



YOU ARE NOT ALONE

You or your family member or friend has just sustained a brain injury. Maybe you're in the emergency room or a doctor's office. You're scared and most likely overwhelmed. This booklet is designed to help you through the initial "shock" that you may be experiencing.*

You are not alone. Every 23 seconds someone in the United States sustains a brain injury - over 1.5 million people each year. An estimated 5.3 million Americans - a little more than 2% of the population - currently live with disabilities resulting from brain injury. It is estimated that each year, one million people are treated for traumatic brain injury and released from the hospital. And, 80,000 Americans experience the onset of long-term disability following traumatic brain injury annually.

Each brain injury is unique. To make this guide most useful much of the information contained in this booklet is broad in scope. It is important that you learn specifically what type of brain injury your family member or friend has sustained, and the specific symptoms/treatments that are associated with that type of injury.

This booklet will help you answer the following questions:

- How do I best work my way through the emergency room/doctor's office?
- What is brain injury?
- What do I look for in cases of mild brain injury?
- What are the long-term symptoms of brain injury?
- Where can I turn for help?

This pamphlet is a starting point in answering your questions. There are resources listed at the end which can provide you with more detailed information.

* Many of the suggestions in this pamphlet were provided by Brain Injury Association of New York State FACTS (Family Advocacy Counseling and Training Services) Coordinators. The FACTS Program is explained in this pamphlet.



SO MANY PEOPLE, SO LITTLE INFORMATION...

As an individual with a brain injury, or a family member or friend of an individual with a brain injury, you probably have never experienced what you are now going through. You may feel overwhelmed. You may never have heard the terms brain injury or traumatic brain injury. You may not know what questions to ask. You may be feeling out of control or that your life no longer makes sense.

Some of the first questions that come to mind may be:

- What is happening?
- Is my family member or friend conscious?
- What are his or her chances for survival?
- Will I be "normal"?
- Will my loved one be "normal"?
- When will I be "better"?
- When will my loved one be "better"?
- How long will this go on?
- What will life be like?
- Who can help?
- Will insurance cover everything?
- What can I do?
- Who can answer my questions?
- Help!!!



Often, medical staff are focused primarily on ensuring optimal care for you, your family member or friend. As a result, they don't always keep you informed of what is happening. In reality, they may not yet have any specific answers. Information regarding survival and quality of life generally doesn't become clear for at least 48 - 72 hours post injury when swelling in the brain begins to subside. Even then, information may be incomplete.

Family members and friends may feel that there's not much they can "do". It may be best to focus on the person with the injury. Put aside insurance concerns, forms and staff attitudes for the moment. Instead, if you want to, insist on being with your family member or friend. You might not feel like you are doing much to change things, but at least you can feel connected to him or her.

Start keeping a journal. Write down your thoughts, feelings, observations and questions as you think of them. This way, you can be sure to remember to ask all your questions and make sure they are answered. Write down answers you receive, so that you can look back at them later. The journal can also help you see the progress of the healing process over time. Sometimes when you are in the middle of a situation, it is difficult to see improvements. A journal can assist you in seeing these changes.

Reaching out to friends and family may feel like a burden at this time. Use of a computer can be helpful in easing that burden through e-mails, or setting up a web page. You can stay in touch with the people you care about without having to answer the same questions over and over again. And they can communicate their support to you. You may also consider leaving an updated "news" bulletin about the progress on your answering machine.



HELP! WHO ARE ALL THESE PEOPLE?

It often seems like many doctors and others are running in and out, and it is hard to keep track of everything and everyone. You should get the names of all doctors involved. Find out their names, their medical specialty, their phone number and the best time to reach them. You also can ask doctors when they would expect to visit again. To get complete information, talk to every doctor. Be willing to ask for clarification of any information you do not understand.

Some of the professionals who might be involved include:

- **Intensivist** - a physician who specializes in treating and managing a critically ill or injured individual in an Intensive Care Unit.
- **Neurosurgeon** - physician trained to care for all types of brain problems and perform brain surgery as needed.
- **Neurologist** - physician who specializes in the nervous system and its disorders.

- **Neuropsychologist** - specialist who evaluates the cognitive (or thinking) functions of the individual following brain injury. Neuropsychologists generally are involved in the treatment process further down the road, after the individual has stabilized.
- **Physiatrist** - physician specializing in physical medicine and the rehabilitation process. A physiatrist may also coordinate the rehabilitation team.
- **Plastic Surgeon** - surgeon who repairs or replaces malformed, injured, or lost organs and tissues. This physician performs cosmetic surgery to correct physical defects as a result of injury.
- **Family physician** - if in the area, can sometimes act as a liaison to the family and provide the family with needed information in a more personal manner.
- **Physical Therapist, Occupational Therapist, Speech Therapist** - professionals involved in the rehabilitation process after the individual has been medically stabilized.

Other staff that you might want to identify are:

Emergency Room or Hospital Social Worker
Patient Liaison (Patient Care Representative)
Nurses/Head Nurse or Nursing Supervisor
Chaplain

Individuals and families need a liaison who can explain and help advocate for the individual with the injury. Often, the best sources of information are the floor nurses. Try to "connect" with the nurse that is involved with you and your family member or friend. Hospital social workers also can help increase the flow of communication.

WHAT IS BRAIN INJURY?

One of the complexities about brain injury is that no two brain injuries are alike. The following is a brief description of the "types" of brain injury. It will give you general information about the brain and brain functioning.

The brain is the body's control center. It governs and regulates all of our body functions, as well as how we think, act, and talk. Damage to any area of the brain can change one or many aspects of who and what we are.

The brain is divided into several distinct sections, each of which has its own particular job to do. Our daily physical, emotional and intellectual functioning is maintained and delivered through a complex and truly remarkable process that all starts with the brain.

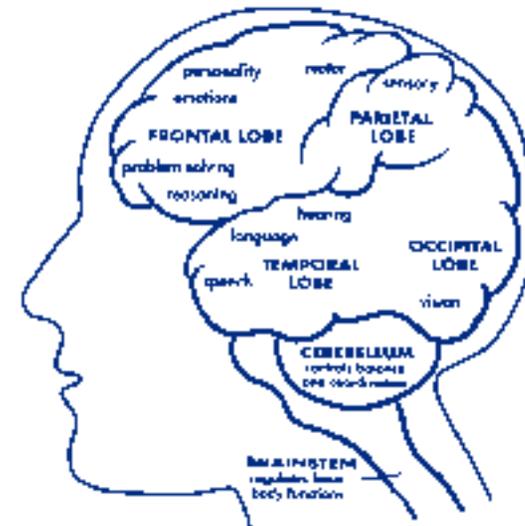
There are several parts of the brain that you might hear mentioned. These include:

I. **Cerebellum** - coordinates movement and balance

II. **Brain Stem** - responsible for consciousness, alertness and other body functions. The brain stem is the region of the brain that controls the very basic functions of survival - breathing, heart rate, wakefulness, muscular tone and reflexes. It is located at the base of the brain and connected to the spinal cord. The brain stem also serves as the conduit of information that is necessary for adequate functioning of all other areas of the brain. Injury to the brain stem can be brief, prolonged or permanent, and therefore will have differing effects on the observed functioning of the individual.

III. **Cerebrum** - controls thought processes. This is the largest part of the brain. It is divided into two hemispheres, joined by a band of nerve fibers (corpus callosum). Each hemisphere has four lobes, each of which has specific functions:

- A. **Frontal Lobe** - governs movement, judgment, reasoning abilities, personality, motivation, initiation, and inhibition (the ability to restrain emotions or behavior)
- B. **Temporal Lobe** - governs memory and the ability to understand language
- C. **Parietal Lobe** - governs sensations and awareness of spatial relationships, such as judging the distance between two objects
- D. **Occipital Lobe** - governs visual perception, or how the brain interprets what the eyes see



ACQUIRED BRAIN INJURY

Acquired brain injuries are caused by changes or problems with the brain itself. These problems can occur for many reasons. Some examples of these brain injuries are:

- **Anoxia / Hypoxia** - Occurs when the brain is either totally deprived of oxygen or deprived of sufficient oxygen. Examples include near drowning, asphyxiation, exposure to toxins, illegal drug use, alcohol abuse, and carbon monoxide poisoning.
- **Tumors** - A tumor in the brain may cause injury to the surrounding brain tissue. Neurosurgical removal of the tumor is usually performed. The surgical process may result in changes to the brain.
- **Stroke or "cerebrovascular accident (CVA)"** - A sudden and often severe impairment of the body brought on by a disruption in the flow of blood to the brain. When the blood fails to get through to parts of the brain, the oxygen supply to those areas is cut off, and the affected brain cells die. The interruption of blood flow can be caused by the blockage of an artery in the brain or neck. A stroke can also be caused by the bursting of a section of the artery wall in the brain with subsequent bleeding into the surrounding tissue.

- **Spontaneous bleeding** - Bleeding within the brain can occur by weak blood vessels (aneurysm) or arterial venous malformations. High blood pressure or rare bleeding disorders can trigger the bleeding as well. A subdural hemorrhage (bleeding within the outside lining of the brain) or an intracranial hemorrhage (bleeding within the brain) are examples of terms used to describe this type of bleeding.

- **Infections or metabolic disorders** - There are many types of infections and metabolic changes (chemical or biological reactions) in the body that can affect brain functioning. For example, a virus may attack the brain, causing injury to the brain tissue. An overdose of drugs or a sudden chemical change because of failure of a body organ are examples of metabolic changes that can injure brain tissue.

TRAUMATIC BRAIN INJURY

Traumatic brain injury (TBI) refers to an acquired brain injury in which an external blow to the head has caused damage to the brain.



OPEN HEAD INJURY

An **open head injury** is a **visible** assault to the head that may result from a gunshot wound, shrapnel, an accident, or an object going through the skull into the brain. This type of injury is more likely to damage a specific area of the brain.

CLOSED HEAD INJURY

A **closed head injury** occurs when there is a blow to the head, such as in a motor vehicle crash or fall. In this case, the skull hits a stationary object and the brain, which is suspended in cerebral spinal fluid inside the skull, may bounce back and forth inside the skull, causing damage to the brain where it comes in contact with the skull. The brain

may also turn on its axis (the brain stem), causing localized (focal) or widespread (diffuse) damage.

Closed head injuries are the most common type of brain injury, often causing both focal and diffuse damage at the same time. Diffuse brain trauma can occur when the nerve fibers throughout the brain stem and into the brain are stretched or distorted. A concussion or a blast injury may cause brain injury.

Terms used to describe closed head injury include:

- **Contusions** are injuries that bruise a portion of the brain.
- **Concussion** literally means "to be shaken violently." It is usually caused by a blow to the head by an external force. Concussions may cause a temporary loss of consciousness. **There does not have to be any loss of consciousness to sustain a concussion.** A concussion may also result in an alteration of mental state (i.e. being confused or dazed). A concussion may cause a mild or moderate brain injury.
- **Coup-contrecoup** describes contusions that are both at the site of the impact and on the complete opposite side of the brain. This occurs when the force impacting the head is not only great enough to cause a contusion at the site of impact, but also is able to move the brain and cause it to slam into the opposite side of the skull, which causes the additional contusion.

- **Acceleration-deceleration** injury is an injury caused when the head is driven forward and backward with such force that the brain bounces back and forth against the skull, resulting in both focal and diffuse injuries, such as a whiplash injury.

Many nerve cells will eventually return to normal functioning. Other nerve cells, however, may be permanently damaged, either functioning abnormally, or becoming totally nonfunctional.

There is also evidence that suggests the effects of repeated concussions are cumulative. With repeated minor traumas, the severity of the damage increases, because of an increase in the number of these damaged nerve cells.

SECONDARY DAMAGE TO THE BRAIN

The brain can sustain further injury when the brain swells inside the skull. Fluid accumulates, causing pressure to increase and impinge on delicate brain tissue. Delayed bleeding from damaged blood vessels can similarly injure the brain. Preventing secondary damage is the primary medical challenge during the initial period following brain injury.



WHAT SHOULD WE WATCH FOR?

IMMEDIATE SYMPTOMS OF BRAIN INJURY

MILD "LESS SEVERE" BRAIN INJURY

In the case of mild brain injury, if the injured person is sent home, family should:

- check his or her pupils (black centers of the eyes) to be sure they are the same size
- awaken him or her several times during the night to assess his or her level of consciousness or disorientation and continue to check to be sure pupils are the same size;
- **Remember! that a concussion without loss of consciousness may cause mild or moderate brain injury.**

Notify your physician if you notice any of the following:

- complaints of a severe headache
- difficulty awakening
- restlessness, irritability or aggression
- vomiting more than twice
- trouble speaking
- blurred vision
- complaints of weakness in arms or legs
- neck pain
- convulsions, strange movements or unusual episodes of staring
- losing consciousness or "needing sleep"
- unequal pupils

WHAT ARE THE LONG TERM SYMPTOMS OF BRAIN INJURY I SHOULD BE LOOKING FOR?

Individuals with mild brain injury or a concussion are often sent home with little or no information about the potential long term effects of brain injury. As the brain heals and the swelling subsides, the cells in the swollen area can begin to function again. Select areas of the brain will be fine while other areas may be affected in some way. A person may do well in one activity, but have difficulty with another. Further, symptoms may not appear immediately; you may see changes weeks, months, or even years later.

The following are physical changes that may occur after brain injury.

- bladder and bowel problems
- dizziness/vertigo
- fatigue
- headaches
- weakness on one side of the body (arm, leg or facial weakness)
- difficulty sleeping
- nausea/vomiting
- seizures
- spasticity/clumsiness or poor coordination
- difficulty with swallowing
- change in sight (double vision)
- change in sense of smell or taste
- change in speaking ability - slowness, difficulty with word finding

The following are emotional and behavioral symptoms that may occur after brain injury:

- aggression, irritability (short-tempered or easily frustrated)
- egocentricity
- restlessness
- sexual disinhibition or lack of sexual desire
- impulsive behavior
- anxiety
- depression
- difficulty controlling emotions
- loss of social networking, feelings of isolation
- decreased ability to cope with unexpected events

The following are cognitive changes or difficulties that may occur after brain injury:

- attention/concentration
- making decisions
- solving problems
- judgment
- memory for new information
- speed of processing
- following directions or completing a task
- processing of visual or verbal information

If the individual with the injury experiences any of these symptoms, seek professional help. These symptoms can be permanent. Any one of these changes can have considerable impact both on the individual and their family and friends. It is extremely important that the professional you work with is familiar with brain injury.

BUT WHO CAN I TALK TO?

The biggest obstacle is finding staff knowledgeable about brain injury. The Brain Injury Association of New York State can help you obtain information about brain injury, rehabilitation, programs and services, as well as provide a sympathetic ear and shoulder for support. Through its toll-free Family Helpline, you will be connected with a knowledgeable individual, and a network of chapters and support groups throughout the state. The number is **1-800-228-8201**, www.bianys.org via e-mail at info@bianys.org.

One of the major programs of the Association is the Family Advocacy, Counseling and Training Services (FACTS) program. FACTS Coordinators are individuals knowledgeable about brain injury who can help the family through stages of brain injury recovery. FACTS Coordinators are located throughout the state and are able to provide free services to individuals (and their families) who have sustained a brain injury prior to age 22. Some of the services FACTS Coordinators provide are: support, advocacy, and information and linkage with state and local systems (such as Supplemental Security Income (SSI) and Medicaid).



Resources:

- ✓ **Brain Injury Association of New York State**
10 Colvin Avenue
Albany, New York 12206-1242
(518) 459-7911 • 1-800-228-8201
E-mail: info@bianys.org
www.bianys.org

- ✓ **Brain Injury Association of America**
1608 Spring Hill Road, Suite 110
Vienna, Virginia 22182
(703) 761-0730
www.biausa.org

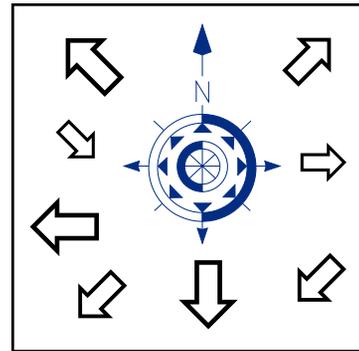
More about the Brain Injury Association of New York State

The Brain Injury Association of New York State is a statewide non-profit membership organization that advocates on behalf of individuals with brain injury and their families, and promotes prevention. Established in 1982, The Brain Injury Association of New York State provides education, advocacy, and community support services that lead to improved outcomes for children and adults with brain injuries and their families. The Brain Injury Association of New York State also offers a toll-free family helpline, chapters and support groups throughout the state, prevention programs, resources and support programs for veterans and their families, LEARNet educational resource, mentoring programs, a speakers bureau, and an information clearinghouse of videos, publications, books, periodicals and other resource materials. The Association plays a central role in the development of public policy on the state and local level. The Brain Injury Association of New York State is the state affiliate of the Brain Injury Association of America.

Notes



THE FIRST STEPS.....



Brain Injury Association of New York State

10 Colvin Avenue

Albany, NY 12206-1242

Telephone: (518) 459-7911 • Fax: (518) 482-5285

Family Help Line: (800) 228-8201

E-mail: info@bianys.org • Web Site: www.bianys.org

when you
or your
family
member
or friend
has a
brain injury