain Injury: Strategies for families & caregivers.
- Living After Brain Injury

- Training family members to work with brain injured
- Psychological Implications for family
- Do's/Don'ts when responding to brain injured
- Effective tools for family education
- A Family Caregivers Guide To Hospital Discharge Planning
- 50 Tips for Family Safety
- What is case management
- Support Groups help families
- Family suggestions
- Meeting children's needs/ TBI Parent
- Coping with Daughters Brain injury
- The right to know: educating families when a child has a BI
- Stress Mgmt a guide for families & Friends Casey Family Services
- Future Planning Network Of NH
- Defining Roles foe Family Members & Caregivers
- Communicating With Families Under Stress
- The Impact Of Head Injury On The Family
- Strategies To Prevent Caregiver Fatigue
- The Effect Of Head Injury On The Family System
- Relatively Speaking
- Home Health Care A view from the front lines
- A Family Caregiver's Guide to Hospital Discharge Planning
- Sibling Needs-Helpful Information for Parents
- A guide to what BI families need from MH professionals

Fatigue

- Fatigue & Lack of Motivation
- Fatigue & Brain Injury
- General Information
- Fatigue, Dizziness, Headaches
- Coping with fatigue
- Fatigue Tiredness

Financial Assistance: Housing

- Union Leader Article Affordable Housing in Concord
- Housing & Urban Development NH Voucher Programs
- Housing & Urban Development Median Area Income for Vouchers & Rental Assistance Programs.
- NH Housing Finance Authority: Directory of Assisted Living
- NH Housing Finance Authority General Information on Tenant Rental assistance Programs.
- NH Housing Finance Authority "How to apply for rental assistance" Guidelines & forms.
- NH Housing Finance Authority Preliminary Application for Section 8.
- NH Housing Finance Authority Section 8 Multi-Family Listing

- NH Housing Finance Authority General Articles on Homeownership
- NH Housing Finance Authority Single Family Mortgage Programs
- NH Housing Finance Authority Section 8 Landlord Listing
- Merrimack County Community Action Program
- Housing Choice Voucher Program
- Fact Sheet: How rent is determined
- Housing Referral Network: Rockingham Community Action Program
- Stewart Property Management Info
- Emergency Shelters
- Southwestern Community Services Shelters & Transitional Housing
- Domestic Violence Programs
- Family Resource Connection NH programs for domestic/sexual violence
- Transitional Housing
- DewolfeCares Inc. Families in Transition
- Homeless Intervention/Prevention Services
- Homeless Hotline
- Shelter and Prevention Services by County
- PATH Service Providers Assists in Transition from Homeless
- Permanent Housing for the Homeless and Handicapped
- Specialty Shelter Programs
- State Shelters
- Special Funding for Housing for Persons with Disabilities
- Housing for Persons with TBI
- The National Home of Your Own Alliance: UNH Institute on Disability
- Habitat for Humanity
- NH Community Loan Fund
- CATCH: Concord Area Trust for Community Housing
- Landlord List for Concord area
- Opening Doors: A Housing Publication for the Disabled
- Easy Access Housing for Easier Living
- The Fair Housing Project
- Community Action Agency Listing
- The Fair Housing Project A program of NH legal Assistance
- Easy Access Housing _ Home Adaptability Checklist
- Rural Development –buying or repairing a home with help from USDA's
- National Home of your own Alliance
- The Housing Partnership
- Division of Elderly & Adult Services Services (Home Care, CHORE, Emergency Support & respite)
- HCBC-ECI Program & Residential Care Facilities enrolled in HCBC-ECI
- NH Family assistance program fact sheet
- NH waiver comparison info.
- The Housing partnership
- MB Housing Partnership
- Rental Assistance

Financial Assistance - General

- NH State Community Action Programs
- NH Counties Resources
- Pharmacy On line
- NH medication bridge prescription sites
- Government Benefits and Services
- Financial Aid for College NH Higher Education Assistance Program
- Disability Services at NH Colleges
- A Unique Internship Providing College Students with Disabilities
- Medicaid Information
- Katie Beckett Program
- NH Waiver Comparison Info
- NH Family Assistance Program Fact Sheet
- Dental Providers Under Medicaid
- Aid to the Permanently and Totally Disabled
- NH Healthy Kids Insurance Program
- TBI Implementation Grant: Proposed Criteria for CMHC Services for Persons with TBI
- Benefits for the Novice
- The Request for Assistance
- NH Infants and Toddlers Program
- ABD Community Based Care Waiver
- Medicaid Waiver Program in Vermont
- Medicare Information
- A Financial Education for Caregivers: Stroke
- Becoming Well Again Through Financial Aid Resources
- NH Catastrophic Illness Program
- Technology Related Assistance May be a Phone Call Away
- Harry Alan Gregg Foundation
- Recovery Awareness Foundation
- David Ryan Memorial Fund, Inc.
- Joseph Corpina Foundation
- High Hopes Foundation
- Harriet Howland Memorial Fund
- WISH Organizations
- SERVE; New England
- Drugs covered under indigent patient program
- Togther RX
- Financial Assistance for Victims of Violent Crime in NH
- Rockingham Community Action Programs: Community Assistance
- Seacoast Healthnet Programs
- Health Insurance Counseling Education Assistance Service
- CHAD Programs: Managed Care & Health/Leadership Project
- Special Medical Services State of NH
- Krempels Foundation
- The Medicine Program

- Adaptive Equipment Loan program
- Purchasing a modified van
- Endowment for Health Newsletter
- Sea Care Health Services
- National Foundation of Dentistry
- Medicaid to Schools Program
- Social Security Programs
- Share Card Health Insurance Program
- Nord's Medication Assistance Programs
- Pfizer Patient Medication Assistance Programs Connection to Care, Living Share Card, Sharing the Card
- Medicare Savings Program
- The Student w/ a brain injury: Achieving goals for higher education
- Creating Options: A resource on Financial Aid for students w/disabilities
- Community Financial Assistance
- Financial Assistance for Victims of Violent Crime
- Americorps Victim's Assistance Program
- TBI Challenge! Housing- a blueprint for independence
- Cover program- Home improvement rehabs
- Consumers Guide to accessible housing
- Seacoast Child Development Clinic
- Emergency Shelters
- Victims Inc
- Medicare for Employed Adults with disabilities
- Student guide- Financial aid from US department of education
- Financial aid college- NH higher education assistance
- College Aid
- Adaptive Equipment Loan programs
- SSI,SSA, SSDI APTD and Waivers
- EMS
- Loans from American Association of people with disabilities
- Youth with chronic health conditions scholarships
- Verizon-Lifeline/ link up NH Telephone assistance programs
- Community Care Waiver for Children
- Dental Assistance
- Utility Assistance
- Vision Assistance
- Council for children & Adolescents with chronic health conditions
- Disabled Childrens relief Fund
- Benefits Planning & Assistance
- Concord Hospital Prescription Assistance
- Astrazenica Foundation
- Gullikson Foundation
- The Washington Center
- Microsoft Internship Program
- Department Health & Human Services Forms

- Equity America Reverse Mortgages
- Estate planning
- Meds for Manchester
- US drug Assistance programs
- Medicare: Drug Discount Card-What You Need To Know
- Medicare: Drug Discount Card-Helping Those With Limited Incomes
- North Country Mobile Dental Services
- NH Health Access Network
- When Your Bills Pile Up
- U Share Prescription Drug Discount Information
- Medicare Approved Drug Discount Card
- BC/BS—Individual Health
- Fannie Clac
- Good News Garage
- Survival & TBI: More Details
- Financial Mtters: Never to late to start planning
- New Hampshire Oral Health Program Profiles
- Families First NH health access application
- Hospitals offer help to self-pay patients
- Partnership for prescription assistance

Guardianships

- General
- Individual Functional Assessment: A Guide to Determining the Need for Guardianship under NH Law
- Planning a Future With Care
- Guardianships
- Primer for Parents
- What is a guardian
- Petitions for guardianship
- Real Choice: Mentorship program
- Handbook for Guardians
- Guardianship training project

Headaches

- This is your brain with a headache
- Head injury & chronic headaches
- Headaches Hope through research
- Post traumatic headaches & brain injury
- Headaches & brain injury
- Post traumatic headaches a pain in the brain

Huntington's Disease

- General Information
- Newsletters Huntington's Disease Society of America
- Huntington's Disease: Cognitive and Psychiatric Features

Independent Living

- General Information
- Post-Acute Neurologic Community Integration Rehabilitation: Ecological Applications
- Independent Living for the Severely Disabled
- General Articles
- Independent Living Programs

Insurance Issues

- Managed Care: A Consumer Guide
- A Family Guide to Common Terms Associated with Managed Care
- Managed Care and Brain Injury
- Managed Care Insurance Practices & Brain Injury Rehabilitation
- What To Do if Catastrophe Strikes
- Unscrambling the Insurance Maze
- What Do You Mean It's Not Covered!
- Advocating for Funds
- Viatical Settlements
- Problems in Insurance Coverage
- What You Should Know About Managed Care and Children w/Special Health Care Needs
- Traumatic Brain Injuries: Challenging HMO Guidelines Are Parent's Powerful or Powerless?
- Coping 3rd party reimbursement & speech pathology
- Your HMO and you
- Discharge Planning, What it's all about
- Community based health plans for the insured: expanding access
- Medical Insurance options
- Medicare talking about Medicare
- Health Insurance: you have rights when purchasing health

Legal Issues: General Information

- TBI: A guide for criminal Justice Professionals
- Influence changes in state and federal law
- Special needs require Long-Range plans
- Clients with special needs children need help clearing complex financial, legal and emotional hurdles

- Lawyer Interview Sheet
- Representing the Professional with TBI
- Brain Injury Litigation Guide for TBI
- Money Matters
- Layman's Guide To Hiring Legal Representation
- Family/Lawyer Relationship: A Long Term Partnership
- Selecting a Neurolawyer
- Introduction to Neurolaw
- Legal Issues & brain injury
- A Laypersons guide to selecting & retaining the most qualified attorney in cases of TBI
- TBI: Analysis, Understanding and Presentation
- Mild to Moderate TB1 & Psychiatric Problems
- Psychological Syndromes in TBI Litigation
- Role of Neuropsychologists in Brain Injury Litigation
- The Importance of Vocational Economic Analyst in Mild/Moderate TBI
- Ask the Doctor: Litigation Regarding Concussion
- Closed Head Injury
- i.e. Magazine: Legal Issues
- Brain Injury Source: NeuroLaw:Legal Issues in Brain Injury
- Legal Techniques for Financial, Medical & Personal Planning for Alzheimer's Families in NH
- Forensic Neuropsychology & Recovering Damages & Compensation for BI
- Actions for Medical Injury
- Five Myths About Traumatic Brain Injury
- What the Lawyer Should Know About Mild Brain Injury
- Just a Few Things a Lawyer Must Know About So-Called Mild Brain Injury
- Making a Will
- Brain Injury Literature by Gordon Johnson, J.D.
- DRC Civil Action Court Case in US District Court, Concord, NH
- Life Care Planning
- Legal Rights of the Head Injured Person in New Hampshire
- The Basic Estate Plan: The Will and the Special Needs Trust
- Estate Planning for Families of Persons with Head Injuries
- Estate Planning: NICHCY
- Estate Planning for Persons with Disabilities
- General things to keep in mind when choosing a lawyer for a brain injury case
- Selecting a Neurolawyer (Spanish)
- Power of attorney
- Living Will & Health Care Power of Attorney
- Pediatric Traumatic Brain Injury Cases in NH

Long Term Care

- A Simplified Guide to Choosing a Nursing Home: Consumer Info Sheet
- Residential Treatment: Have I Done the Right Thing?
- Nursing Homes: How to Choose

- Nursing Homes: When a Loved One Needs Care -
- Medicare & Medicaid: Guide to Choosing a Nursing Home 6
- Medicare and Medicaid Guide to Choosing a Nursing Home NH Medicaid rules for long term nursing homecare 0
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- About Medical Directives 6
- Advance Care Planning Guide 0
- The puzzle of paying for long term care 8