Acute Brain Injury:
A Guide for Family & Friends

Brain Injury Alliance
CONNECTICUT

May 2016

INTRODUCTION

This booklet provides basic information about brain injury and its treatment. Please read it at your own pace. As you learn more about the brain, you will have many questions. Members of the health care team will do their best to answer your questions. Definite answers may not be known because the long term effects of brain injury can be difficult to predict.

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The first edition of this book was made possible through donations from the Volunteer Program, the Department of Nursing, Multispecialty Services and the Department of Physical Therapy at University of Iowa Health Care.

This Connecticut Edition was made possible through the Brain Injury Alliance of Connecticut and the Center for Disabilities and Development, Iowa's nationally designated University Center for Excellence on Disabilities, a component of University of Iowa Health Care.

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Acute Brain Injury

A Guide for Family and Friends

Introduction

This booklet provides basic information about brain injury and its treatment. Please read it at your own pace. As you learn more about the brain, you will have many questions. Members of the health care team will do their best to answer your questions. Definite answers may not be known because the long term effects of brain injury can be difficult to predict.

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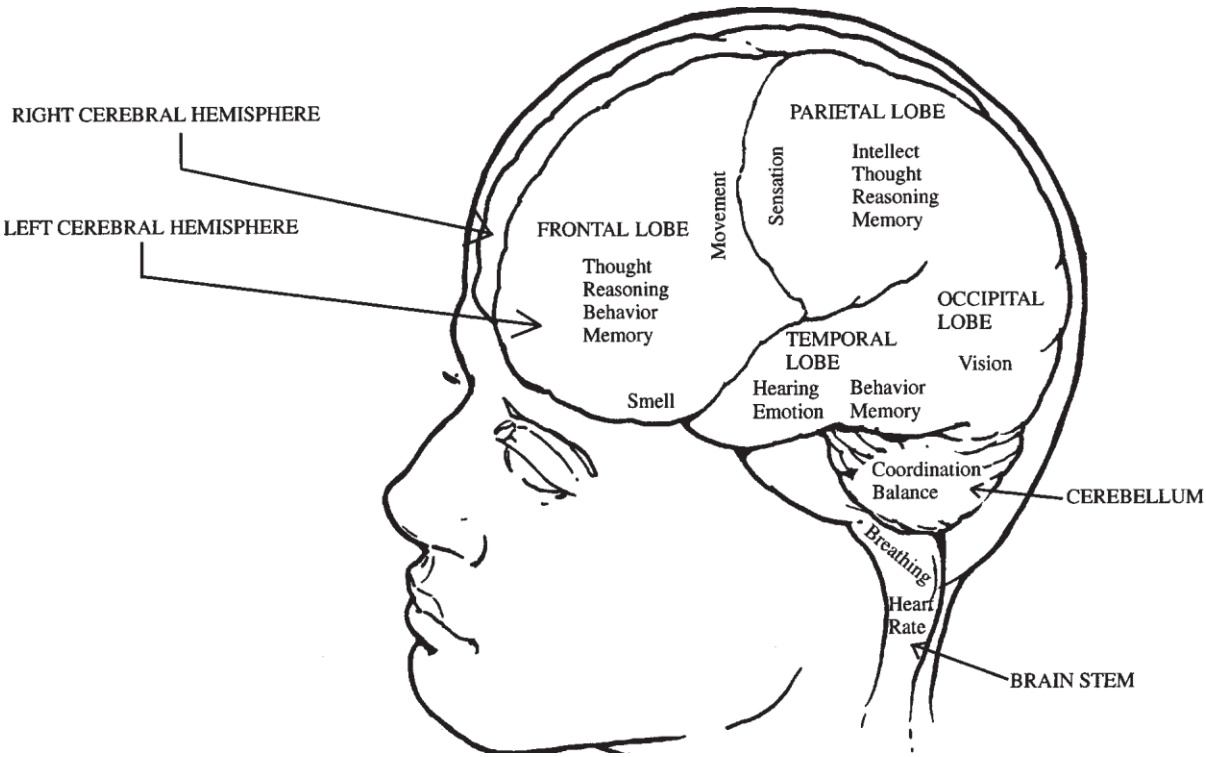
Acute Brain Injury

A Guide for Family and Friends

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

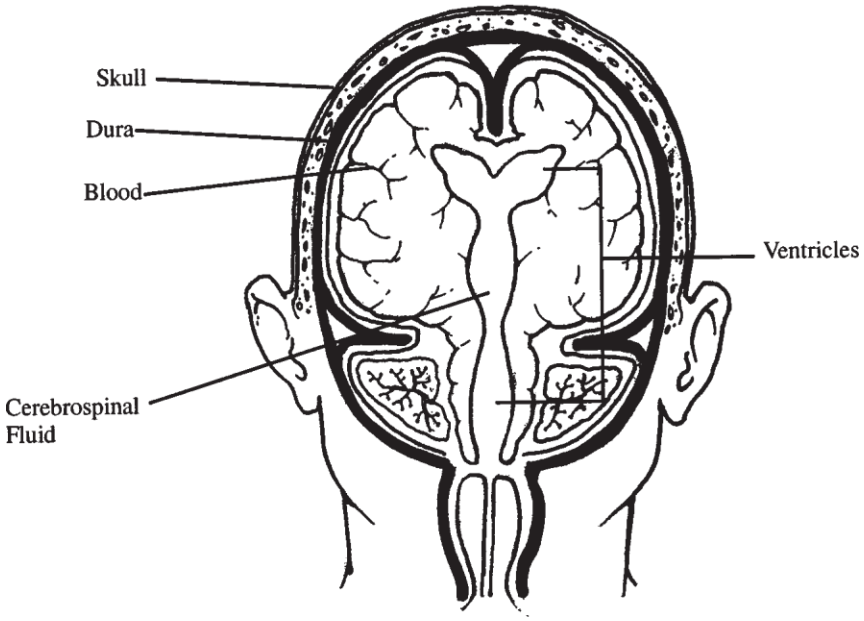
The brain controls many important functions. It needs good protection and oxygen. The brain is protected and receives oxygen in the following ways:

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



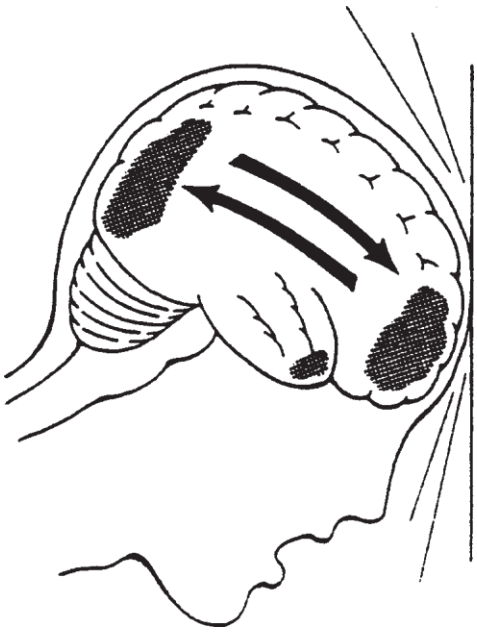
What Types of Brain Injuries May Occur?

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.

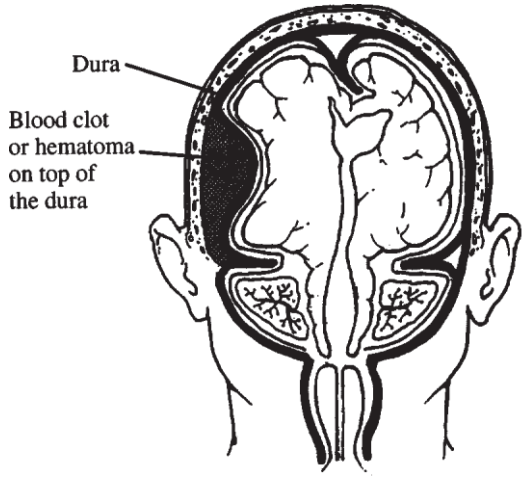
Skull Fracture: A break in the bone that surrounds the brain. These fractures often heal on their own. Surgery may be needed if there has been damage to the brain tissue below the fracture.

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.

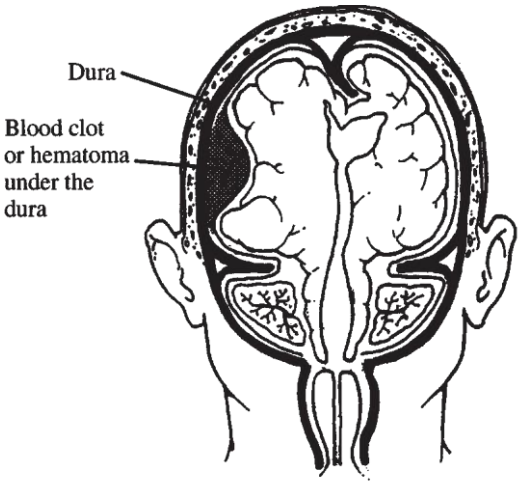
Coup/Contre-Coup: A French word that describes contusions that occur at two sites in the brain. When the head is hit, the impact causes the brain to bump the opposite side of the skull. Damage occurs at the site of impact and on the opposite side of the brain.



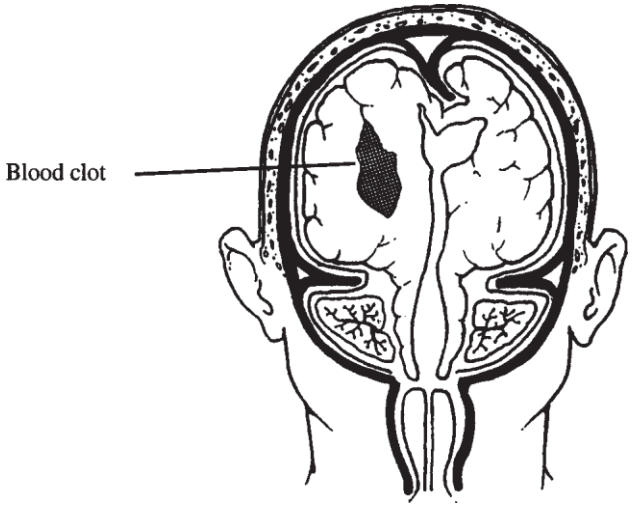
Epidural Hematoma: A blood clot that forms between the skull and the top lining of the brain (dura). This blood clot can cause fast changes in the pressure inside the brain. Emergency surgery may be needed. The size of the clot will determine if surgery is needed.



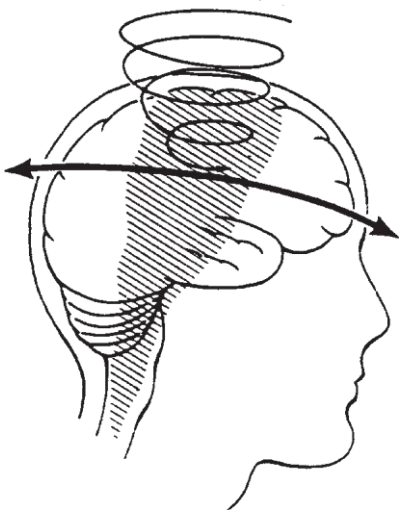
Subdural Hematoma: A blood clot that forms between the dura and the brain tissue. If this bleeding occurs quickly it is called an **acute subdural hematoma**. If it occurs slowly over several weeks, it is called a **chronic subdural hematoma**. The clot may cause increased pressure and may need to be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



Intracerebral Hemorrhage: A blood clot deep in the middle of the brain that is hard to remove. Pressure from this clot may cause damage to the brain. Surgery may be needed to relieve the pressure.



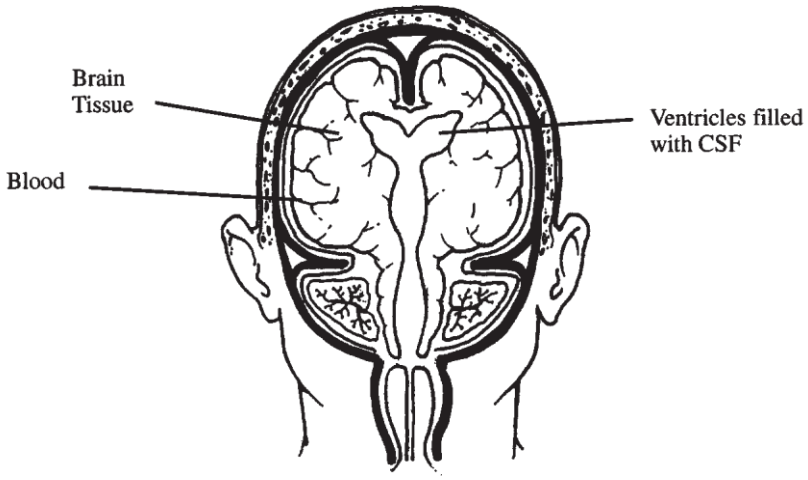
Diffuse Axonal Injury (DAI): Damage to the pathways (**axons**) that connect the different areas of the brain. This occurs when there is twisting and turning of the brain tissue at the time of injury. The brain messages are slowed or lost. Treatment is aimed at managing swelling in the brain because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



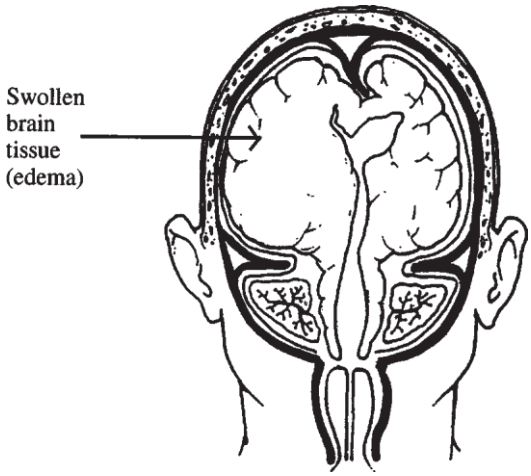
Anoxic Brain Injury: An injury that results from a lack of oxygen to the brain. This is most often from a lack of blood flow due to injury or bleeding.

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:



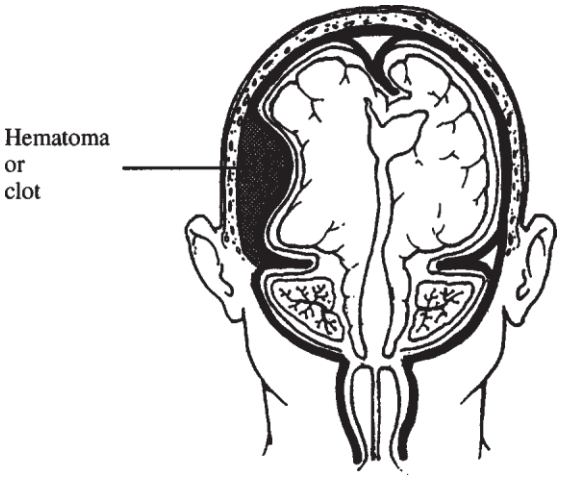
Normal Brain



Brain with Edema

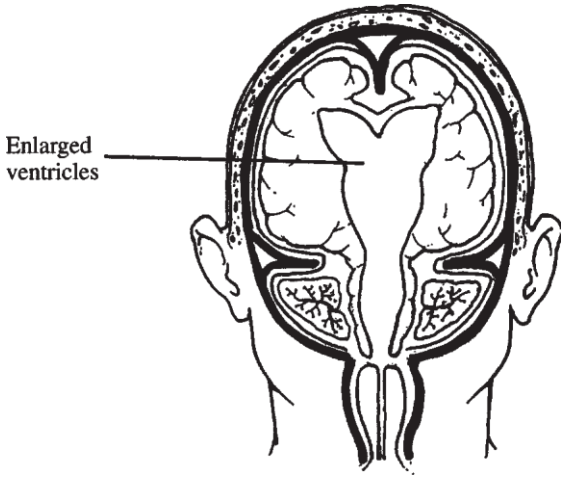
Changes can occur as a result of brain injury. The brain tissue may swell causing it to take up more room in the skull. This is called **edema**. When this occurs, the swollen brain tissue will push the other contents of the skull to the side.

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**.

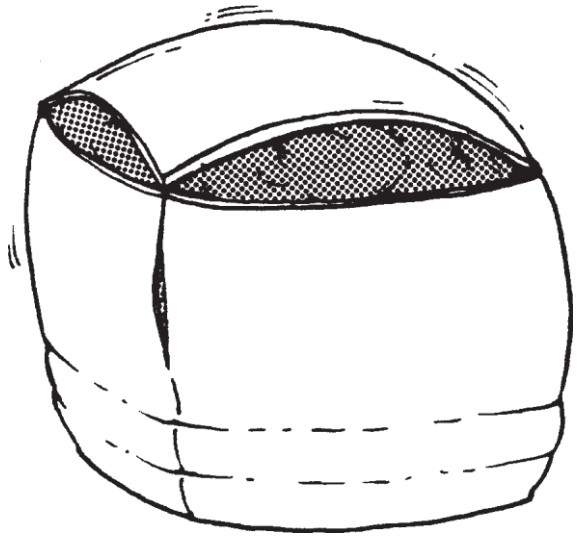


Brain with Hydrocephalus

Any of these changes can cause **increased intracranial pressure**.

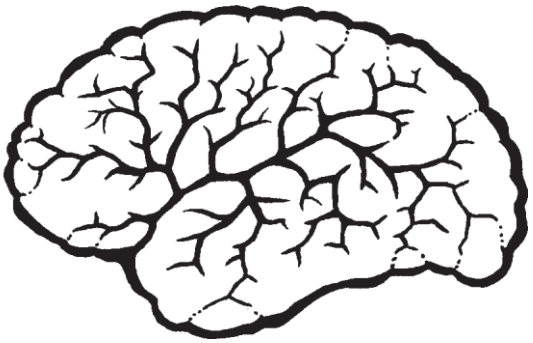
What is Intracranial Pressure?

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**.

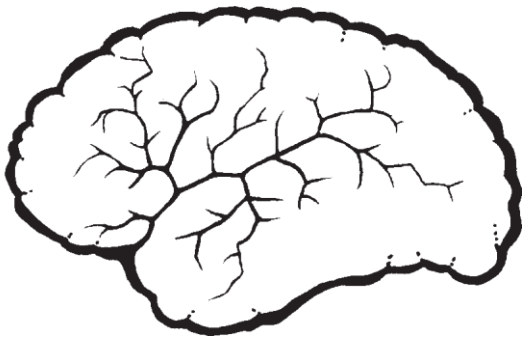


What is Cerebral Perfusion Pressure?

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 on p. 31.

- **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 clots

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:

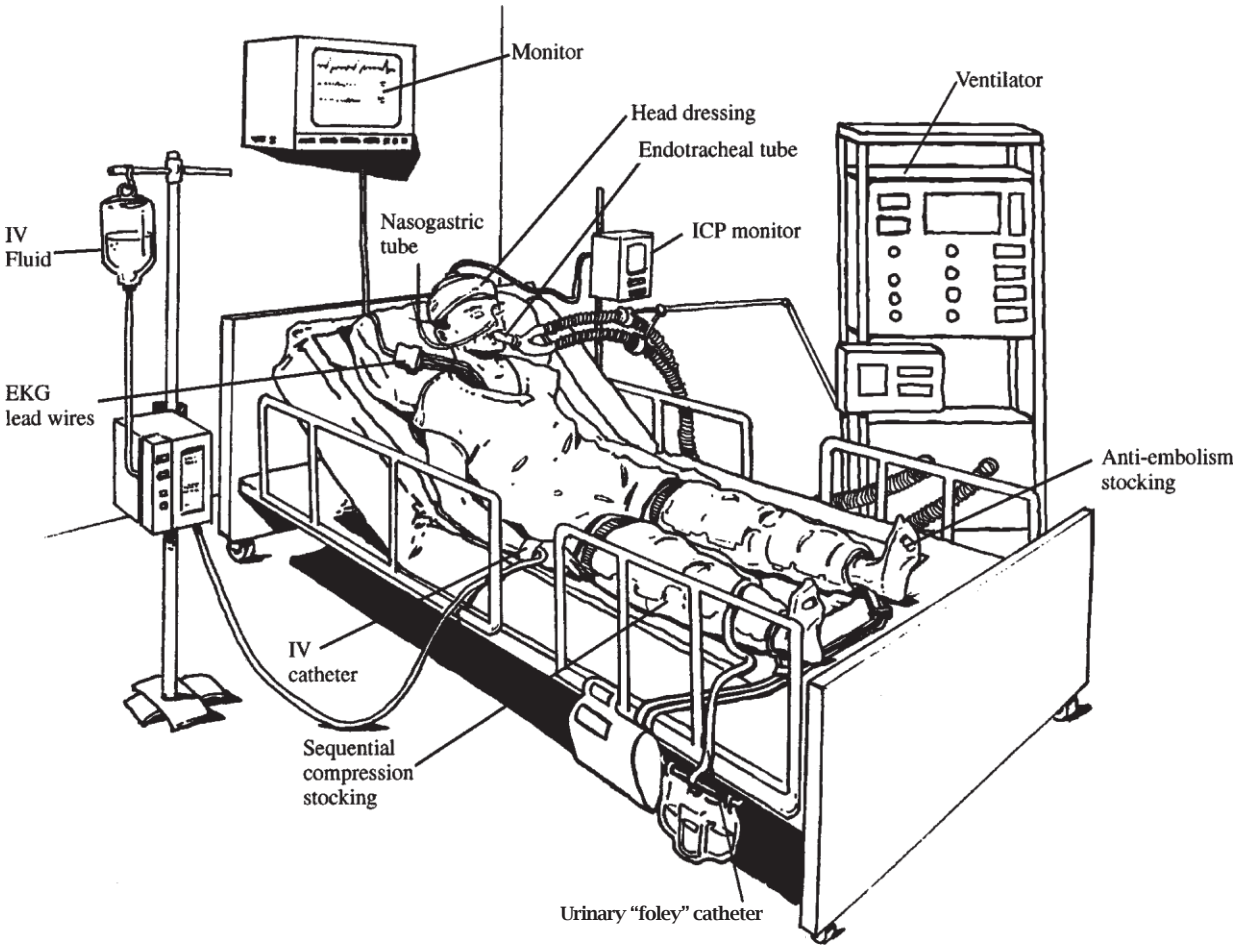
- **Craniotomy** - The skull is opened to relieve the causes of increased pressure inside the skull. Causes may be fractured bones, blood clots, or swollen brain tissue.

- **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.

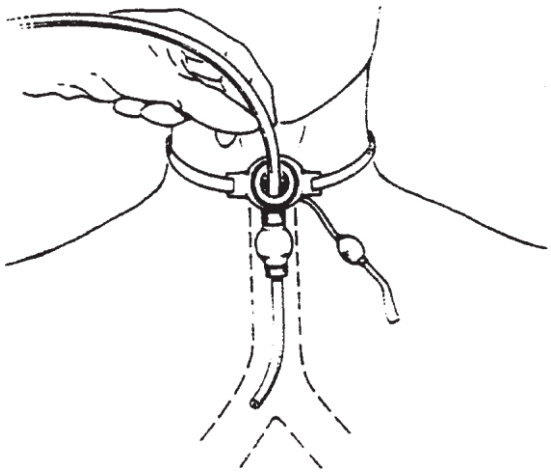
Urinary "Foley" Catheter: A tube inserted into the bladder to drain and allow for accurate measurement of urine.

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.

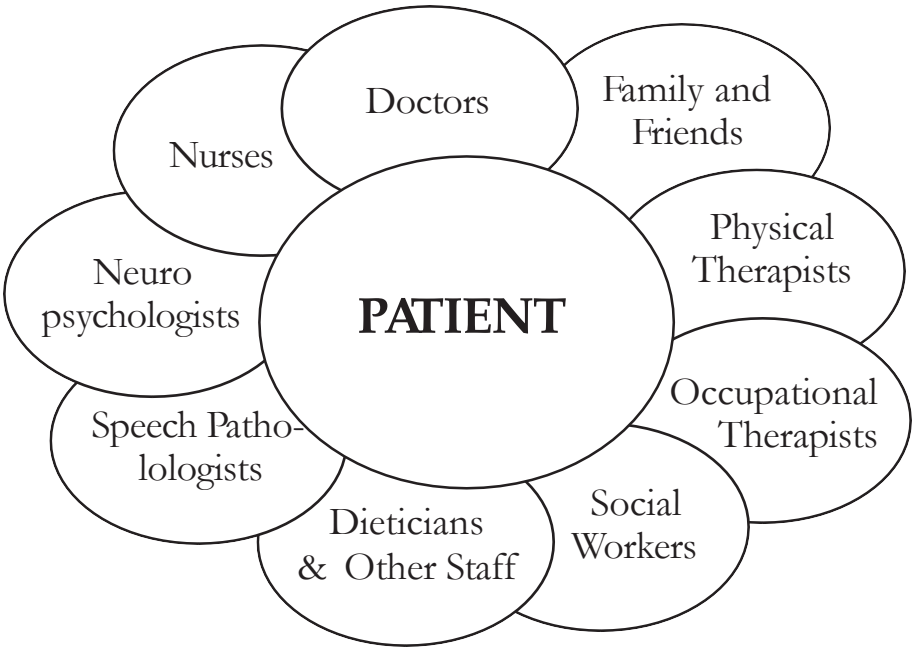
Range of Motion (ROM) and Splints: Patients with brain injury may not be able to move their joints as much as needed. This can cause tight muscles and joints called **contractures**. Range of motion (ROM) exercises and special splints for hands and feet help prevent contractures.

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
- Clergy
- Patient Representatives
- Music Therapists
- Activity Therapists
- Child Life Therapists
- Vocational Counselors
- 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?

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 a freestanding rehabilitation facility that offers 24-hour nursing care. Patients participate in a minimum of 3 hours of intensive rehabilitation services per day at least 5 days per week. 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. Patients participate in rehabilitation a minimum of 1 hour per day at least 3 times per week. Some patients may transfer from this setting to acute inpatient rehabilitation if appropriate.

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 to determine equipment needs. The patient may need therapy or other care. Some of the 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.

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 on 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 Alliance of CT.

The first step to information is the Brain Injury Alliance of CT..

Brain Injury Alliance of CT (BIAC)

Contact us: (860) 219-0291
Toll-Free HelpLine: (800) 278-8242
Email: general@biact.org
www.biact.org

BIAC provides a number of services to assist the individual with a brain injury and his/her family. Call the HelpLine for:

- Information about brain injury
- Resources and services available in your area
- Brain Injury Support Groups
- Individual Consultation
- Social and Recreational Events

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

SSA provides general information and will set up an appointment with your local Social Security office.

Choices (**C**onnecticut's program for **H**ealth insurance assistance, **O**utreach, **I**nformation and referral, **C**ounseling, **E**ligibility **S**creening**)**

(800) 994-9422

Choices provides information and assistance with Medicare related questions.

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

Brain Injury Alliance of Connecticut Helpline

(800) 278-8242 www.biact.org

The Alliance maintains a list of attorneys with experience representing individuals with brain injury.

Office of Protection & Advocacy for People with Disabilities

(800) 842-7303 OR (860) 297-4300 www.ct.gov/opapd/site/default.asp

This program protects and advocates for the rights of citizens with disabilities.

Statewide Legal Services

(800) 453-3320 OR 860-344-0380 www.slsct.org

Provide free civil legal services to income- eligible people, including direct representation, legal counseling, referrals and legal self-help materials.

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.

Connecticut Parent Advocacy Center

1-800-445-2722 OR 860-739-3089 www.cpacinc.org
Spanish Speaking: 203-776-3211

A statewide nonprofit organization that offers information and support to families of children with any disability or chronic illness, age birth through 26.

State Education Resource Center

(860) 632-1485 www.ctserc.org

Provides professional development and information dissemination in the latest research and best practices to educators, service providers, and families throughout the state, as well as job-embedded technical assistance and training within schools, programs, and districts.

Special education advocacy may also be available through the Office of Protection & Advocacy and/or Statewide Legal Services, both listed in the previous legal section.

TRANSPORTATION:

Some individuals, after a brain injury, may be unable to drive. There are public transportation options. The following resources can help with finding suitable transportation.

CT Transit Senior/Disabled Accessibility

Phone numbers vary by region www.cttransit.com

All CTTRANSIT buses have wheelchair lifts or ramps for access by persons with disabilities, along with the ability to "kneel" to lower the first step height.

CT ADA Paratransit Resource Center

203-365-8522, ext. 322 www.ctada.com

If an individual has a disability which prohibits their use of a CT Transit bus, they may be eligible for paratransit services located within CT Transit's service areas.

Travel Training Program

(203) 365-8522, ext. 265

http://www.thekennedycenterinc.org/what-we-do/programs-services/mobility-services/travel-training.html

The Kennedy Center Travel Training is a nationally acclaimed program that teaches people with disabilities and seniors how to properly and safely use the local bus and rail system on a one-to-one basis throughout the state of CT.

CT STATE SUPPORTED ASSISTANCE PROGRAMS: Various

programs are available to assist people with disabilities, although eligibility criteria will vary

Acquired Brain Injury Medicaid Waiver

(888) 794-6337 www.ct.gov/dss/cwp/view.asp

This program provides services in the home and community for those with a brain injury (ages 18-65) who qualify financially and medically.

Acquired Brain Injury (ABI) Program

through the Department of Mental Health & Addiction Services (DMHAS)

(860) 262-6725 http://www.ct.gov/dmhas/cwp/view.asp

A community service program to facilitate person centered recovery and encourage personal empowerment for individuals with brain injury and mental health issues.

Bureau of Rehabilitation's (BRS) Vocational Rehabilitation Program

(800)537-2549 www.ct.gov/brs/cwp/view.asp

A program to assist individuals with significant physical and mental disabilities to prepare for, obtain and maintain employment.

Community First Choices (CFC)

211, option 3 www.ctmfp.com

A new program in CT offered to active Medicaid members as part of the Affordable Care Act, which allows eligible individuals to access Personal Care Attendant Care (PCA) and other services and supports through self-direction.

Department of Developmental Services (DDS)

(866) 433-8192 http://www.ct.gov/dds/site/default.asp

Statewide services for individuals with an intellectual disability that began during the developmental period from before the age of 18 resulting in significant limitations in adaptive functioning, and a full scale IQ score of 69 or below

Katie Beckett Waiver

(800) 445-5394

http://www.ct.gov/dss/lib/dss/pdfs/overview_of_connecticut_medicaid_waiver_programs_2_6_15.pdf

A program that allows children with severe disabilities to be cared for at home and be eligible for Medicaid based on the individual's income and assets alone.

Long-Term Care Ombudsman Program

(866) 388-1888 www.ct.gov/ltcop/site/default.asp

A program to protect the health, safety, welfare and rights of long-term care residents by investigating complaints and concerns.

Money Follows the Person (MFP)

(888) 992-8637 www.ctmfp.com

This federal demonstration programs helps Medicaid eligible individuals, currently living in long-term care facilities - such as nursing homes and hospitals – successfully transition back into the community. To participate in the program the individual must be living in a long-term care facility for three months or more.

Office of the Healthcare Advocate

(866) 466-4446 www.ct.gov/oha/site/default.asp

An independent agency that can assist if an individual needs healthcare or healthcare coverage, or have problems or questions regarding healthcare coverage.

Issues they can assist with include:

- Questions about healthcare enrollment or coverage
- Questions about a benefit, program or coverage definition
- Questions about plans offered in CT
- Questions about your rights and responsibilities as a healthcare plan member
- Questions about the referral and pre-authorization procedures required by your plan
- Questions about your plan's internal and external appeals process

Personal Care Assistance (PCA) Medicaid Waiver

(888) 794-6337 http://www.ct.gov/dss/lib/dss/pdfs/pcapam.pdf

A home and community-based services waiver that provides for personal care assistance services under Medicaid. As a home and community-based waiver, the income eligibility requirement is higher.

AGING & DISABILITY RESOUCE CENTERS IN CT:

These offices serve as central clearinghouses for information about programs and services at a local level.

Community Choices

(800) 994-9422 www.ct.gov/agingservices/cwp/view.asp

An information hub linking older adults, persons with disabilities, and caregivers in CT to the supports and services they seek.

Aging & Disability Resource Centers are located in 5 regions throughout the state – South Central, Western, North Central, Southwestern and Eastern – but can be accessed through the main 1-800 # listed above. For more information, visit their website.

PEDIATRICS: Agencies exist within CT to provide support and information to parents of children and adolescents with disabilities, including brain injury.

Children & Youth w/Special Healthcare Needs

(800) 505-7000 www.ct.gov/dph/cwp/view.asp

Comprehensive and coordinated health care for income-eligible children who have, or are at elevated risk for chronic physical, developmental, behavioral or emotional conditions.

CT Family Support Network

(860) 657-8180 www.ctfsn.org

A network of families who have children with disabilities and are interested in helping other parents to find the supports they need.

Family to Family Health Information Center, PATH Parent to Parent Family Voices of CT

(800) 399-7284 OR (203) 234-9554 www.pathct.org

Offers Health Information Specialists that can assist families in navigating healthcare systems, provide information, education, support and referral services, and offer One to One Connection to a family who has similar needs and experiences.

Websites for Information on Brain Injury:

Brain Injury Alliance of Connecticut
www.biact.org

Brainline
www.brainline.org

The National Resource Center for TBI
www.tbinrc.com

Model Systems Knowledge Translation Center/TBI Consumer Fact Sheets
www.uwmsktc.washington.edu/tbi-factsheets

Lash & Associates Publishing & Training
www.lapublushing.com

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.

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

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

RANCHO LEVELS OF COGNITIVE FUNCTIONING

I. No response to stimulation

II. Generalized response to stimulation

III. Localized response to stimulation

IV. Confused, agitated behavior

V. Confused, inappropriate, non-agitated behavior

VI. Confused, appropriate behavior

VII. Automatic, appropriate behavior

VIII. Purposeful, appropriate behavior

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