

Acute Brain Injury

A Guide for Family and Friends



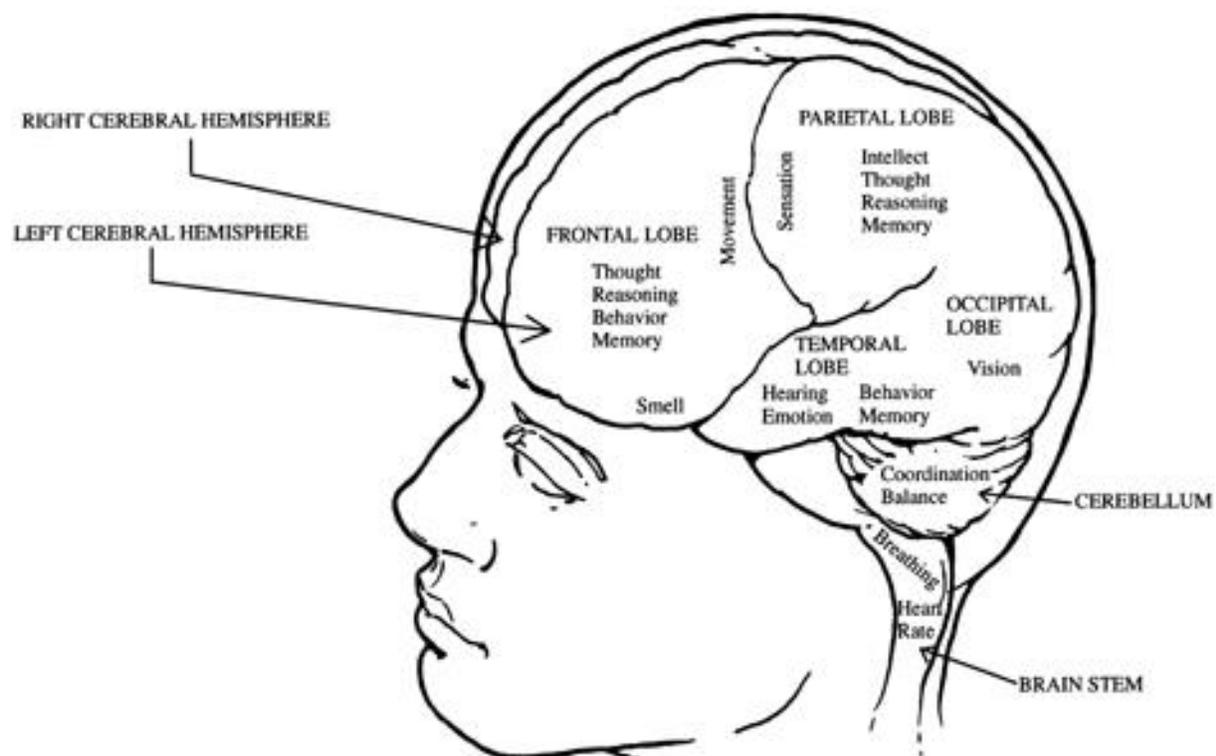
New Hampshire Edition 2015

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How Does the Brain Work?

The brain controls the actions of the body and allows us to think, learn, and remember. The brain has three main sections: the cerebral hemispheres, cerebellum, and brain stem. There are left and right cerebral hemispheres. The cerebral hemispheres are divided into sections called lobes. Each section of the brain has special jobs to do and sections of the brain also work together. The left cerebral hemisphere controls the right side of the body and is usually responsible for speech. The right cerebral hemisphere controls the left side of the body and is usually responsible for creative thinking.



Protection and Oxygen for the Brain

The brain controls many important functions. It needs good protection and oxygen. The brain is protected and receives oxygen in the following ways:

Skull:

A hard bone that surrounds the brain tissue.

Dura:

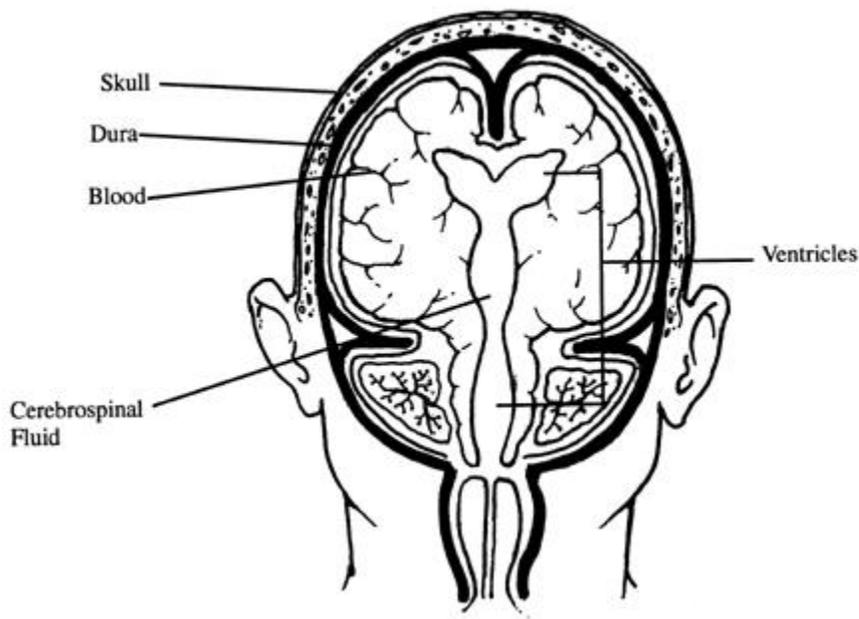
A tough covering around the brain tissue and the spinal cord.

Cerebrospinal Fluid (CSF) or Spinal Fluid:

Fluid that flows through the ventricles and around the brain and spinal cord. The ventricles are spaces inside the brain. The cerebrospinal fluid acts like a “shock absorber” for the brain.

Blood:

Provides oxygen and food for the brain.



What Types of Brain Injuries May Occur?

Even though the brain is well protected, it may be injured. Every injury is different. Most injuries are a result of bruising, bleeding, twisting, or tearing of brain tissue. Damage to the brain may occur at the time of injury. It may also develop after the injury due to swelling or further bleeding. Patients may have more than one type of brain injury.

Skull Fracture: A break in the bone that surrounds the brain. These fractures often heal on their own. Surgery may be needed if there has been damage to the brain tissue below the fracture.

Contusion/Concussion: A mild injury or bruise to the brain which may cause a short loss of consciousness. It may cause headaches, nausea, vomiting, dizziness, and problems with memory and concentration. This injury will not need surgery.

Coup/Contre-Coup: A French word that describes contusions that occur at two sites in the brain. When the head is hit, the impact causes the brain to bump the opposite side of the skull. Damage occurs at the site of impact and on the opposite side of the brain.

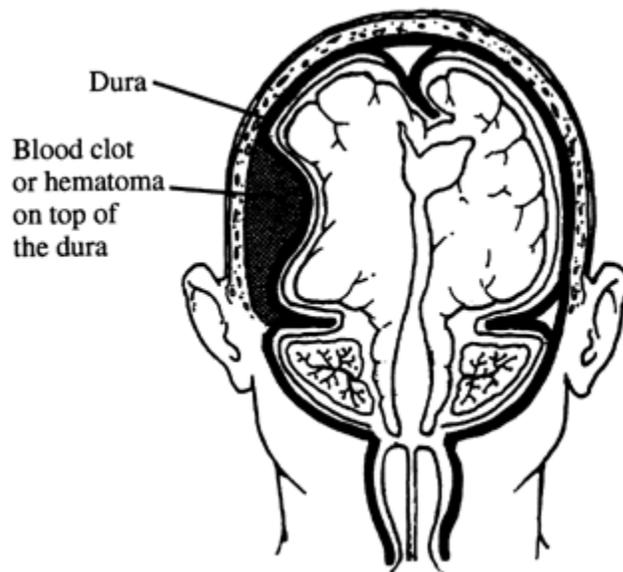


Epidural

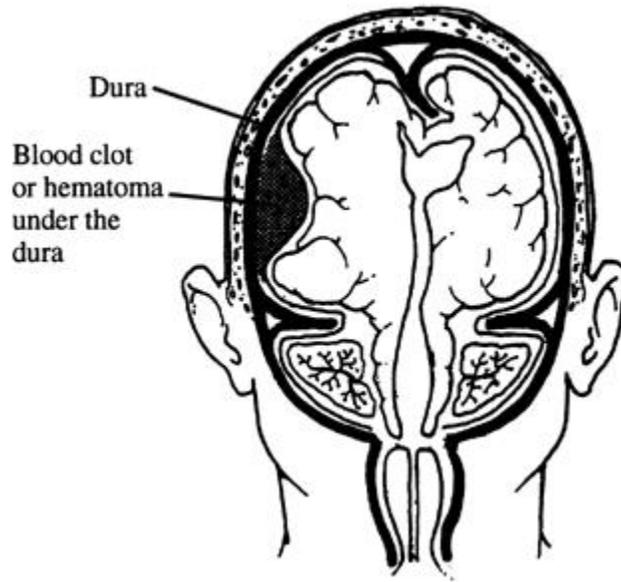
clot that forms
 top lining of the brain (dura). This blood clot can cause fast changes in the pressure
 inside the brain. Emergency surgery may be needed. The size of the clot will
 determine if

Hematoma:

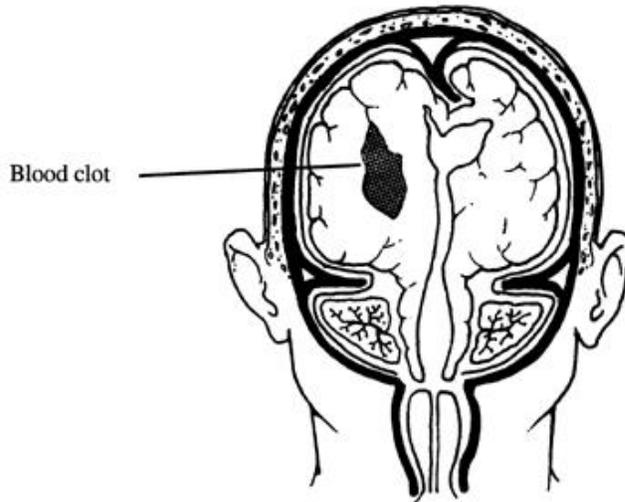
A blood
 between the skull and the
 surgery is needed.



Subdural Hematoma: A blood clot that forms between the dura and the brain tissue. If this bleeding occurs quickly it is called an acute subdural hematoma. If it occurs slowly over several weeks, it is called a chronic subdural hematoma. The clot may cause increased pressure and may need to be removed surgically.



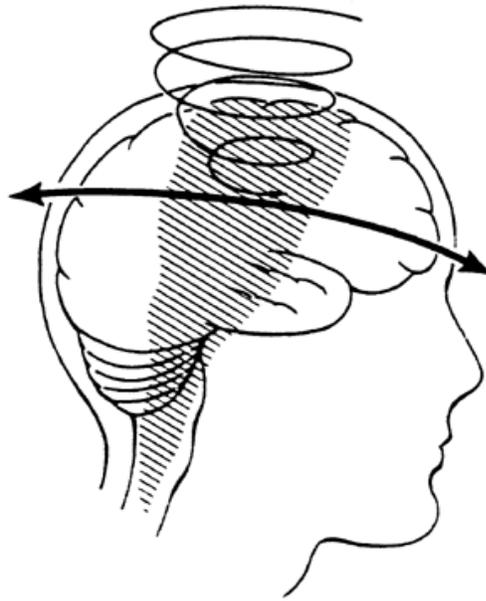
Hemorrhage: A blood clot deep in the middle of the brain that is hard to remove. Pressure cause Surgery relieve



Intracerebral

from this clot may damage to the brain. may be needed to the pressure.

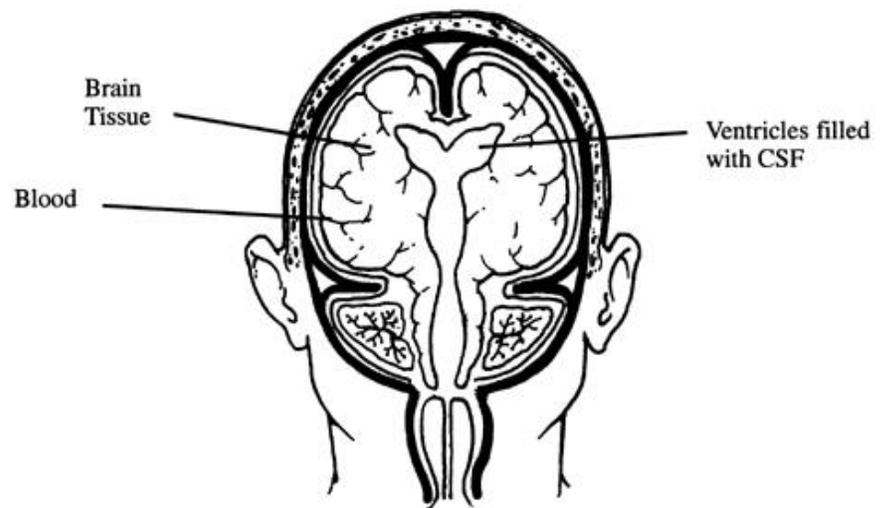
Diffuse Axonal Injury (DAI): Damage to the pathways (axons) that connect the different areas of the brain. This occurs when there is twisting and turning of the brain tissue at the time of injury. The brain messages are slowed or lost. Treatment is aimed at managing swelling in the brain because torn axons cannot be repaired.



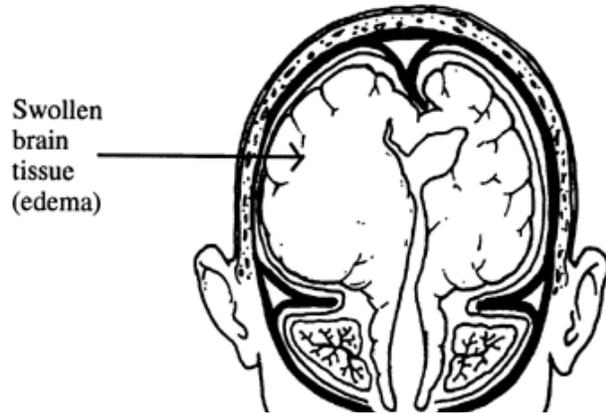
Anoxic Brain Injury: An injury that results from a lack of oxygen to the brain. This is most often from a lack of blood flow due to injury or bleeding.

What Happens When the Brain Is Injured?

Damage to the brain may occur immediately, as a result of the injury, or it may develop as a result of swelling or bleeding that follows the injury. The skull is usually filled like this:

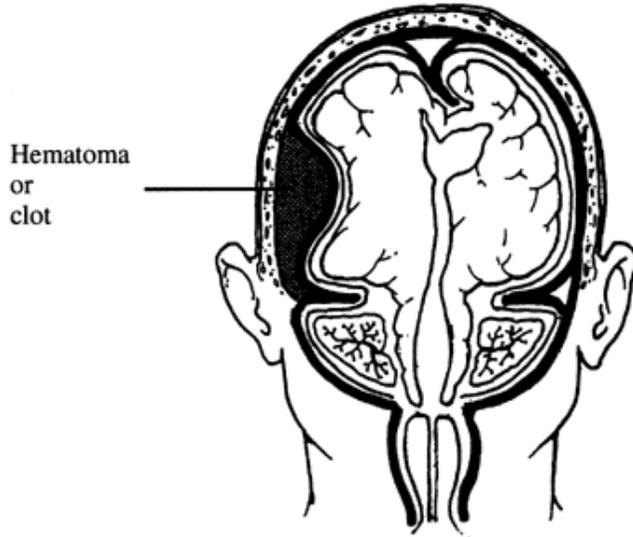


Normal Brain:



Changes can occur as a result of brain injury. The brain tissue may swell causing it to take up more room in the skull. This is called edema. When this occurs, the swollen brain tissue will push the other contents of the skull to the side.

Brain with Edema:

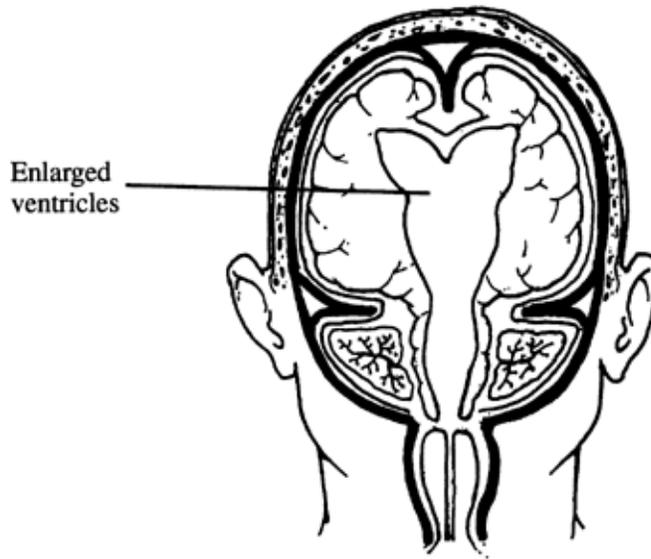


There may be bruising called contusions or a collection of blood called a hematoma or clot. This may also push the other contents to one side.

Brain with a Hematoma:

The flow of CSF may also become blocked. This will cause the open spaces (ventricles) to become enlarged. This is called hydrocephalus.

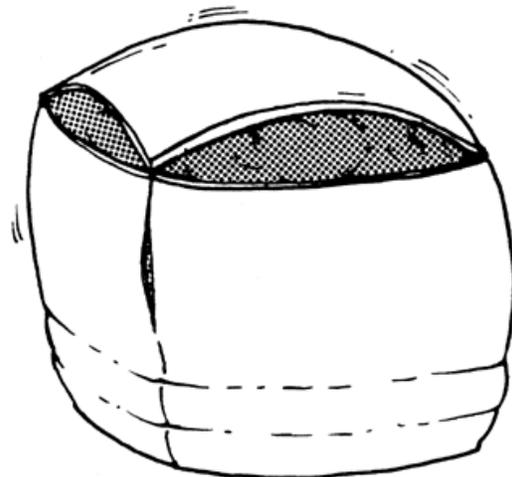
Brain with Hydrocephalus:



Any of these changes can cause increased intracranial pressure.

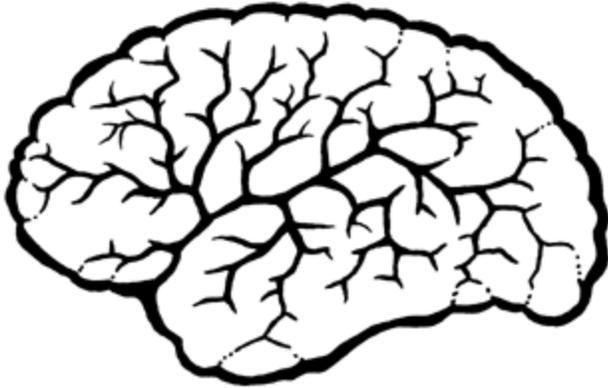
What is Intracranial Pressure?

To understand intracranial pressure, think of the skull as a rigid box. After brain injury, the skull may become overfilled with swollen brain tissue, blood, or CSF. The skull will not stretch like skin to deal with these changes. The skull may become too full and increase the pressure on the brain tissue. This is called **increased intracranial pressure**.

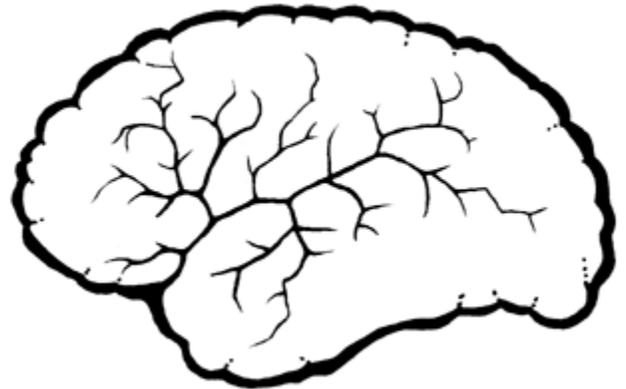


What is Cerebral Perfusion Pressure?

Blood flow to the brain is called cerebral perfusion pressure. Blood pressure and intracranial pressure affect the cerebral perfusion pressure. If the blood pressure is low and/or the intracranial pressure is high, the blood flow to the brain may be limited. This causes decreased cerebral perfusion pressure.



Normal blood flow:



Limited blood flow:

How will the Patient Respond to a Brain Injury?

The patient's responses may vary depending on the type of injury or pressure changes in the brain. Possible responses include: agitation, confusion, decreased responses and **coma**.

Coma: A state of unresponsiveness when patients do not speak or follow commands, and are unaware of their surroundings. The length of time a patient remains in a coma varies.

Patients may also have problems with speech, vision, or muscle weakness in their arms or legs.

How Are Brain Injuries Evaluated?

Patients with brain injury require frequent assessments and diagnostic tests. These include:

- **Neurological Exam:** A series of questions and simple commands to see if the patient can open their eyes, move, speak, and understand what is going on around them. For example: What is your name? Where are you? What day is it? Wiggle your toes. Hold up two fingers. A standard way to describe patient responses may be used. Most hospitals use the Glasgow Coma Scale or Rancho Levels of Cognitive Functioning. You can read about these scales and what the scores mean in the Appendix.
- **X-ray:** A picture that looks at bones to see if they are broken (fractured). It can also be used to take a picture of the chest to look at the lungs. This test may be done at the bedside or in the X-ray department and takes between 5-30 minutes to complete.
- **CT Scan (CAT Scan):** An X-ray that takes pictures of the brain or other parts of the body. The scan is painless but the patient must lie very still. The test takes 15-30 minutes to complete.
- **MRI (Magnetic Resonance Imaging) Scan:** A large magnet and radio waves are used, instead of X-rays, to take pictures of the body's tissues. It is painless but noisy. The machine is shaped like a long tube. The patient must lie still on a flat table in the middle of the machine. The test takes about 60 minutes to complete.
- **Angiogram:** A test to look at the blood vessels in the brain. Using a catheter, or small flexible tube, dye is put into an artery (usually in the groin) that supplies blood to the brain. This test can tell if the blood vessels have been damaged or are spasming. The test takes 1-3 hours.

- **ICP Monitor:** A small tube placed into or just on top of the brain through a small hole in the skull. This will measure the pressure inside the brain (intracranial pressure).
- **EEG (Electroencephalograph):** A test to measure electrical activity in the brain. Special patches called electrodes are applied to the head to measure the activity. The test is painless and can be done at the bedside or in the EEG department. The length of the test varies.

How are Brain Injuries Treated?

The goals of brain injury treatment are to:

- Stop any bleeding
- Prevent an increase in pressure within the skull
- Control the amount of pressure, when it does increase
- Maintain adequate blood flow to the brain
- Remove any large blood clot.

Treatments will vary with the type of injury. The doctor will decide which ones are used. Some common treatments are:

Positioning: Usually the head of the bed will be elevated slightly and the neck kept straight. This position may decrease the intracranial pressure by allowing blood and CSF to drain from the brain. Please do not change the position of the bed without asking the nurse.

Fluid Restriction: It may be necessary to limit the fluids that a patient receives. The brain is like a sponge. It swells with extra fluid. Limiting fluids can help control the swelling. Please do not give fluids without asking the nurse.

Medications: There are several types of medications used to treat brain injury. Some of these include:

- **Diuretics** are used to decrease the amount of water in the patient's body. This makes less water available to the brain for swelling.
- **Anticonvulsants** are used to prevent seizures. Seizures occur as a result of extra electrical activity in the brain. There are several types of seizures. The most common type causes the patient to have jerking movements of the arms and legs followed by sleep. Other types may cause slight tremors of the face, or staring spells. Please notify the nurse or doctor if you see any of these signs. Some patients have a seizure at the time of injury while others may develop seizures after the injury.
- **Barbiturates** are given if the patient's intracranial pressure is very high and hard to control. This medicine puts the patient into a deep "sleep" called a barbiturate coma. This may help prevent more swelling and damage.

Ventricular Drain (Ventriculostomy): A small tube is placed in the ventricle. It measures and controls pressure inside the skull. It can be used to drain some CSF (cerebrospinal fluid) from the brain.

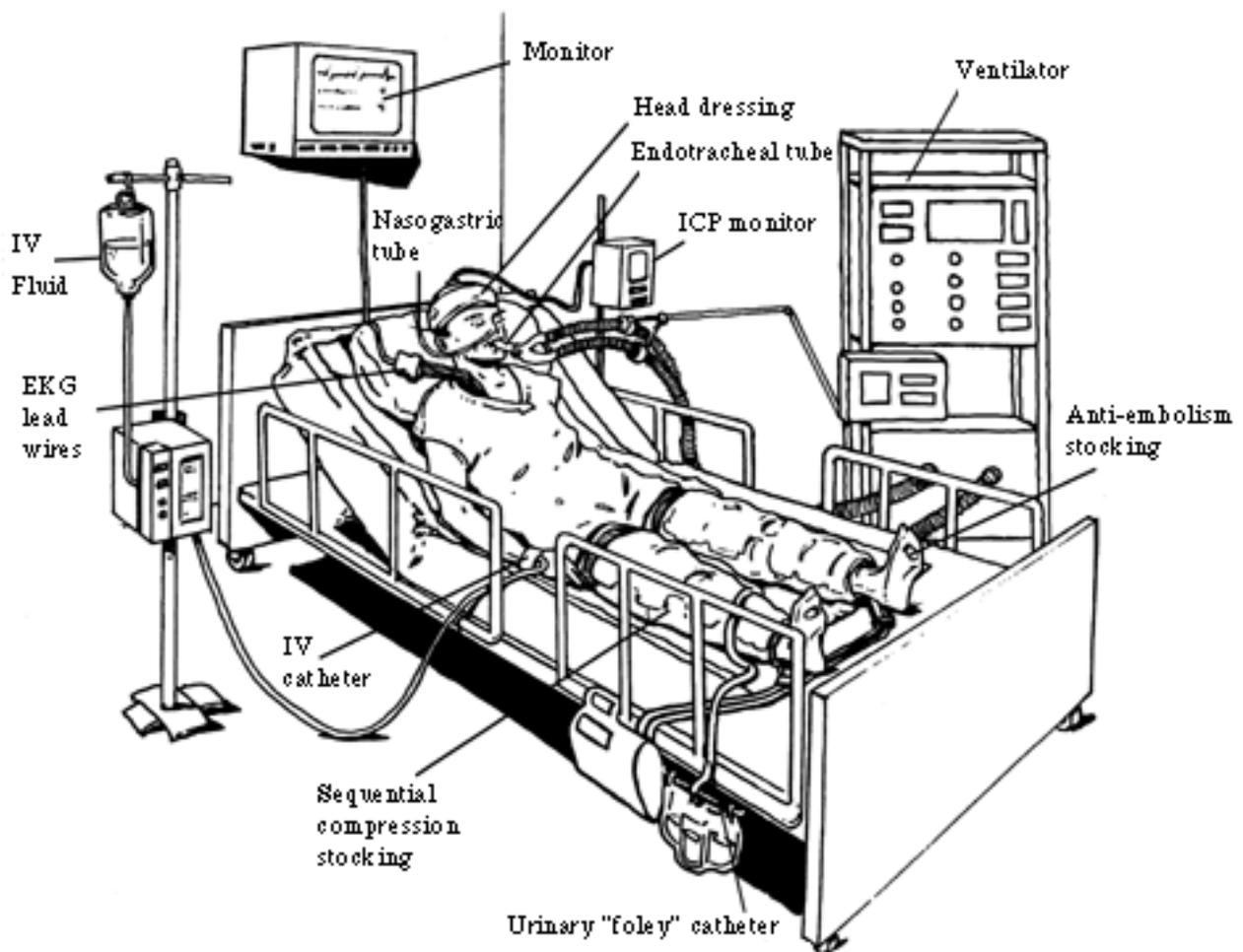
Ventilator: A machine used to support the patient in their own breathing, or give the patient breaths. When the ventilator gives extra breaths, the blood vessels in the brain become smaller. This may help control the intracranial pressure.

Surgery: There are three types of surgery used with brain injury:

- **Craniotomy** - The skull is opened to relieve the causes of increased pressure inside the skull. Causes may be fractured bones, blood clots, or swollen brain tissue.
- **Burr holes** - A small opening is made into the skull to remove blood clots.
- **Bone flap removal** - A piece of bone is removed from the skull to relieve pressure caused by swollen brain tissue.

What Equipment Will You See When You Visit?

Depending on the type of brain injury, different kinds of equipment will be used. Some common equipment is shown in the picture below. Ask a member of the health care team if you have any questions about equipment.



Monitor: A machine that shows heart rate, breathing, blood pressure, intracranial pressure, and cerebral perfusion pressure.

Head Dressing: A bandage around the head used to keep the wound or incision clean and dry.

ICP Monitor: A small tube placed into or just on top of the brain through a small hole in the skull. This will measure the amount of pressure inside the brain (intracranial pressure).

Nasogastric Tube (NG): A tube placed through the nose into the stomach that can be used to suction the stomach or provide liquid formula directly into the stomach.

Endotracheal Tube: A tube inserted through the patient's nose or mouth into the trachea (windpipe) to help with breathing and suctioning.

EKG Lead Wires: Wires connected to the chest with small patches that measure the heart rate and rhythm.

Intravenous Catheter (IV) and Intravenous Fluid: A flexible catheter which allows fluid, nutrients, and medicine to be given directly into a vein.

Ventilator: A machine used in the Intensive Care Unit to support the patient in their own breathing or give the patient breaths.

Anti-Embolism Stockings (Frequently call TEDS): Long white stockings used to help prevent the pooling of blood in the legs.

Sequential Compression Stockings (Frequently called Kendalls): Plastic leg wraps that help prevent blood clots by inflating and deflating around the legs.

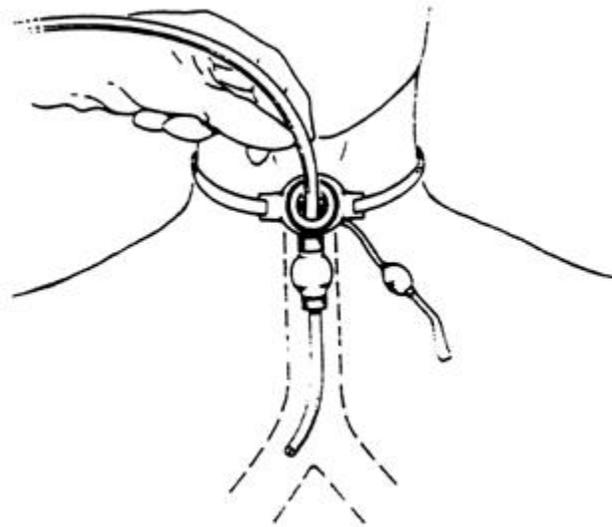
Urinary “Foley” Catheter: A tube inserted into the bladder to drain and allow for accurate measurement of urine

What Other Treatments May Be Used?

Antibiotics: Antibiotics are used to prevent and treat infections that occur. It is not unusual for people with brain injuries to get infections. They may get pneumonia, bladder infections, blood infections, or infections in the brain or cerebrospinal fluid called meningitis.

Chest PT and Suctioning: To prevent or treat pneumonia, staff may use a vibrating machine or may clap on the patient's chest. This loosens the phlegm in the lungs. Then the patient will be asked to cough. If the patient is not able to cough up the phlegm they must be suctioned. When a patient is suctioned a catheter is placed in the back of the throat or into the lungs.

Tracheostomy (Trach): If the patient has a lot of lung secretions or is on a ventilator for a long time they may need a trach. A trach is a tube placed in the trachea (windpipe). It will make it easier for the patient to cough up phlegm. It also allows the nurse to suction the lungs.



Initially the patient will be unable to talk while the trach is in place. As the patient improves, a talking trach may be used. A trach is usually not permanent.

Suctioning of the Stomach: Sometimes after brain injury, the stomach will stop working for a short time. This is called an ileus. Even though the stomach may not be working it continues to make acid. The acid may damage the stomach lining and cause stomach ulcers if they are not removed. A nasogastric tube (NG) will be placed through the nose into the stomach. This tube will be used to help remove stomach secretions. Medications may also be given to help prevent stomach ulcers.

Nutrition: Meeting nutrition and fluid needs is important after brain injury. Patients may be less active, yet have very high nutritional needs. At first, nutrition may be supplied by an IV. When the stomach starts working, an evaluation of chewing and swallowing safety will be completed. If the patient is too sleepy to eat, or unable to swallow, a small nasogastric feeding tube may be used for nutrition. The tube is placed through the nose into the stomach. Liquid formula will be given through the feeding tube. Feedings may be given continuously or several times a day. The dietician will assist with food and fluid selection. Milkshakes and liquid formulas may also be used to provide extra calories and high protein nutrition. A feeding tube may be used if the patient continues to be too sleepy to eat or unable to swallow. A gastrostomy tube is a feeding tube that goes in the stomach. A jejunostomy tube is a feeding tube that goes in the intestine.

Bowel and Bladder Care: Patients may not have control of their bowel or bladder. Catheters or diapers will be used until bowel and bladder control returns.

Skin Care: Some things that help prevent bedsores include turning the patient, padding equipment, keeping skin clean and dry, using special mattresses, and making sure the patient gets enough calories.

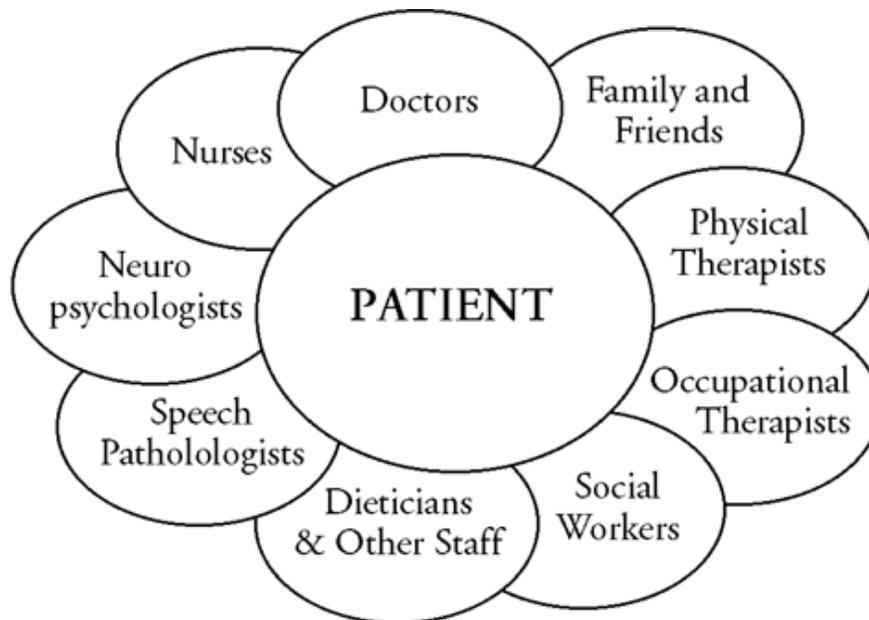
Range of Motion (ROM) and Splints: Patients with brain injury may not be able to move their joints as much as needed. This can cause tight muscles and joints called contractures. Range of motion (ROM) exercises and special splints for hands and feet help prevent contractures.

Pain Control: Comfort measures and medication will be used for pain control. However, medications may be limited to types that do not cause drowsiness.

Who Will Help After Brain Injury?

Members of the health care team will work together with the patient, family, and friends during the hospital stay. Care will be centered on the individual needs of the patient. Family and friends are important members of the team.

Team Members:



Patient: The patient is the most important member of the team. Care will be planned based on how the patient responds to treatment.

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

Doctors: Neurosurgery doctors are specialists who help determine the type of brain injury and its treatment. They may perform surgery on the brain. They will work with other doctors if the patient is in intensive care or has injuries to other parts of the body.

Nurses: Nurses check patient's vitals (temperature, blood pressure, heart and breathing rate) and watch for changes in strength and thinking. They help with daily cares such as eating and bathing. Nurses also coordinate care among the members of the health care team.

Social Workers: Social workers provide emotional support to help the patient and family adjust to being in the hospital. They coordinate discharge planning, referral to community resources, and answer questions about insurance or disability.

Physical Therapists (PT): Physical therapists evaluate and treat weaknesses in the patient's strength, flexibility, balance, rolling, sitting, standing and walking. Treatment may include exercises or instruction in use of equipment such as walkers, canes, or wheelchairs.

Occupational Therapists (OT): Occupational therapists evaluate the patient's ability to perform dressing, bathing, homemaking and activities that require memory and organization. They provide treatment or equipment needed for safe independent living.

Speech Therapists: Speech therapists test and treat speech, language, thinking and swallowing problems.

Neuropsychologists: Neuropsychologists test thinking, memory, judgment, emotions, behavior and personality. This information can be used to help guide treatment. It will also help determine the amount of supervision that the patient needs when they leave the hospital.

Dieticians: Dieticians assess nutritional needs. They work with the patient and other team members to help the patient meet their nutritional goals.

Other staff members may work with the patient and family. These include:

- Respiratory therapists
- Activity Therapists
- Clergy
- Child Life Therapists
- Patient Representatives
- Vocational Counselors
- Music Therapists
- Recreation therapists

How Will You React?

When a friend or family member is hospitalized with a brain injury, it is normal for you to have many different emotions. These emotions will come and go at different times.

Panic and Fear

Panic and fear are common reactions after a family member has a brain injury. Fears are intense because you are worried the patient may not survive. Until the patient becomes medically stable, your physical and emotional signs of panic may continue. These symptoms include rapid breathing, inability to sleep, decreased appetite and upset stomach. Some people may cry uncontrollably.

Shock and Denial

You may feel that what is happening is not real. You may notice things going on around you, but have trouble remembering information and conversations or meetings with others. You may also have a hard time understanding the seriousness of the injury that has occurred.

Anger

Many people feel angry that they or their loved ones are in this situation. This may be justified. You may be angry with the patient for putting themselves in a situation where they could be hurt. You may also be angry with family members, friends, or others involved in the accident. You may be upset with the health care team for not doing or saying what you think is right. These are all normal reactions.

Guilt

Guilt is also a normal reaction. You may feel you could have done something to prevent the accident from happening, even when this may be far from true. You may also think about past events and personal experiences with the patient that you wish could have been different or better. If you are feeling angry with the patient, you may also feel guilty about your anger. We encourage you to talk about your feelings with someone close to you or a professional staff member.

Isolation

During this time you may feel distant from others. In this strange situation, you may have a hard time relating to others. You may think that others will not understand. You may isolate yourself because you think others are scared or disapprove of your feelings. However, a crisis such as a brain injury is a time when it is helpful to accept comfort, support and assistance from others.

Hope

As the patient begins to stabilize, your anxiety about survival will be combined with hope of recovery. Medical complications and slow recovery may increase anxiety. However, hope may be brought about by the smallest changes.

Any of these emotions are normal reactions to a very stressful situation. You may find it helpful to discuss your feelings with friends, family, or the health care team. It may also be useful to write about your feelings and experiences in a daily journal.

What are Suggestions for Coping?

People cope with stressful situations in different ways. What works for one person may not be helpful to another. We hope some of these suggestions will help you get through this difficult time.

Write important information down in a journal or notebook. You can use this to keep track of questions you want to ask members of the health care team. It may also be useful to share with the patient.

Establish a “phone tree.” Name one person for family and friends to call for information on the patient’s condition.

Rotate family visits. If you need or want to leave the hospital, you may want to have someone stay with the patient so you can feel reassured the patient is not alone.

When someone offers to help, accept the offer. Try to be specific about how this person can help.

Express your feelings. Discuss your positive and negative feelings with family members, friends, and staff.

Be kind to yourself. Take time for a walk or have a meal with a friend. Also, try to leave the hospital for a meal or restful night of sleep. It is very important to take care of yourself. By taking care of your own needs, you will be more prepared to make good decisions and support your loved one.

What are the Signs of Improvement?

“How long will it take for my loved one to get better?” “What will he or she be like?” Your health care team may have a hard time answering these questions. Age, extent of damage, length of time since injury, and past mental and physical health of the patient are factors used when predicting the extent of recovery.

Most patients follow a general pattern of recovery after a severe brain injury. This pattern is divided into stages. It is important to know each patient is different and may not follow the stages exactly. Patients vary in the amount of time spent at each stage and their recovery may stop at any stage. Recovery may be grouped into the following four stages:

Stage 1: Unresponsiveness:

During this stage the patient does not respond consistently or appropriately. You may hear this stage referred to as a coma. You may notice different movements in the patient. These are referred to as reflexive or generalized responses.

- **Decerebrate:** A reflex that causes straightening of the arms and legs.
- **Decorticate:** A reflex that causes bending of the arms and straightening of the legs.
- **Generalized responses:** Random movement of the arms and legs for no specific reason.

Stage 2: Early Responses:

During this stage the patient starts to respond to things that are happening to them. The responses will be more appropriate, but may be inconsistent or slow. The patient will start to have localized responses and follow simple commands. Some examples of early responses to watch for are:

- **Localized response:** These are appropriate movements by the patient in response to sound, touch, or sight. Turning toward a sound, pulling away from something uncomfortable, or following movement with the eyes are examples.
- **Following simple commands:** Opening and closing eyes, sticking the tongue out, or gripping and releasing hands when asked are examples.

Stage 3. Agitated and Confused:

At this stage the patient is responding more consistently. The patient will be confused about where he or she is and what has happened. The patient will have difficulty with memory and behavior. The patient's confusion may lead to yelling, swearing, biting, or striking out. Do not be alarmed if soft wrist and ankle ties are used to protect the patient and prevent tubes from being pulled out. It is very important to remember this stage is a step toward recovery and this behavior is not intentional.

Stage 4. Higher Level Responses:

The patient completes routine tasks without difficulty, but still needs help with problem solving, making judgments and decisions. The patient may not understand his or her limitations and safety is a big concern. Unusual or high stress situations make activities more difficult. The patient may seem more like the person you knew before. However, there may be personality changes.

Unfortunately, there is no way to predict how long a person will remain in one stage or what the final outcome will be. The team will work during the hospital stay to achieve the best possible outcome.

How Can You Help with Recovery?



The family and friends of a person with a brain injury are important members of the team. Your knowledge about the patient's emotional and physical needs is valuable, and so is your participation in helping take care of these needs.

The following are suggestions for things you can do that correspond with the stages of recovery.

Stage 1. Unresponsive Stage

At this stage the patient appears to be in a deep sleep and does not respond to their surroundings. The goal is to obtain a response to touch, sound, sight or smell.

- When speaking to the patient, assume he or she understands what you are saying. Speak in a comforting, positive and familiar way.
- Speak clearly and slowly about familiar people and memories.
- When visitors are present, focus on the patient. Keep the number of visitors to 1 or 2 people at a time. Visits should be short. Other distractions (TV, radio) should be turned off when visiting.
- Provide the patient with pictures, music, and personal items that are comforting and familiar. Use poster board or a bulletin board near the bed.
- The nurses and therapists may encourage you to assist in care of the patient. You may be asked to help with hair care, shaving, applying skin lotion or gently stretching and positioning the patient's arms and legs. If you don't feel comfortable with these activities, that is okay. The staff will understand.

Stage 2. Early Responses

At this stage the patient is beginning to respond to people and hospital surroundings. The responses may range from turning toward a familiar voice to moving an arm or leg on request.

The goal is to increase the consistency of responses.

- There may be a delayed response time when asking the patient to move, speak, or pay attention. Always wait 1-2 minutes for the requested response. Repeat your request only a couple of times during this time period.
- Be aware that the patient's attention span may only be 5-10 minutes before fatigue and frustration set in.
- Allow for rest periods. Turn off the TV, music, and lights, and limit visitors. The patient can become stressed by too much noise, light or stimulation.
- Continue with suggestions listed in the "unresponsive" stage.

Stage 3. Agitated and Confused Responses

During this stage, things are confusing. The patient may begin to remember past events but may be unsure of surroundings and the reason for hospitalization. The goal is to help the patient become oriented and to continue to treat his or her physical needs.

- Provide one activity at a time and expect the patient to pay attention for only short periods. Keeping the noise level low helps the patient focus.
- The patient may repeat a word, phrase, or activity over and over. Try to interest the patient in a different activity.
- The patient may do socially unacceptable things during this time, such as swearing or hitting. This is common. Calmly tell the patient the behavior is not appropriate.

- Help orient the patient to his or her surroundings with both visual and verbal information (such as the suggestions below). Remembering information from one time to another is difficult.
 - A calendar with the days marked off.
 - A sign in the room telling them where they are.
 - A posted schedule with meal times, therapies, and special appointments.
- To decrease frustration, allow the patient to move about with supervision.

Stage 4. Higher Level Responses

At this stage the patient is able to take part in daily routines with help for problem solving, making judgments, and decisions. Most of the suggestions from the previous stage continue to apply here. The goal is to decrease the amount of supervision needed and increase independence.

- Help make the environment safe. Safety decisions may still be difficult for the patient to make. Praise safe decisions and give calm explanations about unsafe decisions. Learning is still difficult.
- Encourage the use of memory aids, such as a date book, to help with appointments and daily routines.
- Encourage brief rest periods because the patient will continue to need more rest.
- Check with the health care team on activities that may be completed with or without supervision. These activities may include work or school re-entry, taking medications, driving, or managing money.

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 members.

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 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.

RESOURCES

There are many resources that may be helpful as you support your family member or friend who has a brain injury. The following pages list some resources for information, support, and services. This list is not meant to be comprehensive, but to serve as an introductory guide.

For information about Brain Injury Programs, Rehabilitation Facilities, and Professionals working with individuals with brain injury, contact the Brain Injury Association of New Hampshire.

The first step to information is the Brain Injury Association of New Hampshire.

Brain Injury Association of New Hampshire

(800) 773-8400 Family Helpline (New Hampshire only)

(603) 225-8400 www.bianh.org

BIANH provides a number of services to assist the individual with a brain injury and his or her family. Call the Family Helpline for:

- Information and support
- Resources and services available in your area
- Brain Injury Support Groups
- Speaker's Bureau
- Annual Conferences

Brain Injury Association of America

(800) 444-6443

(Help Support Line)

(703) 236-6000 www.biausa.org

BIA provides information about brain injury and resources throughout the United States. The web page provides dozens of links to brain injury information sites.

AREA AGENCIES: Area Agencies are located in each of the 12 regions of the state and provide eligibility determinations for state-funded services as part of their intake process. Area agencies provide case management, early intervention services, family support respite, residential and day programs for eligible persons in its region. Services are individualized whenever possible according to each person's needs and wishes.

Region I – Northern Human Services, Inc./New Horizons
87 Washington Street
Conway, NH 03818
(603) 447-3347

Region II – PathWays of the River Valley
654 Main Street
Claremont, NH 03743
(603) 542-8706

Region III – Lakes Region Community Services
PO Box 509
719 North Main Street
Laconia, NH 03247
(603) 524-8811

Region IV – Community Bridges, Inc.
70 Pembroke Road
Concord, NH 03301
(603) 225-4153

Region V – Monadnock Developmental Services, Inc.
121 Railroad Street
Keene, NH 03431
(603) 352-1304

Region VI – Gateways Community Services
144 Canal Street
Nashua, NH 03064
(603) 882-6333

Region VII – Moore Center Services, Inc.
195 McGregor St., Suite 400
Manchester, NH 03102
(603) 206-2700

Region VIII – One Sky Community Services
755 Banfield Road, Suite 3
Portsmouth, NH 03801
(603) 436-6111 or (800) 660-4103 (TDD)

Region IX – Community Partners: Behavioral Health Services of Strafford County, Inc.
113 Crosby Road, Suite 1
Dover, NH 03820
(603) 749-4015

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113 Crosby Road, Suite 1
Dover, NH 03820
(603) 749-4015

DEPARTMENT OF HEALTH AND HUMAN SERVICES DISTRICT OFFICES

Berlin District Office:
(603) 752-7800

Claremont District Office:
(800) 982-1001 or (603) 542-9544

Concord District Office:
(800) 322-9191 or (603) 271-6200

Conway District Office:
(800) 552-4628 or (603) 447-3841

Keene District Office:
(800) 642-9700 or (603) 357-3510

Laconia District Office:
(800) 322-2121 or (603) 524-4485

Littleton District Office:
(800) 552-8959 or (603) 444-6786

Manchester District Office:
(800) 852-7493 or (603) 668-2330

Rochester District Office:
(800) 862-5300 or (603) 332-9120

Seacoast District Office:
(800) 821-0326 or (603) 433-8300

South District Office:
(800) 852-0632 or (603) 883-7726

For additional information on the Division of Human Services and its programs, call toll-free (800) 852-3345, M-F, 8am – 4:30pm.

EDUCATION: Participating in a successful educational program is the right of all children. The following resources can help you advocate for your child's needs.

Bureau of Special Education

(603) 271-3741

Special Education provides and promotes leadership, technical assistance and collaboration statewide to ensure that all children and youth with disabilities receive a free, appropriate, public education.

The Bureau carries out its mission by:

- Guiding the continuous improvement and monitoring of special education and related services;
- Supporting effective strategies and specialized support(s) for preschool age children with disabilities to participate and progress in appropriate preschool activities;
- Supporting effective instruction, specialized services, and supports for students with disabilities to participate and progress in the general curriculum;
- Creating partnerships with agencies, organizations, and individuals providing services and supports for students with disabilities;
- Providing and supporting high quality professional development opportunities for teachers, specialties, parents, and other interested parties;
- Supporting Institutions of Higher Education in the professional development and preparation of qualified teachers and specialists to assure appropriate support for students with disabilities;

- Improving and utilizing effective data collection systems that support the provision of quality educational services;
- Disseminating information on special education rules, regulations, professional development activities, and promising practices.

Parent Information Center

(800) 947-7005 or (603) 224-7005

The PIC mission is to serve all individuals regardless of disability issues by providing information, referral, support, and training to parents, family members and professionals to ultimately enable children and adults to achieve their maximum quality of life.

Family Support Program

Contact your Area Agency (contact information listed on page 28).

The Family Support Program has a practice of 'doing whatever it takes' to provide information, services, and supports to all family members. This may include information, referral, counseling, advocacy, transition planning and respite. Each developmental services region in the state has a Family Support Council comprised of family members.

Families of children whose acquired brain disorder occurred before age 22 are eligible for this program.

INFORMATION AND ADVOCACY: After a traumatic brain injury, the family and loved one often feel alone and overwhelmed. Support and information are available through a number of organizations.

New Hampshire Developmental Disabilities Council (603) 271-3236
Recommends policy and advocates for legislative change and issues affecting people with developmental disabilities. Not a direct service agency.

Governor's Commission on Disability (800) 852-3405 or (603) 271-2773
Information and referral service, Client Assistance Program for vocational rehab clients. Barrier Free Design Committee and newsletter.

Client Assistance Program (800) 852-3405 or (603) 271-2773
Provides information about vocational rehab services, advises of rights and responsibilities, investigates complaints and helps resolve problems with your vocational plan.

Granite State Independent Living (800) 826-3700 (voice/TTY) or (603) 228-9680 (voice/TTY)
A grassroots information, advocacy, and peer support organization designed to assist adults with physical disabilities attain and maintain a lifestyle free of unwanted dependence on others. Services include: accessible housing information, sign language services, home modification evaluations, personal care attendant program, independent living skills

training, peer/support counseling, adaptive equipment evaluations, social/recreational events, accessible transportation, advocacy, information, and referral.

National Alliance for the Mentally Ill (800) 242-6264 or (603) 225-5359
Provides support and information to individuals living with mental health issues.

Parent to Parent (800) 698 5465
A statewide network of families willing to share experiences to help other parents understand the special challenges and needs of their children.

LEGAL: Legal issues and concerns can be complicated. Involvement of an attorney may be necessary to advocate for the rights of your loved one.

Disability Rights Center (DRC)

(800) 834-1721 or (603) 228-0432

Legal assistance and advocacy specific to disability issues;

NH Legal Assistance Branch Offices

Berlin

(800) 698-8969 or (603) 752-1102

Claremont

(800) 562-3994 or (603) 542-8795

Concord

(800) 921-1115 or (603) 223-9750

Manchester

(800) 562-3174 or (603) 668-2900

Portsmouth

(800) 334-3135 or (603) 431-7411

NEW HAMPSHIRE STATE SUPPORTED PROGRAMS

Healthy Kids

1-877-464-2447

Free and low cost health insurance for children. Call to request an application kit, or contact your Local, Town or City Welfare Department for more information. Each NH city or town can provide direct relief in the form of vouchers to assist consumers within their jurisdiction obtain such needs as food, heat, rent, and utilities who have no other means of support.

New Hampshire Help Line

(800) 852-3388

Free and Confidential Assistance – 24 hours a day, 7 days a week.

Vocational Rehab/Employment Services

(603) 271-3471

Assistance with vocational training and helping persons with disabilities find employment.

New Hampshire Housing Finance Authority

(800) 472-8623 (rental applications or (800) 649-0470 (mortgage information)

All persons income eligible as set by HUD guidelines. Program consists of rental assistance and home ownership programs.

SOCIAL SECURITY: After a brain injury, many people face significant financial struggles. Early contact with the Social Security Administration can help identify possible sources of income replacement and medical benefits for your loved one.

Social Security Administration
(800) 772-1213 www.ssa.gov

Local Social Security Offices

Concord (603) 225-8475

Keene (603) 352-3487

Littleton (603) 444-2945

Manchester (603) 641-2180

Nashua (603) 880-0295

Portsmouth (603) 433-0716

TRANSPORTATION: Many people with brain injury are unable to drive and must rely on public transportation. The following resources can help with finding suitable transportation.

New Hampshire Transit

NH Rideshare Information: (800) 462-8707
or (603) 271-4043

www.state.nh.us/dot/rideshare

Public Transportation Providers

Dartmouth Coach

(603) 448-2800

Concord

(603) 225-1989

Winnepesaukee Transit

(603) 726-7366 or (603) 528-2496

Keene

(603) 352-2253

Manchester

(603) 623-8801

Nashua

(603) 880-0100

North Country/Berlin

(603) 752-1741

Seacoast (COAST)

(603) 743-5777

Claremont/Newport

(603) 863-0003 or 542-0048

Granite State Independent Living –

operates wheelchair accessible vans for transportation (603) 228-9680 (voice/TTY)
or (800) 826-3700 (voice/TTY)

Appendix:

Coma Scales

There are several scales used to describe the level of response in patients with brain injury.

In acute care the Glasgow Coma Scale is often used. The Glasgow Coma Scale rates eye opening, motor movement (movement of the arms and legs), and verbal response.

Glasgow Coma Scale

Eye Opening

- 4 = Spontaneously
- 3 = To voice
- 2 = To pain
- 1 = No response

Best Motor Response

- 6 = Follows commands
- 5 = Localizes to pain
- 4 = Withdrawal to pain
- 3 = Decorticate
- 2 = Decerebrate
- 1 = No Response

Best Verbal Response

- 5 = Oriented and converses
- 4 = Disoriented and converses
- 3 = Inappropriate words
- 2 = Incomprehensible sounds
- 1 = No response

Rehabilitation centers may use a scale called the Rancho Levels. The Rancho scale measures levels of cognitive or mental functioning.

Rancho Levels of Cognitive Functioning

1. No response to stimulation
2. Generalized response to stimulation
3. Localized response to stimulation
4. Confused, agitated behavior
5. Confused, inappropriate, nonagitated behavior
6. Confused, appropriate behavior
7. Automatic, appropriate behavior
8. Purposeful, appropriate behavior

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