

COMA GUIDE FOR CAREGIVERS



**Delaware Health and Social Services, Division of Services
for Aging and Adults with Physical Disabilities**

1901 N. DuPont Highway • New Castle, DE 19720



OUR VISION

FOR THE 21ST CENTURY

Delaware Health and Social Services' Division of Services for Aging and Adults with Physical Disabilities, while pursuing its mission to its customers, will move into the 21st century by pursuing a multi-faceted approach to success.

It must also prepare to serve the succeeding generations, whose needs may require uniquely different approaches and resources. Our focus on advocacy, diversity, partnering, technology, and education will enhance our efforts for success in providing quality services to our customers, empowering them for greater independence.

Dear Friends:

Families who are going or have been through the experience of having a family member or friend in coma have many needs. As caregivers of a person who is in coma or recently recovering from a coma, they may have many concerns and questions in trying to cope with a serious illness. This guide was developed as a result of the need we identified, when our 29-year-old daughter, Jill Elizabeth Russell Eddy was in coma for 12 months. We had no such guide or central place where comprehensive information and resources on coma could be easily obtained. When we spoke to our State Representative, William Oberle, he understood our concerns and enthusiastically supported the idea of the COMA GUIDE FOR CAREGIVERS.

My family and I would like to thank Representative Oberle and the Division of Services for Aging and Adults with Physical Disabilities for their wonderful support and untiring efforts to make this Guide a reality.

It is my sincere hope that the information supplied in this booklet will be beneficial to families who are dealing with such a tragedy and in some small way will bring support and comfort during their time of need.

Linda Morrison Russell,
Mother of Coma Patient



Michael, Jill, and Megan Eddy

ACKNOWLEDGEMENTS

*OUR SPECIAL THANKS
TO THE FOLLOWING PEOPLE:*

Division of Services for Aging and Adults with
Physical Disabilities, Coma Task Force

Carol Barnett and Linda Heller, Senior Planners,
Division of Services for Aging and Adults with
Physical Disabilities

The Timothy Aberle and Frank Harrington Families
(cover photo)

NOTE:

To obtain a copy of this Guide, or for further information, contact the
Division of Services for Aging and Adults with Physical Disabilities
1901 N. DuPont Highway, New Castle, DE 19720
(302) 577-4791 or 1-800-223-9074
e-mail: cbarnett@state.de.us

Note: You can click on an entry in the table of contents to go directly to the section of the Guide that you want to see.

TABLE OF CONTENTS

1	Dedication
2	Acknowledgements
4	Introduction
5	The Brain
7	What Happens with Brain Injury?
8	How are Brain Injuries Evaluated?
9	How are Brain Injuries Treated?
10	What other Treatments May be Used?
11	What Equipment Will You See?
12	Coma Scales and Coma Stimulation Programs
14	The Effects of a Brain Injury
20	Who Will Help After a Brain Injury?
22	How Will You React?
23	Family Issues
26	How Can You Help with Recovery?
28	Treatment and Rehabilitation
30	Financial Assistance
32	How to Evaluate a Nursing Home
34	TBI Statistics and Facts
35	Regional Coma and Brain Injury Rehabilitation Programs
36	Delaware State Resources
37	Resource Guides
38	Coma Resource List
39	Print Resources
41	Glossary
43	Resources for Families of Persons in Coma

INTRODUCTION

A sudden traumatic brain injury of a family member or close friend can be overwhelming and frightening. Added to this stress is the uncertainty associated with brain injury. It is difficult for any physician to predict the outcome during the first days, weeks, and even months. Along with family members, they must “wait and see” how the patient progresses. Struggling to understand this complex condition, most people feel alone and confused.

Although each family member or friend deals with the crisis in his/her own way, all can benefit from certain basic information. This resource guide provides a variety of helpful material. The first section describes the structure and function of the brain and goes on to explain the effects of injury. Patient care in the intensive care unit (ICU) and in other hospital settings is also addressed. The second section of the booklet discusses post-traumatic reactions of family members and close friends and answers some common questions. A glossary of hospital terms is also included in the back of the booklet.

Although family and friends may be anxious to learn more about brain injury, reading a resource guide may be difficult during such a trying time. It may be hard to concentrate and remember explanations. Each person is different, however. Some want to learn everything they can as quickly as possible. Others prefer taking in information a little bit at a time.

Read this resource guide at your own pace, perhaps a section at a time. In fact, some people like to start with the questions and answers. Many find it useful to jot down questions as they go along. You may wish to use the blank note page in the back of the resource guide for this purpose. In addition, keeping a journal or diary of events, feelings, concerns, and questions is usually helpful.

Plan to use this resource guide as you collect information about brain injury and discuss your concerns with family, friends, and caregivers. We hope this booklet provides a strong foundation of information for the days ahead.

THE BRAIN: *STRUCTURE AND FUNCTION*

The brain is very complex. Though researchers are constantly making new discoveries about how it functions, it is possible through a basic explanation of the organ to gain some understanding of its behavior.

Though the brain looks like a uniform structure, it is actually divided into many parts that perform very specific functions. Many of these different brain areas are active simultaneously or sequentially during daily activities.

Consider, for example, that the simple act of drinking a glass of water requires at least 9 separate brain functions. You decide to drink, initiate the act of drinking, receive visual information about the glass, move your arm and hand to the glass, receive sensations from your hand that the glass is in it, coordinate the movement of the glass to your mouth using your hand and arm, and then coordinate the sequential movements of your mouth, tongue, and throat to take a sip while taking a pause in breathing.

This is quite a bit of activity to occur in just a few seconds. Yet the brain manages to perform these kinds of routine actions regularly and speedily through constant communication between one part and the next. An injury, however, can interrupt the connections between the areas of the brain and so inhibit the simplest tasks.

Although each brain area is involved in many varied functions and each activity requires involvement of many brain areas, certain types of deficits commonly occur after an injury to a specific part of the brain. In fact, in

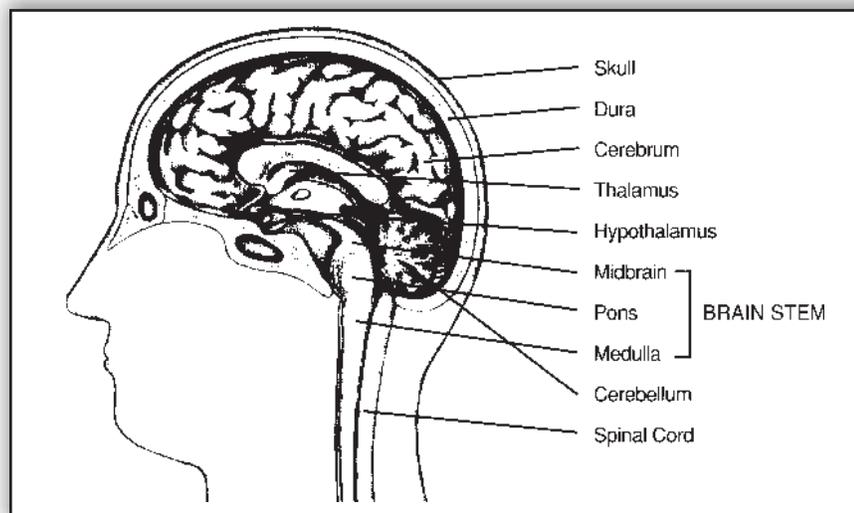


Diagram 1. Cross Section of the Brain

some cases, the areas of the brain that have been damaged can be identified by the changes the individual exhibits afterward.

As the director of all the body's functions, the brain uses a great many resources. At least 20 percent of the blood the heart pumps goes to the brain, and several million nerve cells send, receive, and interpret messages that keep us functioning and acting purposefully.

For the sake of description, the brain is divided into 3 main regions: the brain stem,

NOTICE: The purpose of the following information is to review certain medical issues. The information contained herein has been supplied as a courtesy from Bryn Mawr Rehab, Malvern, PA, and thus shall not be reproduced nor be construed as medical advice or opinion and is not intended as medical advice or opinion.

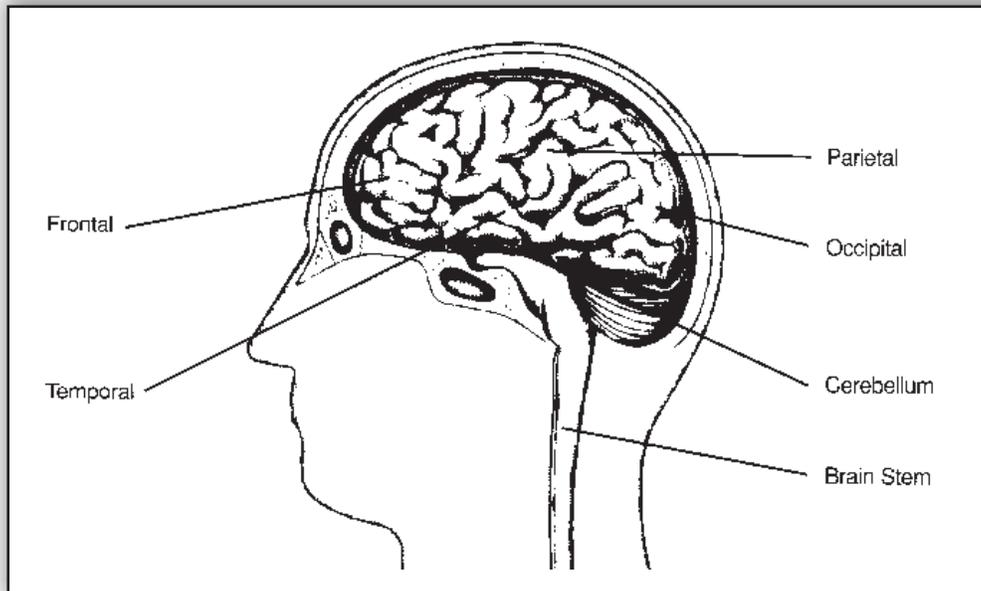


Diagram 2. Lobes of the Brain

the cerebellum, and the two cerebral hemispheres. The cerebral hemispheres are, in turn, divided into four lobes.

The main brain regions and the lobes are identified in Diagrams 1 and 2. Descriptions of the different areas follow, along with the primary functions they control.

SKULL

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

BRAIN STEM

Although this area is anatomically small, it plays a very important role in many brain functions. Injuries to the brain stem can affect motor function, eye movement, speech, swallowing, and the level of consciousness.

CEREBELLUM

This area is particularly important in coordination and balance.

CEREBRUM

The largest part of the brain, it is divided into the left and right cerebral hemispheres. Generally, each hemisphere directs the motor and sensory functions for the opposite side of the

body (i.e., the left hemisphere governs the right side of the body and vice versa). The hemispheres also have specific roles. For example, the left hemisphere of right-handed people governs language functions and the right hemisphere is particularly important in visual-spatial functions. Each hemisphere is then divided into four lobes (as noted in Diagram 2), which have specific functions.

FRONTAL LOBES

Govern personality, expression of emotion, storage of information, abstract thought, problem-solving, ability to organize, concentration, and the ability to initiate action and movement.

PARIETAL LOBES

Important in sensation, perception, attention and complex aspects of brain processing.

TEMPORAL LOBES

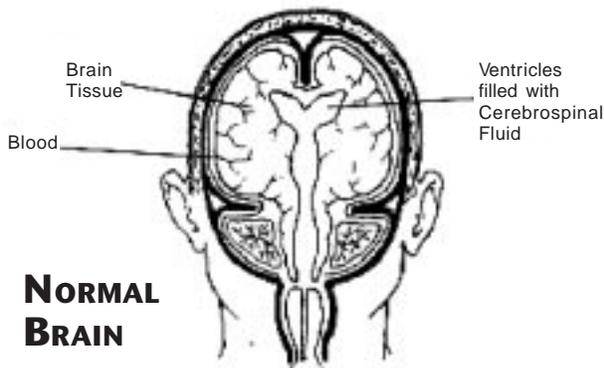
Regulate memory function, language information, and behavior.

OCCIPITAL LOBES

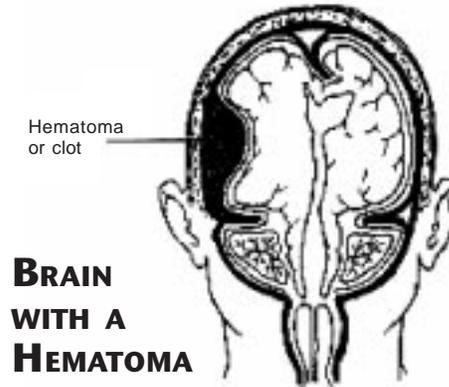
Responsible for aspects of visual function.

WHAT HAPPENS WITH BRAIN INJURY

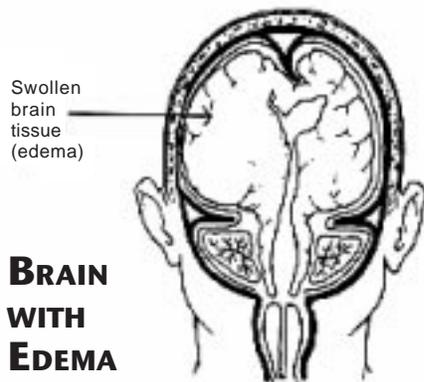
Even though the brain is well protected, it may be injured. Damage to the brain may occur immediately, or it may develop after the injury due to swelling or bleeding. The skull is usually filled like this:



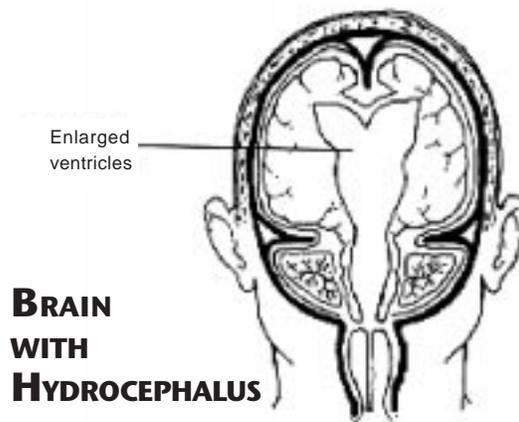
There may be bruising called contusions or a collection of blood called a hematoma or clot. This may also push the other contents to one side.



After brain injury, the contents may change. 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 to the side.



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



Any of these changes can cause increased intracranial pressure.

NOTICE: This section of the document is copyrighted by the University of Iowa and Karen Stenger, R.N., M.A. The Virtual Hospital is a registered trademark of the University of Iowa. The original copy of this document is maintained on the Virtual Hospital (<http://www.vh.org>). Please refer to it for the most up-to-date version of the document.

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.
- **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 can take pictures of the brain or other parts of the body. The scan is painless but the patient must lie very still. The test takes 30-60 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 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. Dye is put into a catheter in an artery (usually in the groin) that supplies blood to the brain. This test can tell if the arteries or veins 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.

NOTICE: This section of the document is copyrighted by the University of Iowa and Karen Stenger, R.N., M.A. The Virtual Hospital is a registered trademark of the University of Iowa. The original copy of this document is maintained on the Virtual Hospital (<http://www.vh.org>). Please refer to it for the most up-to-date version of the document.

HOW ARE BRAIN INJURIES TREATED?

Treatment of brain injury is aimed at:

- Stopping any bleeding
- Preventing an increase in pressure within the skull
- Controlling the amount of pressure, when it does increase
- Removing any large blood clots

Treatments will vary with the type of injury. The doctor will decide which ones are used. These may include:

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 cerebrospinal fluid 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 with 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.
- Steroids are used to decrease swelling in the brain tissue.
- 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.

- 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 signs. Some patients have a seizure at the time of injury while others may develop seizures after the injury.

VENTRICULAR DRAIN (VENTRICULOSTOMY): A small tube that is placed in the ventricle and connected to a drainage bag. It measures pressure inside the skull and drains CSF (cerebrospinal fluid). Some CSF is drained out of the brain to help control the pressure inside the skull. Pressure changes may be quickly seen and treated.

VENTILATOR: A machine used to help the patient breathe. Ventilators may breathe for the patient or they may be used to give extra breaths. When extra breaths are given the patient's blood vessels in the brain become smaller and this helps 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.

NOTICE: This section of the document is copyrighted by the University of Iowa and Karen Stenger, R.N., M.A. The Virtual Hospital is a registered trademark of the University of Iowa. The original copy of this document is maintained on the Virtual Hospital (<http://www.vh.org>). Please refer to it for the most up-to-date version of the document.

WHAT OTHER TREATMENTS MAY BE USED?

ANTIBIOTICS:

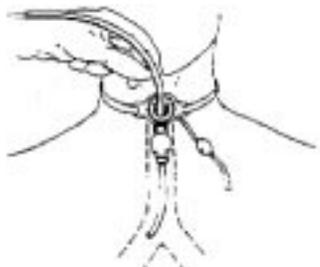
Antibiotics are used to prevent and treat infections that occur. It is not unusual for people with brain injuries to get infections. They may get pneumonia, bladder infections, blood infections, or infections in the brain or cerebrospinal fluid called meningitis.

CHEST PT AND SUCTIONING:

If the patient has pneumonia you may see staff using a vibrating machine or clapping 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 large amount 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 patients will be unable to talk while the trach is in place. A trach is not usually permanent. As the patient improves, they may be able to have the trach taken out.

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 acids. The acids 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 are important after brain injury. Patients may be less active, yet have very high nutritional needs. At first, nutrition can 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 is 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.

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:

Activities such as turning, padding equipment, keeping skin clean and dry, using special mattresses, and making sure the patient gets enough calories help prevent bedsores.

RANGE OF MOTION (ROM) AND SPLINTS:

Brain injured patients may not 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.

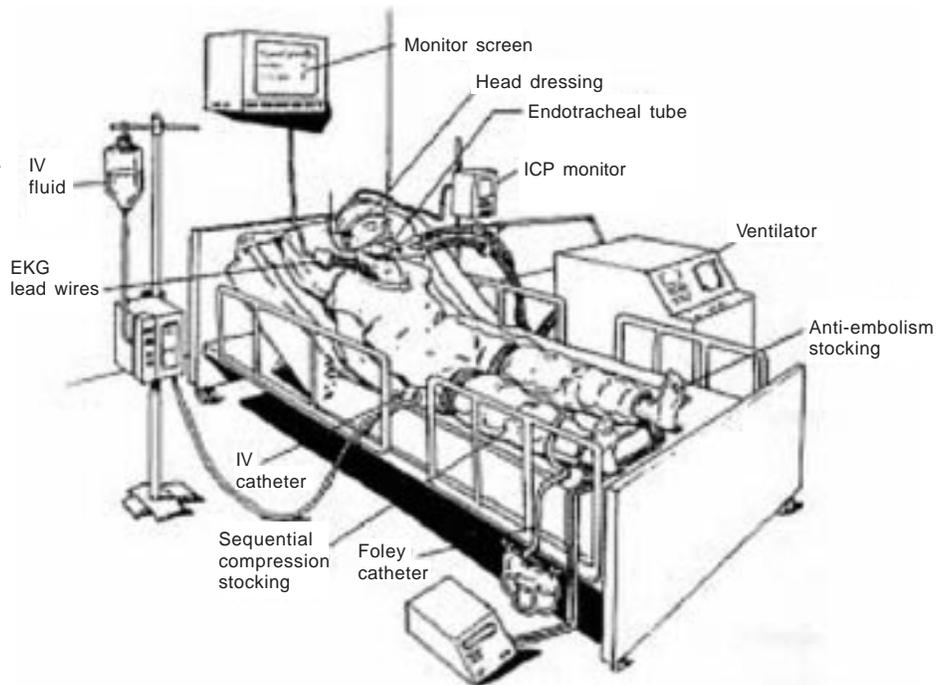
PAIN CONTROL:

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

WHAT EQUIPMENT WILL YOU SEE WHEN YOU VISIT?

INTRODUCTION

When the patient is seen in the emergency room the doctor will decide which treatments to use. A variety of equipment will be needed. It is helpful to know the purpose of equipment used. Please feel free to ask the staff any questions you may have. The following picture and text describe some of the most common equipment.



MONITOR SCREEN: A machine used to keep track of heart rate, breathing, blood pressure, and intracranial 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: 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 LEADWIRES: 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 Surgical Intensive Care Unit that may assist with breathing or breathes completely for a patient.

ANTI-EMBOLISM STOCKINGS (FREQUENTLY CALLED TEDS): Long white stockings used to help prevent blood clots in the legs.

SEQUENTIAL COMPRESSION STOCKING (FREQUENTLY CALLED KENDALLS): Plastic leg wraps that help prevent pooling of blood in the legs by inflating and deflating around the legs.

FOLEY CATHETER: A tube inserted into the bladder to drain and allow for accurate measurement of urine.

COMA SCALES AND COMA STIMULATION PROGRAMS

There are several scales used to describe patients with brain injury. The Rancho Scale is used more often by health care providers to indicate levels of recovery. 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

RANCHOS LOS AMIGOS SCALE

Rehabilitation centers may use a scale called the Rancho Levels. The eight level scale was developed by the professional staff of the Rancho Los Amigos Hospital in Downey, California to describe the stages of recovery after brain injury. What follows is a simplified explanation of each level of recovery.

Remember, the patient never fits neatly into one level of the scale, but rather into a general area, exhibiting characteristics of several levels. Also be aware that individual patients progress through the levels at different speeds, some skipping levels, others "getting stuck" for a while.

The following is a brief description of the Ranchos Los Amigos Scale of Cognitive Functioning:

LEVEL 1 - No response. The patient appears to be in a very deep sleep or coma and does not respond to voices, sounds, light, or touch.

LEVEL 2 - Generalized response. The patient moves around, but movement does not seem to have a purpose or consistency. Patients may open their eyes but do not seem to focus on anything in particular.

LEVEL 3 - Localized response. Patients begin to move their eyes and look at specific people and objects. They turn their heads in the direction of loud voice or noise. Patients at Level 3 may follow a simple command, such as "Squeeze my hand."

LEVEL 4 - Confused and agitated. The patient is very confused and agitated about where he or she is and what is happening in the surroundings. At the slightest provocation, the patient may become very restless, aggressive, or verbally abusive. The patient may enter into incoherent conversation.

LEVEL 5 - Confused, inappropriate but not agitated. The patient is confused and does not make sense in conversations but may be able to follow simple directions. Stressful situations may provoke some upset, but agitation is no

longer a major problem. Patients may experience some frustration as elements of memory return.

LEVEL 6 - Confused but appropriate. The patient's speech makes sense, and he or she is able to do simple things such as getting dressed, eating, and teeth brushing. Although patients know how to perform a specific activity, they need help in discerning when to start and stop. Learning new things may also be difficult.

LEVEL 7 - Automatic, appropriate. Patients can perform all self-care activities and are usually coherent. They have difficulty remembering recent events and discussions. Rational judgments, calculations, and solving multi-step problems present difficulties, yet patients may not seem to realize this.

LEVEL 8 - Purposeful and appropriate. At this level, patients are independent and can process new information. They remember distant and recent events and can figure out complex and simple problems.

For a more detailed explanation of the 8 levels of the scale and effective interventions, read the article "AAC and TBI: Transitioning Systems through the Phases of Recovery," by Dana Scroggs, MHS, CCC-SLP, at the Charlotte (N.C.) Institute of Rehabilitation, at (704) 355-7119. The web site address for the article is www.kaddath.mt.cs.cmu.edu

Coma is an unresponsive state so the patient is not able to open his eyes. Coma may serve as a mechanism for the brain to preserve itself during times of extreme stress, such as following an injury. It is important that families know the rehabilitation process can begin while the patient is still in a coma. The importance of early intervention is supported by recent studies. The length of time that a person is in a coma, does not necessarily determine the degree of recovery.

Health care professionals use a variety of therapeutic techniques and programs to move patients from a state of unconsciousness (coma) toward a greater awareness of their environment. Many of the programs are based on the theory that intense stimulation of the senses will excite the brain's reticular activating system, which is responsible for arousal and wakefulness. Scientists report that the brain is fairly plastic and has the ability to modify its

own structural organization and function, although the actual mechanisms that cause this to occur are not yet fully understood. Many believe that environmental enrichment and sensory stimulation can accelerate the recovery process. Sensory stimulation should focus on verbal conversation, familiar objects and memories, such as personal blankets, recordings of favorite music, pets, and posters. Some researchers recommend vigorous stimulation of the senses, using, for example, ringing alarm clocks, rubbing the skin, pleasant and unpleasant flavors and smells put on the tongue or held to the nose, or bright lights flashed in front of the eyes. The sensory stimulation programs are also careful to modulate the amount of stimulation given to the patient and are working to develop precise, structured regimens to avoid random stimulation and overstimulation.

We have listed, in the appendix to this guide, several sources of information related to coma and coma stimulation and how you may help the therapists with your loved one's rehabilitation.

Using information from the Rancho Scale, the health care team can begin treatment that will help develop skills and promote appropriate behavior. Health care professionals often suggest the following simple measures to family and friends while the patient is still in coma:

- **Always talk as if the patient hears when you are nearby.**
- **Speak directly to the patient about simple things and reassure him or her frequently.**
- **Explain events and noises in the surrounding area. Tell the patient what has happened and where he or she is.**
- **Touch and stroke the patient gently. Tell the patient who you are each time you approach the bedside. Hold his or her hand.**
- **Play favorite music for the patient or tape a soothing message that can be played when you are away from the bedside.**
- **For parents of young children, tape yourself singing or reading your child's favorite stories.**

THE EFFECTS OF A BRAIN INJURY

Because the brain is the center of operations for the body, an injury can affect many different areas. Some effects will be short-term, some may last longer, and some may be permanent. Some effects may appear suddenly and disappear just as fast; others may take a long time to come on and an equally long time to overcome.

A. THE EFFECTS OF A STROKE

Because strokes can occur on either side of the brain, it is important to understand the uniquely different symptoms they cause. The location of the stroke determines which side of the body will be affected. A stroke on the left side of the brain causes right-sided paralysis (hemiplegia) or weakness, while damage to the right side of the brain causes left-sided paralysis or weakness.

Some strokes may produce mild, or only temporary effects. Other strokes can produce permanent damage. The effects of a stroke depend upon which area of the brain has been damaged, which brain cells were damaged, how much damage has occurred, how easily and quickly the body repairs the blood supply system to the brain, and how quickly other areas of the brain can take over the work of the damaged brain cells. Some of the effects of stroke are global, that is, they can occur whether the stroke is on the right or left side of the body. Other effects are unique, depending upon the area of the brain that is damaged.

GLOBAL EFFECTS

Memory is commonly affected following a stroke regardless of which side is affected. Because memory is comprised of many varied components, patients may experience different types of memory impairment. Attention and concentration skills may also be reduced along with reasoning and judgment. Reading may

pose some problem for individuals sustaining a left or right stroke; others may experience trouble writing due to motor weakness, paralysis, or poor coordination.

Depression is a common reaction to illness or injury and should be considered normal after a stroke, if it doesn't last for a prolonged period of time. Some depression may be caused by chemical changes associated with the injury to the brain.

Emotional changes are also common. An individual may cry easily and then begin laughing for no apparent reason or may be more irritable and more easily frustrated than before the stroke.

A person's bowel and bladder functioning may also be affected following a left or right stroke. Many management techniques can be used to improve function.

THE EFFECTS OF A LEFT STROKE

The most apparent physical consequence of a stroke on the left side of the brain is right-sided paralysis (hemiplegia). The weakness or paralysis more often occurs to the hand and arm rather than the leg. For some individuals, the hemiplegia can prevent them from moving the affected limb, while others may experience only a mild weakness. This may cause difficulty standing, walking, dressing, bathing, and eating.

NOTICE: The purpose of the following information is to review certain medical issues. The information contained herein has been supplied as a courtesy from Bryn Mawr Rehab, Malvern, PA, and thus shall not be reproduced nor be construed as medical advice or opinion and is not intended as medical advice or opinion.

LEFT STROKE

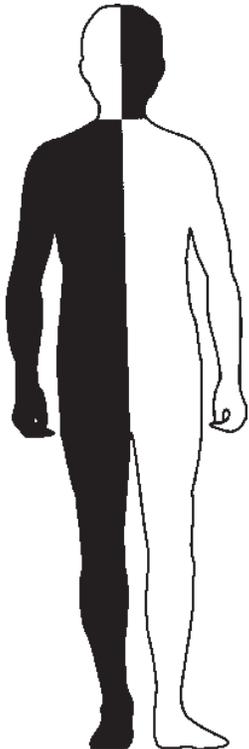
Paralyzed or weak right side

Speech-language deficits and/or swallowing disorders

Memory, attention, and concentration deficits

Poor judgment and reasoning

Behavior: slow, hesitant, disorganized



Persons who suffer right strokes often have difficulty judging distance, size, position, rate of movement, form and how parts are related to wholes.

One-sided neglect, that is, ignoring a weak or paralyzed body part may also develop with a right side stroke. Individuals with one-sided neglect may not even recognize that a body part is theirs.

Right strokes can also cause an individual to have problems understanding body language. A patient may not be able to interpret information from tone of voice, body movements, or facial expressions.

While persons with left strokes are slow and cautious, persons with right strokes tend to be impulsive and quick when completing activities. They are often unaware of their deficits and are unrealistic about their abilities. Some individuals may try to complete activities they cannot perform safely.

Speech and language problems are also common among individuals who have sustained a left stroke. There may be difficulty in both speaking and understanding. In some cases, the muscles in the face, neck, mouth, and throat also become weakened or paralyzed causing slow, labored slurred speech and an abnormal vocal quality.

Other consequences of a left stroke are difficulty swallowing or inability to swallow (dysphagia) and vision problems such as double vision or a partial blindness affecting only half the field of vision in each eye. An individual's behavior may also become slow, or appear hesitant when solving problems.

THE EFFECTS OF A RIGHT STROKE

A stroke on the right side of the brain may cause paralysis or weakness on the left side of the body. A person who has suffered a right stroke may display some degree of muscle weakness and dysphagia, vision deficits, memory, attention and concentration deficits. However, they frequently have adequate communication abilities.

RIGHT STROKE

Weak or paralyzed left side

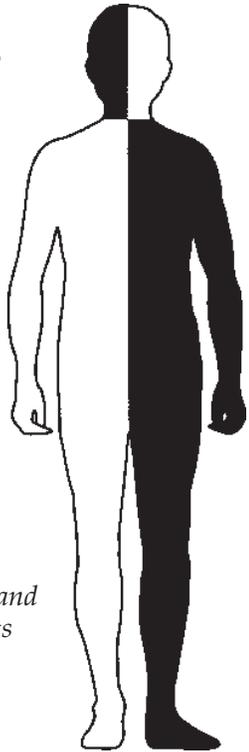
Neglect of weak or paralyzed body part

Difficulty judging distance, size, position, form, and rate of movement

Poor judgment and reasoning

Memory, attention, and concentration deficits

Behavior: quick and impulsive



B. MEDICAL AND RELATED PHYSICAL EFFECTS OF A TRAUMATIC BRAIN INJURY

Many potential deficits are noted in the following 4 sections. But as you read through, remember that only some may apply to your family member. As noted earlier, each person with a brain injury has had a unique injury and will experience a unique recovery process.

PROBLEMS WITH NUTRITION AND EATING

Physical and cognitive changes such as diminished attention, poor hand coordination, and difficulty in swallowing, can disrupt normal eating habits. Proper nutrition is essential to healing, however, so evaluations can be performed to determine the best means for a patient to maintain adequate nutrition. Retraining efforts through nursing, occupational therapy, and speech therapy can help a person recover eating abilities.

Dysphagia is the term that describes swallowing disorders. A swallowing disorder can occur at various points along the food's pathway to the stomach. It is important to recognize that placing food into someone's mouth and having it disappear without outward signs of choking does not assure that the food has been swallowed safely. In a significant number of patients, particularly if they are just emerging from coma or show confusion, food can enter the trachea (windpipe) and proceed to the lungs, where it can cause pneumonia to develop.

A speech/language pathologist conducts an evaluation to determine a person's level of safety in swallowing. This evaluation can be enhanced with a special x-ray study, called a **video fluoroscopic swallowing study**, which can help assess under what conditions swallowing may be safe and can offer direction for swallowing therapy. Evaluations and studies also will indicate if a feeding tube is necessary.

Many people are able to eat only under certain conditions. For example, they may tolerate small amounts of a selected food consistency (a soft diet, for example) in a carefully controlled therapy setting but may be at significant risk if fed under even slightly different conditions. Such patients may require tube feedings to maintain or supplement adequate nutrition.

The feeding tube will maintain proper nutrition until a patient is able to swallow properly again. Several feeding tubes are common: the **nasogastric** (NG) tube, which does not require a surgical procedure for use and is passed through the patient's nose and into the stomach; the **jejunostomy** (J) tube, which is surgically inserted directly into the small intestine, and the **gastrostomy** (G) tube, which is inserted directly into the stomach.

FEVER

If fever occurs, blood and urine tests and x-rays may be needed to help find the cause. Fevers are most often caused by urinary tract infection or pneumonia and these can be treated with antibiotics.

FRACTURES

Many people who sustain traumatic brain injury also sustain fractures. Rehabilitative care can assist in recovery from effects of these injuries and orthopedic care can continue in the rehabilitation setting.

HETEROTOPIC OSSIFICATION

Many patients with severe brain injury develop bone in the soft tissue around their joints — usually shoulders, elbows, knees, and hips. This formation, called **heterotopic ossification**, can cause pain and diminish the range of motion in the affected joints. Range of motion therapy can help to alleviate the problem and may be used in conjunction with medication. In more severe cases, surgery may be necessary over the long term.

HYDROCEPHALUS

Cerebrospinal fluid (CSF) acts to cushion and protect the brain and spinal cord from physical impact. CSF flows through a series of pathways around the brain.

The amount of CSF in the skull must be maintained at a relatively constant volume for the brain to function normally. **Hydrocephalus** is a condition in which the production of CSF exceeds its absorption and results in enlargement of cerebral ventricles. Hydrocephalus can be caused by abnormalities in production or reabsorption of CSF or by obstruction of the circulation of the fluid.

Hydrocephalus may be suspected if a person begins to deteriorate in mental or physical functioning or suddenly develops **incontinence** (i.e., cannot control urination). CT scans and sometimes additional tests may be required to establish the diagnosis. In some cases, a small catheter or shunt may be required to drain excess fluid from the brain.

INCONTINENCE OF BOWEL AND BLADDER

The inability to control bowel and bladder functions is common to people recovering from a brain injury. Many management techniques can be used to improve function. For example, laxatives and suppositories can help regulate the emptying of the bowel. Taking the person to the bathroom at scheduled times (time voiding) and using catheters and external collecting devices can improve bladder management. Both functions also may be improved by changes in diet.

PROBLEMS OF INACTIVITY

The long period of inactivity that may be part of recovering from a brain injury can cause certain physical problems. **General deconditioning** is the generally decreased strength and stamina that a person may experience as a result of extended bed rest. Individual exercise programs can help restore lost muscle strength and physical endurance. **Skin problems** such as pressure ulcers can develop after lying in one position for a long time. The best prevention is frequent inspection of the skin and shifting and repositioning. **Blood clots**, called **deep vein thrombosis (DVT)**, may develop especially in the legs when patients have limited mobility. Though the clots are not always apparent, they may be accompanied by pain, warmth, and swelling. An additional risk is for a clot in the leg to break off and enter the lung (called a **pulmonary embolus**). Anti-coagulant medications frequently are prescribed to manage these conditions. In some patients who may not tolerate anti-coagulants, a filter is sometimes placed in a large vein to prevent clots from going to the lungs.

SEIZURES

Seizures are common complications in people with traumatic brain injury. The symptoms of a seizure can range from generalized shaking

and loss of consciousness, to a discrete episode of altered attention, emotion, sensation, or movement.

Seizures are caused by an abnormal electrical discharge by brain cells. The risk of seizures is greater with prolonged unconsciousness, depressed skull fracture, or intracranial hemorrhage. Seizures can be subdivided into early (one to two weeks after injury), and late post-traumatic seizures. Patients with late seizures are generally treated with anti-convulsant medication for a period of years. Patients without late seizures, but at high risk, are sometimes treated with anti-convulsants for briefer intervals.

SENSORIMOTOR EFFECTS

This term refers to the relationship between movement and sensory perceptions. The brain interprets information sent by the senses, and directs physical movement according to the needs expressed by this information. Any of several movement disorders can result if a brain injury interrupts the smooth operation of this process.

Different types and levels of paralysis can affect different parts of the body and last for unpredictable periods of time. **Hemiparesis** is weakness on one side of the body; when this weakness is more severe, it is called **hemiplegia**.

Motor control in general can decrease because the injury has affected the way the brain directs the muscles to move. This can result in complete or partial interruption of certain movements, uncontrollable spasms, and/or a general inability to control movements. Another common deficit in motor controls is **apraxia**, the inability to carry out purposeful movements. For example, a person may have the ability to lift an arm, but can only do it spontaneously, not upon request. The instructions cannot be willfully communicated from the brain.

A person's balance and coordination also may be affected by a brain injury. Balance depends upon vision, hearing, and position sense information reaching the brain and being

properly analyzed there. Any interruption in these connections can disrupt balance. Poor coordination can be caused by injury to the cerebellum or portions of the inner ear and their connections to the brain. Called **ataxia**, this condition can interfere with the performance of even the most basic movements and tasks.

PROBLEM WITH MUSCLE TONE

AND RANGE OF MOTION

Muscle tone is frequently abnormal after a brain injury. Sometimes muscle tenseness may increase with movement. This is called **spasticity**. These changes in muscle tone can be painful and can lead to decreased range of movement and abnormal posture. For example, the arms may be held tightly across the chest and the legs may be held in a straight, rigid position.

Treatment for abnormal muscle tone includes exercises to normalize the tone, gain posture control and improve flexibility. These may include slow rocking, range-of-motion exercises, balance training, and serial casting (the application of casts to prevent deformity and gradually increase range of motion). Anti-spasticity medication, selected nerve block injections, and selected muscle injections may also be used. Orthopedic or neurosurgical procedures may be required in severe or chronic situations.

DYSARTHRIA

This term describes any of a variety of speech difficulties caused by muscle weakness or paralysis. The problem could be located anywhere in the mechanism of speech production: the muscles of the mouth, the passageway between nose and mouth, the voice box (larynx), or the respiratory system. Dysarthria causes slurred speech and an abnormal voice quality.

VISUAL DEFICITS

Vision can be impaired in one eye, in both eyes, or on one side of the visual field (called **visual field cut** or **hemianopsia**). **Diplopia**, or double vision, is also common after brain injury and is usually due to nerve damage. An eye patch often relieves initial discomfort and improve-

ment usually occurs over several months. If symptoms persist, prism lenses or eye muscle surgery may be considered. Vision therapy may also be considered.

Often, people have visual-spatial difficulty that is not due to nerve damage. This is called **visual perceptual deficit** and is caused when the brain has difficulty interpreting what is seen. These problems include **unilaterals neglect**, in which a person neglects items located on one side or ignores one side of the body, **decreased depth perception**, difficulty in perceiving how far away something is, and **diminished object recognition**.

OTHER PERCEPTUAL DEFICITS

Because sensory information is processed in the brain, any of the other senses of hearing, taste, smell, and touch may also be affected by a brain injury. The abilities to taste and smell are often diminished and must be compensated for. Hearing itself or the quality of what is heard (**auditory acuity**) may diminish. Certain sensitivities may be heightened, including sensitivity to touch (**tactile defensiveness**) and to movement (**vestibular deficit**). Even the perception of one's own limbs, their connection to the body and their relationship to the environment may be impaired (**proprioceptive disorder**).

C. BEHAVIORAL EFFECTS OF A TRAUMATIC BRAIN INJURY

Two of the most striking problems many people with brain injury experience are a **lack of insight** about their condition and **denial** about their condition. These problems can range from complete denial of obviously severe physical impairments to underplaying the extent of cognitive deficits. As a result, patients often do not take their limitations into account when planning future activities. Family members and rehabilitation staff need to have a realistic appraisal of the patient's strengths and weaknesses so they can provide guidance for planning and problem solving.

D. COGNITIVE EFFECTS OF A TRAUMATIC BRAIN INJURY

ATTENTION AND CONCENTRATION

Patients in early recovery often can remain completely alert for only a brief period. Later, it may be difficult for them to focus their attention entirely or to stay with one project or conversation for a significant period without becoming distracted. Patients can be distracted by their own emotions, thoughts, and physical responses or by any element in their environment, such as voices, music, noises, or sudden changes in the room. A related concern is an inability to turn one's attention from one subject to the next.

MEMORY

Memory impairment, or **amnesia**, is common after traumatic brain injury. There can still be islands of preserved memory during post-traumatic amnesia, but during this time there is usually a limited attention span. Precise assessment of how much actual memory loss has occurred is difficult. Patients in a confused state often will not remember things because of their severely impaired attention, but they may exhibit good memory function once their attention improves. The duration of the period of post-traumatic amnesia often indicates injury severity.

Every person has different types of memory, and one aspect of memory can be affected differently than another. Memory of things seen (**visual memory**) differs from memory of things heard (**auditory memory**), and a strength in one area can be used in therapy to help improve functional memory.

Short-term memory is the ability to recall things occurring within a few seconds to a day. **Long-term memory** is the ability to recall things occurring within a longer period of weeks and months, and **remote memory** is the ability to recall events that occurred many years ago.

Often, remote memory begins to return before short-term or long-term memory. Functionally speaking, it is the ongoing ability to make new, day-to-day memories that is important. Many patients with severe memory difficulty can recall events from years ago, but cannot remember if they had breakfast that day.

People who are confused or who misinterpret events and statements often may offer responses that appear made up. This behavior is a condition called **confabulation**. The person is trying to respond as well as possible to a statement or a situation that may not make any sense and is calling upon different and often unrelated memories to create their response.

It also is important to realize that a person may learn something new and remember it, but not remember the experience of learning it. Research has indicated that some people with brain injury learn information or motor skills taught in a therapy session even though they may not remember the session itself.

COMMUNICATION

A brain injury can greatly diminish a person's ability to understand language and communicate thoughts in return. Language processing may be impaired and, early in recovery, a person may have little or no understanding of words. This can be followed by a period in which some words or commands are known and not others, or some words may be known at one time and not at another. Later in recovery, a patient may not understand complicated statements and may need to interpret a statement before responding.

Aphasia is another type of communication problem in which a person can no longer connect the correct word with a particular object or find the words to express a particular thought. People who have difficulty understanding have **receptive aphasia**; those with difficulty saying/producing speech have **expressive aphasia**. Often, a person may experience both.

A similar problem is **paraphasia**, in which the individual will substitute an incorrect word that may sound like the desired word or relate to its meaning in some way.

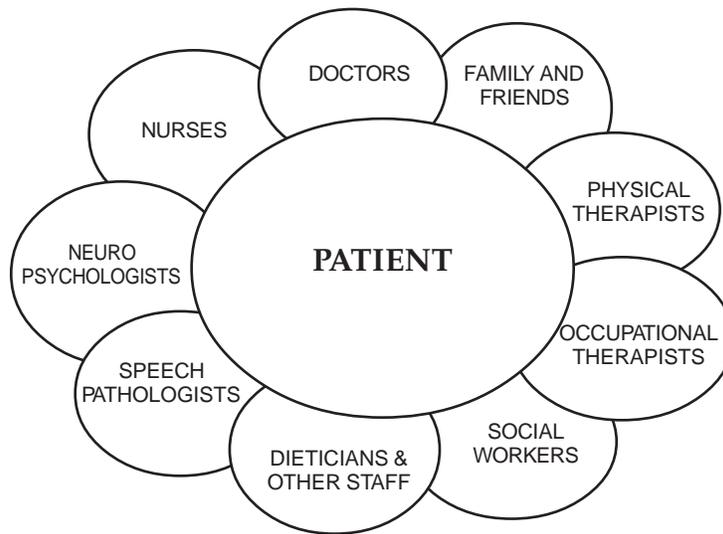
People may be able to speak or write correctly, but it is either off the point entirely or becomes irrelevant as it moves further off the point. This is called **tangential communication**.

Perseveration, when a person repeats a verbal or physical response inappropriately, is also common.

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 also teach you activities that you can do to help with the recovery process. The importance of family and friends to a person's recovery

cannot be over-emphasized.

DOCTORS:

Neurosurgery doctors are specialists that 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.

NOTICE: This section of the document is copyrighted by the University of Iowa and Karen Stenger, R.N., M.A. The Virtual Hospital is a registered trademark of the University of Iowa. The original copy of this document is maintained on the Virtual Hospital (<http://www.vh.org>). Please refer to it for the most up-to-date version of the document.

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 deal with questions related to 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 PATHOLOGISTS:

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.

RESPIRATORY THERAPISTS:

Respiratory therapists assess the patient's respiratory care, status, and treatment progress.

Services provided include:

- oxygen therapy
- aerosol medication therapy
- ventilator management
- pulmonary diagnostic procedures

In addition, respiratory therapists provide education to patients, family members, and hospital personnel and act as a resource to the medical staff for research and consultation.

OTHERS:

There are many other staff members that may work with brain injured patients and family.

These include:

- Clergy
- Activities Therapists
- Patient Representatives
- Child Life Therapists
- Music Therapists
- Vision Therapists
- Vocational Rehabilitation

HOW WILL YOU REACT?

When a friend or family member is hospitalized, it is normal to have many emotional reactions. You may have these emotions at different times. The emotions you may experience include:

PANIC AND FEAR

One of the first reactions you may have after a family member suffers a brain injury is panic and fear. Fears are intense because you are worried the patient may not survive. Until the patient becomes medically stable, physical and emotional feelings of panic may continue. Some of your physical symptoms may be 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. This is a normal reaction and it is okay to have these feelings.

GUILT

Guilt is a very normal reaction during this time. You may feel you could have done something to prevent the accident from happening, even when this is 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. This too is a normal reaction. 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. You may have a hard time relating to others in this abnormal situation. You may think that others will not understand. You may also think others are scared or disapprove of your feelings, and as a result isolate yourself. However, a crisis such as a brain injury is a time where it is helpful to accept comfort, support and assistance from others.

HOPE

As the patient begins to stabilize, 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.

NOTICE: This section of the document is copyrighted by the University of Iowa and Karen Stenger, R.N., M.A. The Virtual Hospital is a registered trademark of the University of Iowa. The original copy of this document is maintained on the Virtual Hospital (<http://www.vh.org>). Please refer to it for the most up-to-date version of the document.

FAMILY ISSUES: *COPING WITH RECOVERY*

You most likely will have gone through a tremendously difficult period marked by sadness, anxiety, fear, confusion, and frustration or anger. A brain injury to one family member can be devastating to the family as a whole. And while the person who was injured is the actual patient, the entire family needs both support and information during this difficult adjustment period.

Brain injury is a family matter and it affects families in many different ways. Families can undergo many changes as their loved one progresses through recovery. During the initial crisis period, there may have been no time to focus on anything other than the injured relative's life and problems—yet the health of each family member is important to the overall health of the family. Parents, spouses, children, and siblings can all go through difficult reactions unique to their relationship to the injured person. If a family balance is not restored that considers each person's needs, family members can experience isolation, poor health, prolonged fear, and depression.

Each family has its own style of expressing feelings, dividing chores, and solving problems. All of this may change when a family member acquires a serious disability, particularly a brain injury. It is common that in addition to feeling sad about the loved one's injury, family members feel a sense of loss for how the family itself has been altered. Family members may relate differently to one another and have different demands put on them.

An especially painful change involved family roles. Families operate like a small organization, providing food, shelter, comfort, support, and love. Different people in the family organization have different roles to play, and

those roles go beyond just the prescribed definitions of mother and father, son and daughter. For example, the roles can include who listens to emotional problems, who sends out the holiday cards, who takes care of the house repairs. If one family member becomes unavailable due to an injury, the entire system usually changes. People naturally pitch in and help during a crisis, taking on new and additional roles. There can be increased stress on family members as they do things they never thought they would or could do. But once a family member has a disability, pitching in temporarily usually leads to a permanent shift in responsibilities. Often, people have emotional reactions to such permanent role changes that include resistance, sadness, and even guilt at replacing a loved one in a particular function. There are two essential elements for coping with the shifts in roles: **openly expressing feelings and enlisting support.**

First, family members need to discuss the feelings they have about everything that has happened. For example, they may feel sadness and anger about the accident or illness itself and similar feelings about the changes the event has necessitated. Whatever the exact feelings are—there are no right and wrong ones—expressing them openly and directly is extremely important.

Second, the family needs to rally whatever resources it can to deal with strong feelings and

NOTICE: The purpose of the following information is to review certain medical issues. The information contained herein has been supplied as a courtesy from Bryn Mawr Rehab, Malvern, PA, and thus shall not be reproduced nor be construed as medical advice or opinion and is not intended as medical advice or opinion.

increased demands. The recovery process can be long and stressful. Family members need to assemble a support system of friends and relatives that will help relieve the tension that naturally builds.

Many times families don't want to ask for help. They don't want to impose on others or they are embarrassed to be in a needy position. Some people may think, too, that if they must ask for help, then the situation must be very serious. It is important to remember when these feelings arise that social support can be drawn from many people and many types of organizations. Extended family, neighbors, and members of your religious community often are waiting to be asked for help. In addition, support is available from institutions and community groups through hospital staff members, psychologists, and established support groups.

Every family will react differently to the crisis and will find its own means of coping. **You are encouraged to use your intuition, participate fully in the rehab program, make suggestions, and ask questions.** The more information you have about your family member's recovery, the better able you will be to handle the changes that can arise during the process.

The hope is that individuals who have experienced a brain injury or stroke will return home as independent as possible, with the help of the people who love them. In this way, families can be the most important part of the treatment team, as they will often continue the care of the recovering person at home. We've compiled the following list of suggestions for you to consider.

A. INTERACTING WITH THE INJURED PERSON

- The personality changes that can accompany a brain injury or stroke may be more difficult to cope with than any physical disability. If your family member behaves inappropriately, or in an unfamiliar way, it may be the result of his or her injury. You need not feel embarrassed about behavior that naturally occurs during the recovery process.
- Information may need to be presented to your injured family member as simply as possible. Use straightforward language and direct, uncomplicated gestures and expressions.
- Your family member's emotional reactions may not be what you would normally expect. They may be heightened or they may be absent. Often the types of reactions displayed may be best explained by the nature of the injury and the stage of recovery at which your loved one may be currently functioning. (See page 10 for the Rancho Scale).
- A person recovering from a brain injury or stroke sometimes has little capacity to fully grasp the extent of his or her deficits. Do not assume that your family member feels as you would if you were in his or her situation. Individuals are often unaware of their problems and are not depressed when we would expect them to be. The only way to know how they feel is to ask them. Even behaviors such as laughing or crying do not necessarily mean that the patient is happy or sad. Their behavior can be disconnected from their feelings. As your family member improves, however, so does his or her insight into losses or changes. This is the time when he or she will most need your support and the help of the team.
- People recovering from brain injury or stroke often have a diminished capacity for empathy. They are often incapable of seeing any point of view other than their own. Be aware that your family member may not seem as mature as he or she once was, but responding to him or her as one adult to another is still important.
- Try to be objective about your family member's capabilities. Patients often deny their disabilities and try to influence your point of view about them. You can make your assessments based on the information that you have.

- Your family member will benefit from structure. Help him or her work through problems by providing input likely to lead in the right direction.
- Your efforts may not always result in immediate improvement. You can feel discouraged and even guilty as a result. It is important then, and at all times, to keep your sense of hope. While it is vital to remain realistic in your goals, you do not need to give up on future possibilities.

B. GENERAL GOALS

- Take care of yourself and your family — not just your injured relative. It will not help him or her if you become exhausted. Do not be concerned that asking staff members for help for yourself will limit our attention to your relative.
- Pace yourself. This process can be a long one. Do not expend all of your energy in the early stages because you will need it in the months ahead.
- Remember that dealing with a brain injury or stroke is difficult and no one has all the answers. Common sense, however, will carry you a long way. Counseling can also help and can be found through your religious institution or through psychologists, psychiatrists, and social workers.
- Participate in your family member's rehabilitation program to gain a better understanding of the processes and effects of a brain injury or stroke.
- Write important info down in a journal or notebook. Keep records and info together in a file for easy reference.
- Remember that every person is unique and so an injury to the brain will have unique effects. Try not to compare your family

member's progress to that of others in the rehabilitation program. The treatment team individualizes the care for each person, so your family member is receiving the most appropriate treatment. One therapist recommended, 'Don't look back one day and compare your loved one's accomplishments; look back one week and you will really see a difference.'

- Acknowledge all of your feelings. You may not understand why you feel as you do at certain times, but it is important to recognize even those that seem odd or unreasonable. Sharing them with other relatives and friends may also provide some relief; they may be feeling the same way.
- Holding a family get-together, particularly one with dependent children, can be very difficult. Try to appraise the situation as honestly as possible. If you are under stress, turn to professionals for help.
- Try to maintain your normal contacts. Stay in touch with relatives and friends and make plans to do recreational activities outside of the hospital. Such outings will help to keep you connected to the community.
- Maintain a sense of humor. A sense of humor has a healing influence. Once a patient's condition stabilizes and improves, family members find their ability to laugh returns. They find that laughter helps them as well as the patient.
- Every person in coma will react in a unique way. Some persons with a coma experience complete recovery and others do not. Always be hopeful that your loved one will come out of their coma.
- Join a brain injury support group. Contact the Brain Injury Association of DE at 1-800-411-0505 for dates and locations.

HOW CAN YOU HELP WITH RECOVERY?

The family and friends of a person with a brain injury are important members of the team. Friends of those with brain injuries may find it uncomfortable to visit when the patient is confused or agitated. Honest explanations from family members may help them continue to offer the attention and support that is so helpful to patients. Sharing this guide is another way to help them understand. The following is a list of suggestions that correspond with the stages of recovery.

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 from various senses (hearing, smell, sight, touch).

- When speaking to the patient assume they understand 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 and personal items that are comforting and familiar to them (use poster/bulletin board).
- The nurses and therapists may encourage you to assist in care of the patient. This

includes: grooming, hair care, shaving, applying skin lotion, gently stretching and positioning patient's arms and legs. If you don't feel comfortable with these activities, that is okay. The staff will understand.

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 at the staff's 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.

NOTICE: This section of the document is copyrighted by the University of Iowa and Karen Stenger, R.N., M.A. The Virtual Hospital is a registered trademark of the University of Iowa. The original copy of this document is maintained on the Virtual Hospital (<http://www.vh.org>). Please refer to it for the most up-to-date version of the document.

- Continue with suggestions listed in the unresponsive section.

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 their 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.
- Socially unacceptable behavior may occur at this level. This is common. Calmly tell the patient the behavior is not appropriate.
- Provide visual as well as verbal information about the patient's surroundings to assist with orientation. Remembering information from one time to another is difficult. It may be helpful to provide cues for the patient such as:
 - A calendar with the days marked off
 - A sign in the room telling them where they are
 - Post a schedule with meal times, therapies, and special appointments

- Allow the patient to move about with supervision to decrease frustration.

HIGHER LEVEL RESPONSES

At this stage patients are able to take part in their daily routine 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. Here are a few additional suggestions for this stage.

- Assist with making the environment safe. Safety decisions may still be difficult for the patient to make.
- Discuss with the patient decisions that he or she makes. Provide praise for safe decisions and a calm explanation for unsafe decisions. Learning is still difficult.
- Encourage the use of a memory and 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.

TREATMENT AND REHABILITATION

WHAT IS THE REHABILITATION PROCESS?

1. The goal of rehabilitation is to help people regain the most independent level of functioning possible.
2. The rehabilitation process is different for everyone. Rehabilitation programs should be individualized, catering to each person's unique needs. Just as no two people are exactly alike, no two brain injuries are exactly alike. The person with a brain injury and his or her family should always be the most important members of the treatment team. Cultural, religious, social and economic backgrounds must always be taken into consideration when planning a person's rehabilitation program.
3. Rehabilitation channels the body's natural healing abilities and the brain's relearning processes so that an individual recovers as quickly and efficiently as possible. Rehabilitation also involves learning new ways to compensate for abilities that have permanently changed due to brain injury. There is much that is still unknown about the brain and brain injury rehabilitation. Treatment methods and technology are rapidly advancing as knowledge of the brain and its functions increases.

MODELS OF REHABILITATION

In the past, rehabilitation services for people with brain injury were largely provided in a "medical model," located in a medical facility with a cadre of physicians, nurses, and trained professionals providing services. While this model still predominates, the trend today is toward more community-based rehabilitation models, and more options are available than ever before. Rehabilitation service delivery and funding are changing rapidly as managed care continues to replace the traditional fee-for-service and indemnity insurance plans.

MEDICALLY BASED REHABILITATION:

- Early intervention is crucial. Rehabilita-

tion should ideally start in the Intensive Care Unit. At this point, rehabilitation is generally preventive in nature. Range of motion, bowel and bladder hygiene (i.e. initiation of regular bowel program and removing indwelling catheters), prevention of pressure sores, and orientation are all very important, right from the beginning. Frequently, rehabilitation activities initiated in the ICU can reduce complications and sometimes, the length of hospitalization.

- Acute Rehabilitation: Once a person is medically stable, transfer to an acute rehabilitation facility often occurs. There, he or she will spend several hours a day in a structured rehabilitation program. This program usually includes a team of profes-

Reprinted with permission from The Brain Injury Assn., Inc. website at www.bia.org

sionals with training and experience in brain injury rehabilitation. Additional staff support the brain injury rehabilitation team's efforts, and often includes respiratory therapy, pharmacy, lab, nuclear medicine and radiology and even housekeeping, dietary and central supply.

- “Subacute” Rehabilitation: People who are minimally aroused for a prolonged period often have limited attention and stamina, and need a less intensive level of rehabilitation services, over a longer period of time. Subacute rehabilitation may be provided in a variety of settings, but is often in a skilled nursing facility or nursing home. It is important to note that the services provided by subacute programs vary widely, as there is no generally accepted definition of subacute services at this time.
- It is important to recognize that “more therapy” does not make a person “better”, but that “appropriate” therapy does. Subacute rehabilitation programs require the same appropriately trained professionals as acute rehabilitation programs do. The goals of sub-acute rehabilitation should include minimizing morbidity, maintaining functional positioning, hygiene, nutrition, and medication management, as well as providing support for the person with a brain injury and his or her family. Sub-acute rehabilitation programs may also be designed for persons who have made progress in the acute rehabilitation setting and are still progressing, but are not making rapid functional gains.
- Day Treatment/Day Rehab: Day rehab (sometimes called “Day Hospital”) provides intensive rehabilitation in a structured setting during the day and allows the person with a brain injury to return home to their family at night. The treatment team is often made up of a variety of trained rehabilitation professionals.

COMMUNITY-BASED REHABILITATION

- Out-patient Facilities: Following acute rehabilitation or sub-acute rehabilitation, a person with a brain injury may continue to receive outpatient treatment in specific areas (i.e. ongoing speech pathology to continue to work on language and cognition, or occupational therapy to work on daily living skills, etc.). Often, this treatment can also be provided in the home by a home-health agency.
- Home-based Rehabilitation: There are a few rehabilitation companies which focus on providing acute rehabilitation within the home, or community setting. Once medically stable, some persons with a brain injury may be able to participate in such a program, if there is such a program in their community.
- Community Re-entry: Community re-entry programs generally focus on developing higher level motor and cognitive skills in order to prepare the person with a brain injury to return to independent living and potentially to work. Treatment may focus on safety in the community, interacting with others, initiation and goal setting and money management skills. Vocational evaluation and training may also be a component of this type of program. Community Re-entry programs generally run for part or all of the day, with participants returning home to sleep and be with their families.
- Independent Living Programs: Independent Living programs provide housing for persons with brain injury, with the goal of regaining the ability to live as independently as possible. Usually, independent living programs will have several different levels, for people requiring more assistance, to those who are living independently and being monitored. In addition to physical, occupational, speech and recreation therapists, these programs usually have life skills technicians, who assist the person with a brain injury towards independence.

FINANCIAL ASSISTANCE

Brain injury is a long term illness that continues long after hospital discharge. As a result, financial planning for short and long term care needs to begin immediately. Health insurance can pay for a few days in the hospital but funding needs to be identified for services after discharge. Social Security Disability or Medicaid may pay for some of the services needed. Most people have not planned ahead and will need to find sources of "hidden funding."

ON ADMISSION, families should begin to take these steps:

- Establish open communication with hospital staff, the social worker, financial aid office, discharge planner and make appointments to seek their help in finding "Hidden Funding."
- Call the Claims Supervisor of their health insurance provider and ask their doctor's office claims managers to help.
- Do not take "no" for an answer. Ask why, and consider appealing decisions.
- Call state agencies for assistance.
- Contact organizations that family, friends or co-workers belong to for help.
- Keep track of ALL contacts, recording the date, time, name of person and conversation or agreements.
- Ask a rehabilitation facility to evaluate the consumer for admission.

The following resources may offer assistance:

SOCIAL SECURITY -

provides a monthly income for eligible elderly and disabled individuals. Call the Social Security Administration at 1-800-SSA-1213, from 7 a.m. to 7 p.m., Monday through Friday. The lines are busiest early in the week and early in the month. If you have a touch tone phone, recorded information and services are available 24 hours a day, including weekends and holidays.

SUPPLEMENTAL SECURITY INCOME (SSI) - supplements Social Security payments for individuals who have certain income and asset levels. SSI is administered by the Social Security Administration. Call 1-800-SSA-1213.

MEDICARE -

is a federal health insurance program for those who receive Social Security benefits. Eligible individuals include those who are 65 and older, people of any age with permanent kidney failure and disabled people under age 65 who have received Social Security disability benefits for at least 24 months. Call 1-800-SSA-1213.

MEDICAID -

provides health insurance for eligible low income people who are elderly, blind, or disabled as well as for certain groups of children. Services are coordinated by state government through Delaware Health and Social Services Division of Social Services. Call 1-800-372-2022 in Delaware.

VETERANS' BENEFITS -

eligible veterans and their dependents may receive treatment at a V.A. Medical Center. Treatment for non-service connected conditions may be available, based on the veteran's financial need. Call 1-800-827-1000.

If you have life insurance and have a life threatening illness you may be able to use those funds to pay for medical or other expenses. Call the Viatical Association of America at 1-800-842-9811.

Hill-Burton is a program through which hospitals receive construction funds from the federal government. Hospitals that receive Hill-Burton funds are required by law to provide some services to people who cannot afford to pay for their hospitalization. For more information about hospitals covered by the Hill-Burton Act, call 1-800-638-0742.

There are several agencies that offer lower cost prescription drugs directly from the drug manufacturer for people who qualify. These companies work with the patient's doctors. The internet address for these companies are www.needymeds.com and www.themedicineprogram.com. For information about The Medicine Program call 1-573-778-1118.

There are private sources of funds to help you pay your medical bills. Many disease and disability related, civic, social welfare and religious organizations have funds available for at least emergency or short-term medical needs. For a list of local civic groups, such as the Jaycees, Elks, and Moose Lodges, see the Thursday's Crossroads section and the Monday's Business Journal section of the Wilmington News Journal. Sometimes, families ask their local newspapers to feature an article about their family's situation and ask readers to donate money toward the cost of a particular device or piece of equipment. Most requests will need to be made in writing and you may have to schedule an appointment to speak to the funding source.

Reference books, such as Financial Aid for the Disabled and their Families, published by Reference Service Press will be available in libraries, in the grants collection at the University of Delaware Library, and through local social service agencies. These books list local and national sources of possible funding. In Delaware, contact the Delaware Community Foundation at 302-571-8004 to purchase a copy of the yearly Directory of Delaware Grantmakers.

HOW TO EVALUATE A NURSING HOME

A nursing home is one option for post-hospital care you may want to explore. This checklist is designed to help you evaluate and compare the nursing homes that you visit. It would be a good idea to make several copies of this checklist, so that you will have a new checklist for each home you visit. After you have completed checklists on all the nursing homes you plan on visiting, compare your checklists. Comparisons will be helpful in selecting the nursing homes that might be the best choice for you. Call the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) for a list of licensed nursing homes in Delaware at 453-3820 or 1-800-223-9074.

NURSING HOME CHECKLIST

PART I — BASIC INFORMATION

Name of Nursing Home _____

Address _____

Phone _____ Cultural/Religious Affiliation (if any) _____

	YES	NO
Medicaid Certified	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Certified	<input type="checkbox"/>	<input type="checkbox"/>
Admitting New Residents	<input type="checkbox"/>	<input type="checkbox"/>
Convenient location	<input type="checkbox"/>	<input type="checkbox"/>
Is home capable of meeting your special care needs?	<input type="checkbox"/>	<input type="checkbox"/>

PART II — QUALITY OF LIFE

	YES	NO
1. Are residents treated respectfully by staff at all times?	<input type="checkbox"/>	<input type="checkbox"/>
2. Are residents dressed appropriately and well-groomed?	<input type="checkbox"/>	<input type="checkbox"/>
3. Does staff make an effort to meet the needs of each resident?	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there a variety of activities to meet the needs of individual residents?	<input type="checkbox"/>	<input type="checkbox"/>
5. Is the food attractive and tasty? (sample a meal if possible)	<input type="checkbox"/>	<input type="checkbox"/>
6. Are resident rooms decorated with personal articles?	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the home's environment homelike?	<input type="checkbox"/>	<input type="checkbox"/>
8. Do common areas and resident rooms contain comfortable furniture?	<input type="checkbox"/>	<input type="checkbox"/>
9. Does the facility have a family and residents' council?	<input type="checkbox"/>	<input type="checkbox"/>
10. Does the facility have contact with outside groups of volunteers?	<input type="checkbox"/>	<input type="checkbox"/>

PART III — QUALITY OF CARE

YES NO

- 11. Does staff encourage residents to act independently?
- 12. Does facility staff respond quickly to calls for assistance?
- 13. Are residents and family involved in resident care planning?
- 14. Does the home offer appropriate therapies (physical, speech, etc.)
- 15. Does the nursing home have an arrangement with a nearby hospital?

PART IV — SAFETY

- 16. Are there enough staff to appropriately provide care to residents?
- 17. Are there handrails in the hallways and grab bars in bathrooms?
- 18. Is the inside of the home in good repair and exits clearly marked?
- 19. Are spills and other accidents cleaned up quickly?
- 20. Are the hallways free of clutter and well-lighted?

PART V — OTHER CONCERNS

- 21. Does the home have outdoor areas (patios, etc.) for resident use?
- 22. Does the home provide an updated list of references?
- 23. Are the latest survey reports and lists of resident rights posted?

- 24. (Your Concern) _____
- 25. (Your Concern) _____

Additional Comments: _____

This checklist may be reproduced and circulated. It is designed to be used in concert with the Health Care Financing Administration’s booklet, *The Guide to Choosing a Nursing Home*. This booklet can be obtained by calling (800) 638-6833.

TBI STATISTICS AND FACTS

GENERAL

- There are 2 million Traumatic Brain Injuries each year (One every 15 seconds).
- 500,000 of these injuries require hospital admission.
- Every 5 minutes someone dies from a head injury:
 - 140,000 people each year.
 - 75,000 - 100,000 in the U.S.
 - Over half of the deaths occur at the time of the incident or within two hours of hospitalization.
- Every 5 minutes someone becomes permanently disabled due to a head injury.
- 70,000 - 90,000 of those who survive will have lifelong disabilities.
- 2,000 more will live in a persistent vegetative state.
- Over 50% of those who sustain a Brain Injury have been intoxicated at the time of injury. The cost of Traumatic Brain Injuries in the U.S. is over \$48 Billion each year!

CAUSES

- 51% - Motor Vehicle Accidents
- 21% - Falls
- 12% - Assaults and Violence
- 10% - Sports and Recreation
- 6% - Other

SURVIVORS

- A survivor of severe brain injury faces 5 to 10 years of intensive services and rehabilitation.
- The costs of a severe brain injury often exceed 4 million dollars.
- A majority of head injury survivors are under the age of 30.
- 2/3 of those who survive will live a normal life span, but will require life long services such as vocational rehabilitation and physical therapy.

INJURY

- A person does not need to be knocked out or lose consciousness to have sustained a traumatic brain injury.
- A person does not need to strike their head to sustain traumatic brain injury. (eg., whiplash, shaken baby syndrome.)
- Even mild traumatic brain injuries can cause cognitive impairments serious enough to impact a person's ability to enjoy life and to be able to work and earn a living.
- People who sustain a brain injury are 3 times as likely to sustain a (second) brain injury.
- Those who sustain a second brain injury are 8 times as likely to sustain a (third) brain injury.

BICYCLING

- About 75% of all bicyclists who die each year die of head injuries.
- 85% of head injuries in bicycle accidents can be prevented by wearing a helmet.

DEMOGRAPHICS

- Males between the ages of 14 and 24 have the highest rate of injury.
- Males are almost twice as likely to suffer serious brain injuries than females.
- Brain Injuries kill more Americans under the age of 34 than all other diseases combined.

CHILDREN

- Child abuse is the cause of 64% of all infant head injuries.
- Approximately 1 in 500 school-age children each year receive a head injury severe enough to be hospitalized.
- 1 million children sustain a head injury each year.
- 165,000 children will be hospitalized due to a head injury.
- 1 in 10 of those children hospitalized will suffer moderate to severe impairments.
- Traumatic brain injury is the leading cause of death for children and young adults.

REGIONAL COMA AND BRAIN INJURY REHABILITATION PROGRAMS

DELAWARE

Christiana Care System, Center for Rehabilitation at Wilmington Hospital
Wilmington

Admissions Information:

Usually take Rancho Scale Level 4 and above
No Coma Stimulation Program
Call 302-428-6600

St. Francis Hospital Rehabilitation Center
Wilmington

Admissions Information:

Usually take Rancho Scale Level 5 and above
No Coma Stimulation Program
Call: 302-421-4541

Milford Hospital Rehabilitation Program
Milford

Admissions Information:

Usually take Rancho 5 and above and evaluate on individual basis
Call 302-424-5962 or 5971

PENNSYLVANIA

Bryn Mawr Rehabilitation
Malvern

Admissions Information:

Usually take Rancho Scale Level 2 and above
Call 610-251-5411

Moss Rehabilitation Hospital
Philadelphia

Admissions Information:

Usually take Rancho Scale Level 1 and above
Coma Stimulation Program
Call 215-456-9700

Magee Rehabilitation Hospital
Philadelphia

Admissions Information:

Usually take Rancho Scale Level 1 and above
Coma Stimulation Program
Specialized Spinal Cord Injury Program
New Contract with Blue Cross/Blue Shield of DE
Call 800-96-MAGEE (62433) or 215-587-3157

NEW JERSEY

Mediplex Rehabilitation
Cherry Hill, New Jersey

Admissions Information:

Usually take Rancho Scale Level 1 and above
Coma Stimulation Program on a case-by-case basis
Take Rancho Scale Level and above
Call 609-342-7600

MARYLAND

Bryn Mawr Rehabilitation
Baltimore

Admissions Information:

Usually take Rancho Scale Level 2 and above
No Coma Stimulation Program
Call 410-225-8522

Kernan Rehab and Deaton Specialty Rehabilitation
Baltimore

Admissions Information:

Usually take Rancho Scale Level 1 and above
Coma Stimulation Program
Call Kernan @ 410-328-8680 or Deaton @ 410-328-1513

DELAWARE STATE GOVERNMENT RESOURCES

STATE DEPARTMENT OF EDUCATION: SPECIAL EDUCATION

Director
Exceptional Children and Early Childhood
Group
Department of Education
P.O. Box 1402
Dover, DE 19903
(302) 739-5471

OFFICE OF STATE COORDINATOR OF VOCATIONAL EDUCATION FOR STUDENTS WITH DISABILITIES

Education Associate
Vocational Technology Education & School to
Work Transition
Department of Education
P. O. Box 1402
Dover, DE 19903
(302) 739-4638

PROGRAMS FOR CHILDREN WITH DISABILITIES: AGES 3 THROUGH 5

619 Coordinator
Exceptional Children and Early Childhood
Group
Department of Education
P.O. Box 1402
Dover, DE 19903
(302) 739-4667

STATE MENTAL HEALTH AGENCY

Director
Division of Alcoholism, Drug Abuse &
Mental Health
Department of Health & Social Services
1901 North DuPont Highway
New Castle, DE 19720
(302) 577-4461

PROGRAMS FOR INFANTS AND TODDLERS WITH DISABILITIES: AGES BIRTH THROUGH 2

Part C Coordinator
Management Svcs. Division Health and
Social Services
2nd Floor, Room 204
1901 North DuPont Highway
New Castle, DE 19720
(302) 577-4647

STATE MENTAL HEALTH REPRESENTATIVE FOR CHILDREN

Director
Division of Child Mental Health Services
Department of Services for Children, Youth,
and Their Families
1825 Faulkland Road
Wilmington, DE 19805-1195
(302) 633-2600

STATE DIVISION OF VOCATIONAL REHABILITATION

Director Delaware Division of Vocational
Rehabilitation
Dept. of Labor
4425 North Market Street
P. O. Box 9969
Wilmington, DE 19809-0969
(302) 761-8275; (302) 761-8336 (TTY)

STATE MENTAL RETARDATION PROGRAM

Director
Division of Mental Retardation
Department of Health & Social Services
Jesse Cooper Building
P.O. Box 637/Federal Street
Dover, DE 19903
(302) 739-4386

RESOURCE GUIDES

A Guide To Federal Programs For People With Disabilities

National Academy for State Health Policy
50 Monument Square, Suite 502
Portland, ME 04101
(207) 8574-6524

Consumer Resource Manual

List of resources & support groups for people with a loss of vision

Delaware Health and Social Services
Division for the Visually Impaired
305 West 8th Street
Wilmington, DE 19801
Phone: (302) 577-3333 Ext. 25 or
(302) 577-4730 (V or TTY)

Delaware Assistive Technology Resource Guide

Delaware Assistive Technology Initiative
Applied Science & Engineering Laboratories
University of Delaware/A.I. DuPont
Institute
1600 Rockland Road
Wilmington, DE 19899
(302) 651-6790

Delaware Central Directory of Services For Young Children With Special Needs

List of resources and services for children with special needs from 0 to 3 years of age
Part H - Birth to Three Program
Delaware Health and Social Services
Division of Management Services
1901 N. DuPont Highway
New Castle, DE 19720
(302) 577-4643

Directory of Human Services For Delaware

Delaware Health and Social Services
Division of State Service Centers
1901 North DuPont Highway
New Castle, DE 19720
(302) 577-6420

Guide To Programs And Services

Department of Services for Children, Youth
and their Families
Office of Prevention
Delaware Youth and Family Center
1825 Faulkland Road
Wilmington, DE 19805
(302) 633-2704

Guide To Services For People With Disabilities In Delaware

Delaware Health and Social Services
Division of Services for Aging and Adults
with Physical Disabilities
1901 North DuPont Highway
New Castle, DE 19720
(302) 577-4791

The Legal Handbook for Older Delawareans

Community Legal Aid Society
913 Washington Street
Wilmington, DE 19801
(302) 575-0660

Parent Education and Support Inventory

List of parent education and support groups
The Parent Education Committee for
the Family
Services Cabinet Council
A.I. DuPont Institute
1600 Rockland Road
P.O. Box 269
Wilmington, DE 19899
(302) 651-4560

Services Guide

List of mental health services for children
Delaware Health and Social Services
Division of Child Mental Health Services
1825 Faulkland Road
Wilmington, DE 19805
(302) 633-2599

COMA RESOURCE LIST

Coma Recovery Association Inc.

100 East Old Country Rd.
Suite 9
Mineola, New York 11501
(516) 746-7714
<http://www.comarecovery.org>

Forget Me Not (FMN)

<http://www.forget-me-not.org>

Head Injury Hotline

P.O. Box 84151
Seattle, WA 98124
(206) 621-8558
e-mail: brain@headinjury.com
<http://www.headinjury.com/brain>

National Brain Injury Association help support line:

(800) 444-6443
Staffed 9-5 EST, Monday-Friday;
answering machine 24 hrs/day, 7 days/wk.

National Rehabilitation Information Center (NARIC)

8455 Colesville Rd.
Suite 935
Silver Spring, MD 20910-3319
(800) 346-2742
<http://www.naric.com>

NOVA Online

<http://www.pbs.org/wgbh/nova/coma/resources/html>

TBI General Resources

<http://teach.virginia.edu/go/cise/ose/categories/tbi.html#res>

The Perspectives Network

<http://www.tbi.org>

Who is Waiting.com

Brain Injury Information Page
(800) 992-9447
<http://www.waiting.com>

BRAIN INJURY PRINT RESOURCES

Many of these sources offer several resources. Call or write and ask for a publications list.

STATE BRAIN INJURY ASSOCIATION RESOURCES

Head Injury: A Family Guide

(Available in Spanish)
Brain Injury Assc. of Florida
201 East Sample Road
Pompano Beach, FL 33064

Living Well After Brain Injury (Survivors share their perspectives/strategies)

Brain Injury Assc. of Minnesota
43 Main Street SE, S-135
Minneapolis, MN 55414

Making Life Work After a Head Injury

Brain Injury Assc. of Florida
201 East Sample Road
Pompano Beach, FL 33064

Self Advocacy for Independent Living

Brain Injury Assc. of Colorado
6825 E. Tennessee Avenue, #405
Denver, CO 80224

TBI Manual: What You Need to Know

BIA of Michigan
8137 W. Grand River, Suite A
Brighton, MI 48116

When A Parent Has a Brain Injury:

Sons and Daughters Speak Out
by Marilyn Lash, M.S.W.
Massachusetts Head Injury Assc.
484 Main Street, #325
Worcester, MA 01608

Why Did It Happen on a School Day: My Family's Experience with Brain Injury

Brain Injury Association
105 North Alfred Street
Alexandria, VA 22314

You, Me, Community: Connecting the Pieces

Connecticut Traumatic Brain Injury Assc.
1800 Silas Deane Hwy., Suite 224
Rocky Hill, CT 06067

COMA

The Catastrophe of Coma: A Way Back

by E. A. Freeman, MB, BS, FRCS (Ed.)
ISBN: [0911378936](#)
Sheridan House Inc.
145 Palisade Street
Dobbs Ferry, NY 10522

GENERAL

Coming Home: Discharge Manual for Families of Persons w/a Brain Injury

Dana S. DeBoskey, Ph.D., Editor
ISBN: [1882855345](#)
HDI Publishers
P.O. Box 131401
Houston, TX 77219

Coping with Mild Traumatic Brain Injury

Diane Roberts Stoler, Ed.D. (Survivor)
ISBN: [0895297914](#)
Avery Publishing Group
120 Old Broadway
Garden City Park, NY 11040

Educating Families: A Guide to Medical, Cognitive & Social Issues

By D. DeBoskey, J. Hecht and C. Calub
ISBN: [083420231X](#)
Aspen Publishers, Inc.
200 Orchard Ridge Drive
Gaithersburg, MD 20878

Living With Head Injury

M.D. van den Broek, W. Schady & M.J. Coyne
ISBN: [0719041899](#)
Manchester University Press
Fifth Avenue, Room 400
New York, NJ 10010

CHILDREN'S ISSUES

Children with Acquired Brain Injury

Edited by: G. Singer, A. Glang & J. Williams

ISBN: 1557662339

Paul H. Brookes Publishing Co.

P.O. Box 10624

Baltimore, MD 21285

Pediatric Traumatic Brain Injury: Proactive Intervention

by Jean L. Blosser and Roberta DePompei

ISBN: 1565931688

Singular Publishing Group, Inc.

4284 - 41st Street

San Diego, CA 92105-1197

Teaching Your Child The Language of Social Success

by M. Duke PhD, S. Nowicki PhD, E. Martin MEd

ISBN: 1561451266

Peachtree Publishers, Ltd.

494 Armour Circle NE

Atlanta, GA 30324

When Your Child is Seriously Injured: The Emotional Impact on Families

When Your Child Goes to School After an Injury

Exceptional Parent

Dept ML, P.O. Box 8045

Brick, NJ 08723

WRITTEN BY SURVIVORS OR FAMILY MEMBERS

Blessed Tragedy

by Karen Wells (Survivor)

ISBN: 0964940175

Rhodes & Easton

121 E. Front Street, 4th Floor

Traverse City, MI 49684

Brainlash: Maximize Your Recovery from Mild Brain Injury

by Gail L. Denton, Ph.D. (Survivor)

Attention Span Books

P.O. Box 788

Niwot, CO 80544-0788

Crushed But Not Destroyed

by Sharon Longenecker (Spouse)

ISBN: 0961424400

Sun Ray Publishing Co.

27885 S. E. Sun Ray Drive

Boring, OR 97009

In Search of Wings

by Beverly Bryant (Survivor)

ISBN: 1882332008

Wings Publishing

1 Clifford Court

South Paris, ME 04281

GLOSSARY

TERMS

ANOSMIA - Loss of the sense of smell.

ANOXIA - A lack of oxygen. Brain cells need oxygen to exist. When blood flow to the brain is reduced or when oxygen in the blood is low, brain cells are damaged.

BRAIN SCAN - An imaging technique in which a radioactive liquid is injected into the blood stream so that pictures of the brain can reveal tumors, blood clots, hemorrhages, or abnormal anatomy.

BRAIN INJURY - Damage to living brain tissue caused by external mechanical force or non-traumatic causes such as tumors, strokes, infections, or other biological events.

CATHETER - A flexible plastic tube of varying sizes utilized for withdrawing fluids from or introducing fluids into a cavity of the body. This tubing is also used in specialized medical procedures.

CEREBROSPINAL FLUID - The liquid which fills the ventricles of the brain and surrounds the brain and spinal cord.

CLOSED HEAD INJURY - Trauma to the head that does not penetrate or fracture the skull, but damaged the brain.

COGNITION - The conscious process of the mind by which we are aware of thoughts and perception, including all aspects of perceiving, thinking, and remembering.

COMA - A state of unconsciousness from which the patient cannot be aroused, even by powerful stimulation.

CT SCAN/COMPUTERIZED TOMOGRAPHY - A series of computerized X rays of the brain at various levels to reveal its structure. This procedure shows the more obvious changes such as a hematoma.

DECUBITUS - A bed sore or discolored, open area of skin damaged by pressure. Common areas to this breakdown of skin include buttocks, hips, shoulder areas, ankles, heels, and elbows.

DEFICIT - A lacking or deficiency in the amount or quality of functioning.

DIPLOPIA - Double vision; the perception of two images of a single object.

EEG/ELECTROENCEPHALOGRAPH - Recording electrical activity of the brain by positioning electrodes on the scalp or on in the brain itself.

ECG/EKG ELECTROCARDIOGRAM - Monitoring heart rate and rhythm by positioning electrode pads on the patient's chest, which are connected to a monitor.

EYE TAPE - Tape used to close the eyes of a patient who is unable to blink. Blinking is important to keep the eyes moist. This natural reflex is lost in patients who are unresponsive but have open eyes. Eye drops may be utilized and the eye tape would be used to keep them closed.

HALO - A metal ring used for patients with upper spinal cord injuries which surrounds or encircles the patient's head, allowing for proper alignment of the neck and spinal column. In order to prevent further injury to the spinal cord it is important that the patient with a broken spine remain still.

HOSPICE - Home health care choice when recovery is not possible, focusing on care, not cure, including pain and symptom management and emotional support.

JEJUNOSTOMY TUBE (J-TUBE) - A type of feeding tube surgically inserted into the small intestine.

MRI/MAGNETIC RESONANCE IMAGING - A diagnostic procedure that uses magnetic fields to create pictures of the brain's soft tissue. MRI can provide a more detailed picture than the CT scan.

ORTHOSIS - Splint or brace used to support, align, and improve function of movable parts of the body.

PERSISTENT VEGETATIVE STATE - A condition in which the patient is unable to speak or follow simple commands and does not respond in any psychologically meaningful way. The transition from coma to a vegetative condition reflects changes from a period of no response to the internal environment, other than reflexively, to a state of wakefulness but with no indication of awareness. Normal levels of blood pressure and respiration are automatically maintained.

PLATEAU - A temporary or more permanent leveling off in the recovery or rehabilitation process.

RT/RANDOM MOVEMENT - An action of moving without obvious reason or purpose.

RANGE OF MOTION - An exercise in movement to the joint, so to prevent contractures.

RESPIRATOR - (see ventilator)

SCANNING - An active, usually visual search of the environment for information. Used in reading, driving, and other daily activities.

SEIZURE - An uncontrolled discharge of nerve cells which may spread to other cells throughout the brain. The sudden attack is usually momentary, but may be accompanied by loss of bowel and bladder control, tremors, and/or aggressiveness.

SENSORY INTEGRATION - Interaction of two or more sensory processes in a way which enhances the adaptiveness of the brain.

SENSORY STIMULATION - Arousing the brain through any of the senses.

SEQUENCING - Contracting muscles in an orderly and meaningful manner or reading, listening, and expressing thoughts.

SHUNT - A procedure of removing excessive fluid in the brain. A surgically placed tube connected from the ventricles deposits fluids into the abdominal cavity, heart, or large veins of the neck.

VENTILATOR - Equipment that does the breathing for the unresponsive patient. The machinery serves to deliver air in the appropriate percentage of oxygen and at the appropriate rate.

MEDICATION TYPES

ANTIBIOTICS - Used to treat a variety of infections which often occur in unconscious patients. Pneumonia and urinary tract infections are most common. Patients may also be placed on antibiotics to help prevent possible infections.

ANTICOAGULANTS - Medications, such as heparin or coumadin, utilized to slow down normal blood clotting and prevent blood clots from forming.

ANTICONVULSANTS - Anti-seizure medications that help prevent the temporary seizures or convulsions which occur during abnormal electrical brain activity.

ANTIDEPRESSANTS - Depression and feelings of low self-worth are common after brain injury. These medications help the patient deal with these negative feelings.

ANTIPSYCHOTICS - Brain injury is often accompanied by anxiety, personality change, and aggressiveness. These medications add a calming influence and prevent mood swings.

BETA RECEPTOR BLOCKERS - A group of medications used to block the nerves in certain areas of the brain, to reduce agitation, rapid heart beat, elevated blood pressure, and tremors.

DECADRON (DEXAMETHASONE) STEROIDS - A medication which appears to help improve function of the brain. It also decreases brain swelling and excessive water accumulating in the brain.

DIDRONEL (ETIDROVATE DISODIUM) - Given to patients who demonstrate a tendency to form calcium deposits and abnormal bone formation around joints and in injured soft tissues.

LAXATIVES - These stool softeners are used along with a carefully supervised dietary program to promote bowel regularity, which is frequently affected because of nervous system damage and long periods of inactivity in bed.

MUSCLE RELAXANTS - Brain-injured individuals often lose the ability to regulate the forces of muscle fibers resulting in spasticity and pain. These drugs relax the muscles for greater comfort, to ease therapy, and to prevent spasticity.

NOTES