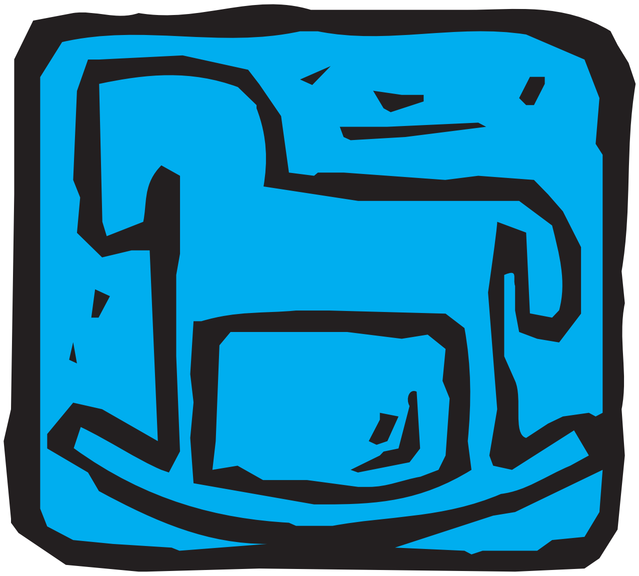
MY CHILD'S
BRAIN INJURY....



helping
kids
and
families
cope
with
brain injury

NOTES

INTRODUCTION

This booklet is designed for the family and friends of a child who has experienced a brain injury. This booklet will help you understand ways to care for and support your child. Feel free to contact the Brain Injury Association of New York State to ask questions about any information in this booklet, or any other questions about your child's care. A description of the Association and the contact information can be found on page 14.

One person who can be extremely helpful to you is the Brain Injury Association of New York State's FACTS Coordinator. "FACTS" stands for the Family Advocacy, Counseling, and Training Services program of the Association. The FACTS Coordinator is a knowledgable individual who can provide you with information about brain injury and community resources, as well as support. You can find out the name of the FACTS Coordinator in your area by contacting the Association.

Through the course of your child's recovery, you will meet many professionals. You can learn more about them and what they do in the "Professionals Who Might be Involved in Working with You and Your Child" section on pages 15-16. You might also hear a number of new words. An explanation of commonly used terms can be found in "Words We Use" on pages 17-19. Because you will be meeting so many different people, keeping track may become a challenge. There is a place on the back page of this booklet for you to keep your own list.

Remember, you are not alone. The Brain Injury Association of New York State is here to help.

BRAIN INJURY AND CHILDREN

An acquired brain injury

- happens after birth;
- damages the brain; and
- results from an outside force (traumatic injury) or from changes within the brain (non-traumatic).

There are two types of acquired brain injury.

An acquired traumatic brain injury is caused by a contact injury or the brain moving back and forth inside the skull and being bumped, bruised or twisted. The injury can be mild, moderate, or severe.

This booklet has been adapted from "My Child's Brain Injury" developed by the Hennepin County Medical Center, Minneapolis, MN. Special thanks to Dr. Mary Hibbard and Dr. Paul Berger-Gross for their invaluable assistance. This booklet is printed with funding support from the N.Y.S Office of Mental Retardation and Developmental Disabilities.

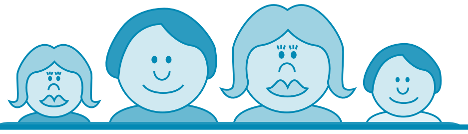
Causes of an acquired brain injury include:

- car crash
- fall
- bicycle crash
- abuse
- sports injury
- physical fight
- being shaken by someone
- gunshot or other assault

An acquired non-traumatic brain injury is caused by changes within the brain. This injury can also be mild, moderate, or severe. This is often called an anoxic or hypoxic brain injury.

Causes of an acquired non-tramatic brain injury include:

- suffocation
- near drowning
- carbon monoxide poisoning
- smoke inhalation
- inhaling or swallowing chemicals (paint, lead, glue, gases, etc.)
- stroke
- brain infection (meningitis, encephalitis)



WHEN A CHILD’S BRAIN IS INJURED

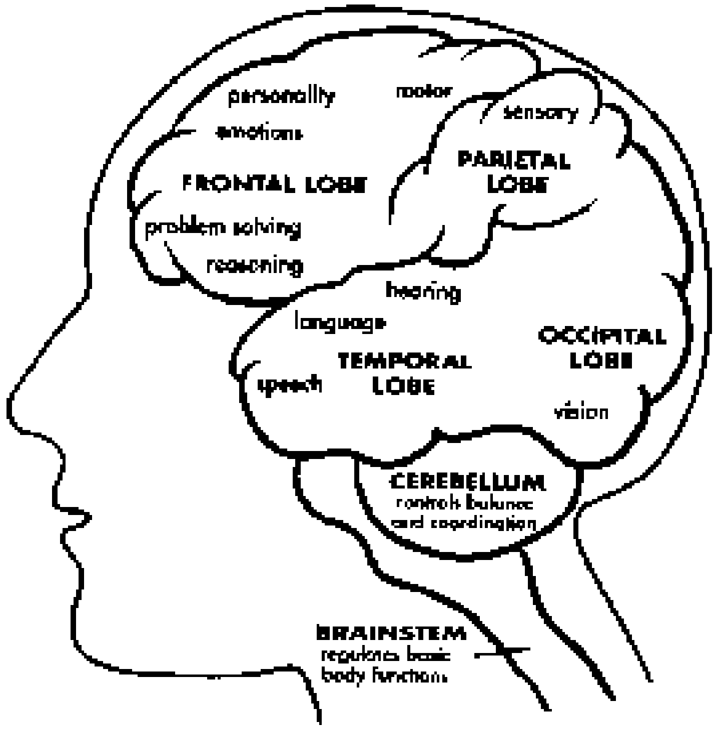
Changes occur in how a child does everyday things such as:

- walk
- talk
- organize tasks
- write
- remember (memory)
- start or initiate activities
- sleep
- pay attention
- see
- smell
- touch
- hear
- taste
- interact with others
- eat or feed himself or herself
- make safe decisions
- read
- behave or control himself or herself
- solve problems

These changes can be short-term or life-long.

AREAS OF THE BRAIN

What each area of the brain does



What Happens Next?

The next steps will depend on the extent of your child's injury. It will also depend on any other injuries your child may have.

- Your child may be discharged home. While your child may not need rehabilitation, your child still needs to be watched for difficulties in the future.
- Your child may be discharged and go home, but may still need outpatient rehabilitation.
- Your child may receive short-term rehabilitation in the hospital or an inpatient rehabilitation program and may require post-discharge rehabilitation.
- If the rehabilitation process will be longer, your child may be transferred to another hospital or rehabilitation setting.

MILD TRAUMATIC BRAIN INJURY OR CONCUSSION

- ✭ After a blow to the head, a person is dazed or confused for a brief time. The person may or may not lose consciousness for a short while.
- ✭ Even though your child may look fine, nerve cells in the brain may have been injured.
- ✭ This type of injury cannot always be seen on x-rays or CT scans.
- ✭ The care of a child with a mild traumatic brain injury includes watching the child closely.

What may happen to my child while he or she is in the hospital?

The doctors and nurses will watch your child closely for about 24 hours. If your child still has brain injury-related problems or becomes worse, the medical team will evaluate your child. If your child does not appear to have any brain injury-related problems after 24 hours, no further treatment is needed at this time. However, it is important that you watch your child closely for any changes in behavior or health.

How can I help my child during the initial recovery in the hospital?

Your child has had a mild brain injury and may seem different than his or her usual self. Some of the following ideas might be helpful while your child recovers.

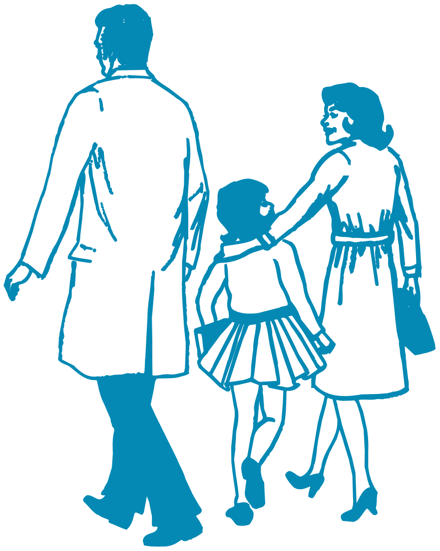
- ✭ Keep your child's room calm and quiet.
- ✭ Lower the lights.
- ✭ Limit the number of visitors and how long they stay.
- ✭ Limit TV and radio, talking, noise, and unnecessary movement, since these behaviors can confuse your child even more.
- ✭ Talk to your child in a calm voice.
- ✭ Answer your child's questions.
- ✭ Avoid discussing your child's condition at his or her bedside.

- Avoid a repeated injury to the child’s brain.
- Bring in pictures, a favorite toy, book or music. Your child needs to hear, see, and touch things that are from home.
- Siblings and friends may be welcome to visit one or two at a time. Check with the nurse first.
- Keep to daily routines as much as possible.
- If you have questions, feel free to ask. Your nurse can direct you to the right person.
- You should call your health insurance plan. Tell them your child is in the hospital. Call your member services number. This should be done as soon as you can.

What should I watch for after my child comes home?

It is important to watch your child closely for the first few days. Call your child's regular doctor or clinic, or call the local hospital immediately if you see any of the following changes.

- Blood or fluid coming out of nose or ears
- The pupil of one eye is bigger than the other one
- A convulsion (seizure)
- Weakness in the face, arms, or legs
- Vomiting more than once
- Blurred or double vision
- Slurred words or difficulty talking
- Looks pale, sweaty, or weak
- A fever over 101 °F
- Complaints of a severe headache
- Confused or unusual behavior



In the first week, it is common for your child to

- have headaches
- feel dizzy, unsteady, or have trouble walking
- be sleepy, moody, or crabby
- be confused or mixed up
- experience slowed thinking
- have difficulty sleeping
- seem unusually tired

If any of these do not get better, or things get worse, call your child's regular doctor or clinic, or call the hospital emergency department.

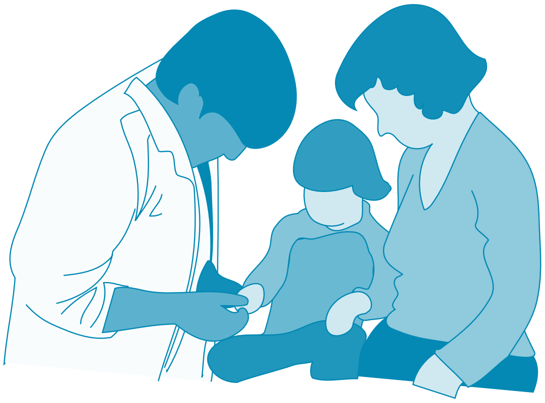
After the first week

Your child may seem back to normal physically, but it may take several months for the brain to heal. As your child heals, you may notice some of the following problems. These changes may get better or go away in the next few weeks. Other times, these changes may continue and may require additional help.

- Headaches
- Dizziness
- Sensitivity to noise or lights
- Hearing problems
- Feeling tired
- Difficulty sleeping
- Poor memory
- Trouble paying attention or concentrating
- Moody or crabby
- Increased anger

Your child should see his or her regular doctor in 2-3 weeks after being discharged from the hospital.

If you have questions or are concerned, call your child's doctor and the Brain Injury Association of New York State. If these problems have not gone away in 2-3 months, contact your child's doctor. Your child may need further evaluation.



MODERATE TO SEVERE BRAIN INJURY

- Brain is bumped, bruised or twisted resulting in a period of confusion or loss of consciousness.
- There may be bleeding in one or many parts of the brain.
- Nerve cells in the brain are damaged.
- Damage is usually seen on X-rays or CT scans.
- There may be swelling of the brain.
- There may be tearing of the small blood vessels and nerves. This is called a "shearing injury" and it may affect many parts of the brain.
- Recovery will depend on the extent of the injury.
- A severe brain injury can result in coma or even death.

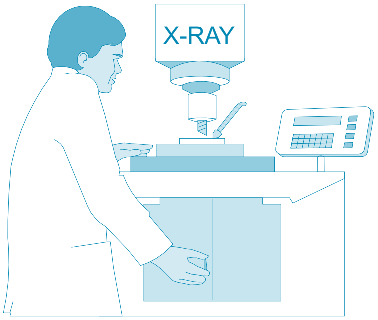
What may happen to my child in the hospital?

A medical team will watch your child closely.

Your child may have some of the following equipment. This may be scary to see at first, but know that this equipment is helping your child.

- A **ventilator** to help your child breathe. As your child gets better, the equipment will be removed.
- A **monitor** that shows your child's heart rate, blood pressure, and other vital signs.
- A **pressure monitor** in your child's head to monitor brain pressure and swelling.
- Several **IV's and pumps** to give fluids, medicine, and to draw blood.
- A **nasogastric tube** (NG tube) to feed. This may be inserted through the nose or belly.
- A **feeding tube** (NJ tube) for liquid nutrition.
- A **catheter** in your child's bladder to drain urine.

In addition, your child will be frequently checked by hospital staff to monitor brain function, including checking your child's response to pain, ability to follow commands, and how his or her pupils react to light. There may be X-rays, CT scans, and MRI scans to evaluate the brain injury, as well as blood tests.



What if my child is in a coma?

A coma is when a child is unconscious and cannot respond and talk. It may last for hours, days, weeks, or even months. Your child's ability to respond to light, sound, and follow commands is affected. He or she may not be aware of what is happening around him or her. Your child may react to pain, touch, or sounds. In addition, your child may make sounds, grind his or her teeth, smack his or her lips, or grab items put in his or her hand.

It is hard to judge how "deep" the coma is. Being in a coma is not as simple as being "asleep" or "awake." The level of coma may change from day to day. It is unknown what a child hears or understands while in a coma.

Children don't just "wake up" from a coma. This is a slow process. Television programs and movies that show people waking up from a coma quickly and behaving normally are not generally realistic. Your child will gradually become aware of his or her surroundings and begin to respond. Your child may be confused, agitated, swear, or behave in strange or violent ways. These behaviors are usually temporary and are a normal part of coming out of a coma. For more information about the stages of coma recovery, ask the nurse for written handouts such as the Rancho Los Amigos Cognitive Functioning Scale or other articles that will help you understand what is happening.

Are there supports for me and my family while my child is in the hospital?

- You will be kept informed about your child's condition by the child's doctors and nurses. This may include meeting with members of the team treating your child.

- You will be encouraged to participate in your child's care to the extent you are comfortable, and it is medically safe. Nurses and therapists will show you how you can be involved in your child's care.

- When available, rooms with beds and bathroom are set aside for families with children in or near the pediatric intensive care unit. Check with your hospital.

Your FACTS Coordinator will be able to offer support and answer questions

How can I help my child at this point?

- The medical team is not allowed to give information to extended family or other visitors. It is your responsibility to share this information with them. It may be helpful to name one family member who will be the person to speak to the rest of the family and friends. Some families have found that setting up a web site containing updated information is a good way to share information.

- Keep your child's area calm and quiet.

- Lower the lights.

- Limit the number of visitors and how long they stay.

- Limit TV and radio, noise, and movement. Too much talking, noise, touching, or activity can confuse your child even more.

- It is best to have one thing happening at a time. Your child will have limited ability to process things.

- Talk to your child in a calm voice.

- Let your child know who you are and who is with you.

- Answer your child's questions with simple and direct answers. For example, "It's morning. You're in the hospital."

- Avoid discussing your child's condition at his or her bedside.

- Avoid using questions; instead, give your child simple instructions. For example, "Try to move your arm," rather than, "Can you move your arm?"

- Calmly remind your child of where he or she is and what has happened.

- Tell your child what you are about to do. For example, "I'm going to brush your hair."

- Tell the staff about your family's routines at home (such as bedtime).

- Encourage your child to practice skills, but give your child time to respond.

- If your child is unable to speak, staff will help identify a way to respond (for example, thumbs up for "yes").

- Let your child rest. Rest helps reduce confusion and agitation, and heal the damaged brain.

- Bring in pictures, a favorite toy, book, or music. Your child needs to hear, see, and touch things that are from home.
- Be sure to call your health insurance plan. Tell them your child is in the hospital. Call your member services number. This should be done as soon as you can.

Take Care of Yourself

- It is normal to have many emotions, including sadness, anger, and grief, and to feel overwhelmed and frustrated.
- Take frequent breaks for meals and rest.
- Allow family members and friends to help you by cooking, babysitting, doing laundry, buying groceries, and shopping.
- Ask questions frequently. Keep a journal of questions and responses, thoughts, and progress.
- Remember, each child heals at a different rate.

What are the likely next steps?

- Your child may be transferred from the intensive care unit to the regular pediatric unit.
- Your child may receive short-term rehabilitation while at the hospital.
- If rehabilitation treatment will be longer than 2 weeks, your child may be transferred to another hospital or rehabilitation setting.
- Your child may be discharged and go home, but may still need outpatient rehabilitation.

The FACTS Coordinator can help your child's transition to home

What should I watch for after my child comes home?

Your child may seem back to normal physically. Children who have had a severe brain injury may have additional problems with physical activity or movement. Many children who have a moderate or severe brain injury will have some of the following problems during their recovery.

- Headaches
- Tire easily
- Trouble sleeping
- Forget things, poor memory
- Trouble learning new things
- Act differently at school
- Difficulty starting or organizing homework or new projects
- Difficulty calming down
- Poor judgement (acts without thinking, does something dangerous)
- Cry, laugh, or talk at the wrong times
- Quick changes in mood
- Get frustrated more quickly
- A hard time finding the right words
- A shorter attention span
- Changes in hearing or vision

Planning for your child's return home depends on his or her age and level of injury.

Your child should see his or her regular doctor 2-3 weeks after being discharged from the hospital.

What do I need to know to care for my child at home?

Before your child returns home, there are questions you need answered by the hospital staff.

- What are my child's medications? When should they be taken (on an empty or full stomach)? What are the potential side effects? Can my child take over the counter medication with these prescriptions, such as vitamins, aspirins, etc.?
- Does the pharmacy I use have the special medications or tube feedings that are needed?
- What special equipment is needed? How does the equipment work?
- Is a special bed needed? Are rails or a special mattress needed? Where do I purchase them?
- If a child needs casts and splints, how are they worn?
- Can you lift the child, especially if he or she is an adolescent? Is a lift necessary? If the child walks with a cane or walker, can he or she walk alone?
- Are home modifications necessary? If so, what kind?

Speak with the FACTS Coordinator before making expensive renovations or additions to your home.

- What therapy does my child need to do at home? What are the home programs for occupational, physical therapy, speech pathology, and cognitive rehabilitation? If so, how do I get these services?
- What respite services are available to me? Who will help me with the care of my child? Who can be there if I need to shop, take care of other children, or have other responsibilities?

What happens when my child is ready to go back to school?

The medical team will work with you and your child's school to decide when your child is ready to return to school.

Your child should return to school as soon as your doctor says it is okay. The number of school days missed will depend upon your child's injury. It may take time for your child to return to full school days.

Your child may experience changes in his or her school abilities because of changes after moderate to severe brain injury. He or she may experience some of the difficulties in the areas listed below.

- organizing school assignments
- paying attention
- solving problems
- reading
- writing
- remembering new information
- starting activities
- interaction with peers

Teachers, other family members, and your child's friends and classmates may see changes in your child that you don't see. Some changes may be more noticeable when your child gets involved with more difficult tasks.

If you have questions about school issues, please contact your child's doctor or the FACTS Coordinator.

At first your child may need

- tutoring at home
- shortened school days
- frequent rest periods
- changes in how schoolwork is presented
- help with daily school activities (going from class to class, completing school, work)

Some of the changes your child may have from the injury could cause problems at school. The Association's FACTS Program helps with re-entry to school and helps to identify learning needs.

It is important that you talk to your child's teacher to find out how your child is doing at school and if there are any problems.

How can I prevent another brain injury?

Because your child has already had a brain injury, he or she is at an increased risk of having another brain injury.

- Your child should not ride a bike or participate in sports or other physical activity without first getting the doctor's approval. If you have questions, ask your child's doctor.
- Your child should use relevant protective gear when partcicipating in sports, such as a helmet, knee and elbow pads, and mouth guards.

- Depending upon your child's age and size, use car seats and seat belts.
- Store firearms safely.
- Keep medicines and chemicals (cleaning supplies) out of children's reach.
- Make sure your home has working carbon monoxide and smoke detectors; check monthly.
- Never leave a child unattended near any source of water.

For more safety information, contact the Brain Injury Association of New York State.

The Brain Injury Association of New York State is here to help

10 Colvin Avenue
Albany, New York 12206-1242
Phone: 518-459-7911 • Fax: 518-482-5285 • Family Help Line: 1-800-228-8201
E-mail: info@bianys.org • Web Site: www.bianys.org

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. The Association provides many programs and services to assist families in advocating for a family member with a brain injury. These services include a statewide network of chapters and support groups and a TBI Mentoring Partnership Program.

The Family Advocacy, Counseling and Training Services Program (FACTS) of the Association is a support service for individuals who have sustained a brain injury before age 22 and their families. FACTS Coordinators are located throughout the state and are able to provide services in each county. The FACTS program provides persons with TBI and their families with the following free services:

- supportive counseling and on-going emotional support for the individual and family
- assistance in locating appropriate services in the community
- information and linkage with state and local systems
- education, advocacy, and training of persons with brain injury and their families regarding TBI
- assistance with the development of brain injury support groups
- assistance with repatriation and the prevention of out-of-state placements
- assisting with outreach and training to local service providers such as hospitals and schools regarding TBI and with the development of services for persons with brain injury

PROFESSIONALS WHO MIGHT BE INVOLVED IN WORKING WITH YOU AND YOUR CHILD

Audiologist: identifies, evaluates, and provides non-medical treatment for hearing loss and balance problems.

Chaplain: provides hospitality and spiritual support to the child and family members; helps child, family members, and friends cope with child's injuries and hospitalization.

Child Life Specialist: helps provide for education, recreation, and socialization needs of a child while in a hospital.

Child Psychologist: evaluates and treats emotional, behavioral, and adjustment problems which may arise following a brain injury, during hospitalization or after discharge; also monitors the emotional needs and psychological adjustment of siblings and other family members.

Dietitian/Nutritionist: evaluates and makes plans to meet the child's nutritional needs. This may include feedings by mouth, through a tube, through an IV or a combination of these methods.

FACTS Coordinator: a knowledgable resource available to families who provides information about brain injury and community supports, as well as advocacy. Works for the Brain Injury Association of New York State.

ENT (Ear, Nose and Throat) Specialist: a doctor, also called an otolaryngologist, who evaluates and treats problems with the ears, nose, and throat such as facial bone fractures, tinnitis, facial tissue trauma; works closely with the audiologist.

Intensivist: a doctor who specializes in treating and managing critically ill or injured children in a Pediatric Intensive Care Unit.

Neurologist: a doctor who specializes in assessing a child's neurological problems after a brain injury; works with child and family in managing seizures, assists in determining need for rehabilitation services, and makes recommendation for where child's rehabilitation needs can best be met.

Neurosurgeon: a doctor who operates on the brain, spinal cord, and other parts of the nervous system.

Nurse: provides direct care for children and coordinates other care activities such as lab or x-ray tests, therapy sessions, and visitors. Supports the child and the family throughout the hospital stay; works closely with other members of the team including care conferences with the family and team members.

Occupational Therapist: evaluates the child's hand and arm use, coordination, and muscle strength, visual perception, and their ability to play, food and dress.

Ophthalmologist: a doctor who evaluates, operates on and treats children with eye injuries and vision disturbances from brain damage, eye, or optic nerve damage.

Oromaxillofacial Surgeon (OMFS): doctor who specializes in surgery of the mouth, jaw, and face.

Orthopaedic Surgeon: a doctor who assesses, operates on, and treats children with muscle/ skeletal bone problems, such as broken bones, joint problems, torn muscles, and ligaments.

Pediatric Neuropsychologist: evaluates a child's trouble with thinking, understanding, remembering, reasoning, and behaving. Standardized tests are used to check for the child's thinking strengths and weaknesses to aid in retraining thinking skills, and selecting appropriate school and community services.

Pediatricians and Resident Physicians: doctors who specialize in treating and managing a child's health care needs for both well-child care, and when the child is sick or injured.

Physiatrist: a doctor who assesses and treats children with brain injuries and medically manages all phases of their rehabilitation, such as therapies and special equipment.

Physical Therapist: evaluates parts of large motor skills (such as walking), movement, muscle strength, muscle tone, posture, coordination, endurance, and general mobility (such as transfers and walking).

Social Worker: provides emotional support to help the child and family adjust to being in the hospital; works with the team to make sure the family's needs and level of understanding of the child's condition are known; coordinates discharge planning, referrals to schools, community resources, and helps with financial and insurance concerns.

Speech-Language Pathologist: evaluates and treats the child's ability to understand (receptive) and express language, cognitive skills (paying attention and problem-solving), reading and writing; evaluates and manages problems with feeding and swallowing.

Don't forget - - you and your child are an important part of the team!

WORDS WE USE

Sometimes it is hard to understand the words used to describe your child's condition or treatment. This is a list of commonly used words.

Activities of Daily Living (ADL): routine activities of personal hygiene and health (including bathing, dressing, feeding). Also called Self-Help Skills.

Amnesia: not being able to remember; forgetful.

Anoxia: a lack of oxygen to the brain causing brain damage. Occurs when blood flow is reduced as in suffocation, near drowning, carbon monoxide (CO) poisoning and injuries.

Aphasia: unable to speak or understand words.

Ataxia: poor balance and coordination.

Attention: the ability to focus or respond to a task for a normal amount of time.

Brain stem: the lower portion of the brain, which connects it to the spinal cord. The brain stem controls the body's most important functions, such as breathing, blood pressure, heart rate, and sleeping.

Cerebellum: the area in the back of the brain which helps control balance and fine motor movements (moving fingers).

Cerebrospinal Fluid (CSF): the liquid made by the brain that fills the ventricles (cavities) in the brain and surrounds the brain and spinal cord.

Cognition: processes of thinking, understanding, reasoning, and memory.

Coma: a state of unresponsiveness where the person cannot be aroused and/or does not respond. The coma may be for a brief period of time or last several hours to weeks.

Concussion: a blow or jolt to the head that disrupts the normal functions of the brain; often described as a mild traumatic brain injury. After a concussion, some people lose consciousness for a short time, but not always. You can have a brain injury without losing consciousness.

Cortex (cerebrum): the largest part of the brain. It contains two cerebral hemispheres where most thinking and cognitive functioning takes place.

Craniotomy: a surgical opening through the skull.

CT Head Scan: a series of x-rays taken at different levels that show details of the skull and brain.

Diffuse Brain Injury: brain damage which covers many areas of the brain; common in closed head injuries due to the brain moving about inside the skull.

Disinhibition: not able to control impulses and emotions.

Disorientation: difficulty recognizing people, a place, day of the week, or the time of day.

Dura: the outermost tissue covering of the brain.

Edema: collection of fluid (water) causing tissue swelling.

Emotional Lability: strong mood swings that happen suddenly or without a clear reason.

Evacuation of Hematoma: a surgical procedure to remove a collection of blood from the brain.

Focal Brain Injury: damage that is in one area of the brain.

Frontal Lobe: the area of the brain located at the front of the skull behind the forehead. This area plays a role in controlling emotions and impulses, motivation, social skills, and expressive language.

Glasgow Coma Scale: a scale from 3 (no responding) to 15 (fully alert) that indicates how severe the brain injury is. This scale rates someone's level of consciousness using three factors: motor (muscle) responses, eye opening, and verbal responses.

Hematoma: collection of blood in tissues or space caused by broken blood vessels.

> **Epidural Hematoma:** bleeding between the skull and the dura (the outermost tissue covering of the brain).
>
> **Intracerebral Hematoma:** bleeding into the brain itself. This often happens following bruising or tearing of the brain tissue.
>
> **Subarachnoid Hematoma:** bleeding around the surfaces of the brain between the dura and arachnoid membranes.
>
> **Subdural Hematoma:** bleeding into the space between the dura and the brain. This creates pressure on the brain.

Hemiparesis: weakness on one side of the body due to injury to the motor areas of the brain.

Hemorrhage: bleeding following traumatic injury; bleeding may occur within the brain when blood vessels in the skull or the brain are damaged.

Hydrocephalus: when too much cerebral spinal fluid (CSF) is collected in the ventricles, putting pressure on the brain.

IV (intravenous): this is a method of delivering fluids directly into the bloodstream through a needle in a vein.

Rancho Los Amigos Cognitive Scale: an assessment tool used in rehabilitation to describe the behavioral stages of an individual with a brain injury.

MRI (magnetic resonance imaging): a computerized picture, often used to show injury to soft tissue, like the brain or spinal cord.

Memory: the process of organizing and storing information, and then being able to recall these things at a later time.

Occipital Lobe: the area of the back of the brain involved in how you understand what you see.

Parietal Lobe: the upper middle area of each side of the brain behind the temples. This area is involved in how sensations are processed by the brain; linked to speech and writing.

Post-Traumatic Amnesia: a loss of memory related to a traumatic event and the period immediately following the trauma.

Problem-solving: skills used in reasoning, judgement and insight in solving problems.

Range of Motion (ROM): exercises or movement of a joint or limb to help avoid limiting movement.

Retrograde Amnesia: memory loss of events and periods of time before an injury or accident.

Self-Help Skills: routine activities of personal hygiene and health (including bathing, dressing, feeding). Also called ADLs.

Shearing Injury: the tearing of the brain tissue and blood vessels caused by movement of the brain tissue within the skull or against the skull's sharp, bony edges.

Shunt: A procedure for removing excess 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.

Temporal Lobe: the lower middle part of each side of the brain used in processing sounds; involved in memory.

Ventilator: also known as a respirator; a machine that helps a person breathe when they cannot breathe on their own.

Ventricles: four cavities in the brain which are filled with cerebrospinal fluid. These filled spaces act as cushions when the brain is hit.

Ventriculostomy: an opening through the skull into the ventricles; special equipment to monitor pressure inside the skull or to drain cerebral spinal fluid (CSF), special equipment is used to place a small tube into the ventricles through the surgically made opening in the skull.

Ventriculo-Peritoneal Shunt (VP shunt): a surgical procedure that places a tube connecting a ventricle (cavity in the brain) to the peritoneum (space in the abdomen); excess cerebral spinal fluid (CSF) in the ventricles drains through the tube into the peritoneum, to prevent unnecessary presure to build in the brain, the CSF is absorbed into the body.

Visual Field Deficit: not being able to see anything in a specific area of vision.

Visual Perception: the ability to understand, explain, and give meaning to what is seen.

RESOURCES

NEW YORK STATE AGENCIES

New York State agencies provide a wide range of services to individuals with disabilities. Some of the agencies listed below have special programs for persons with brain injury and their families. You will also find information about financial assistance, educational/vocational resources, advocacy, and legal counseling.

New York State Department of Health (DOH)

Bureau of Long Term Care Brain Injury Program
Office of Medicaid Managment
1 Commerce Plaza
Albany, NY 12260
518-474-6580
nyhealth@health.state.ny.us (e-mail)
www.health.state.ny.us (web site)
Provides many essential services for individuals with brain injury and administers the Home and Community Based Services TBI Medicaid Waiver.

The Commission on Quality of Care (CQC)

401 State Street
Schenectady, NY 12305
800-624-4143 • 518-381-7000
Serves people with mental disabilities and their families by providing independent oversight of the quality and cost effectiveness of services provided by all mental hygiene programs in New York State. The Commission provides legal and non-legal advocacy services to persons with disabilities to assist them in obtaining the services and protections of federal and state laws.

New York State Office of Advocate for Persons with Disabilities

One Empire Plaza, Suite 1001
Albany, NY 12223-1150
800-522-4369 • 518-473-6005 (Fax)
information@oapwd.state.ny.us (e-mail)
www.advoc4disabled.state.ny.us (web site)
This organization's mission is to ensure that people with disabilities have every opportunity to be productive and participating citizens through access to emerging technology and information, legislation, and state policy development.

Office of Mental Retardation and Developmental Disabilities (OMRDD)

Statewide TBI Coordinator
44 Holland Avenue
Albany, NY 12229
518-474-8652
OMRDD serves individuals with developmental disabilities resulting from traumatic brain injury sustained before the age of 22. OMRDD operates district offices known as Developmental Disabilities Service Offices (DDSOs) throughout New York State.

State Education Department; Office of Vocational and Educational Services for Individuals with Disabilities (VESID)

Special Education Policy and Quality Assurance
New York State Education Department
One Commerce Plaza
Albany, NY 12234
800-222-5627 • 518-474-2714
www.nysed.gov/ (then click on VESID)
VESID promotes educational equity and excellence for students with disabilities, and advocates for the rights and protections to which they are entitled.

OTHER RESOURCES:

Brain Injury Association of New York State

10 Colvin Avenue
Albany, NY 12206
Telephone: 518-459-7911 • Fax: 518-482-5285
Family Help Line: (800) 228-8201
E-mail: info@bianys.org • Web Site: www.bianys.org

Resources for Children with Special Needs

200 Park Ave. South, Suite 816
New York, New York 10003
Telephone: 212-677-4650
Web Site: www.resourcesnyc.org

National Information Center for Children and Youth with Disabilities (NICHCY)

P.O. Box 1492
Washington, DC 20013
Telephone: 1-800-695-0285 (voice/TTY)
Fax: 202-884-8441
E-mail: nichey@aed.org • Web Site: www.nichcy.org

Parent Advocacy Coalition for Education Rights (PACER Center)

8161 Normandale Blvd.
Minneapolis, MN 55437
Telephone: 888-248-0822 • Fax: 952-838-0199
E-mail: pacer@pacer.org • Web Site: www.pacer.org

Lash and Associates Publishing/Training

708 Young Forest Drive
Wake Forest, N.C. 27587
Telephone: 919-562-0015
Web Site: www.lapublishing.com

National Early Childhood Technical Assistance Services (NECTAS)

137 East Franklin Street, Suite 500
Chapel Hill, NC 27514-3628
Telephone: 919-962-2001 • TDD: 877-574-3194
Fax: 919-966-7463
E-mail: nectas@unc.edu
Web Site: www.nectas.unc.edu

PEOPLE INVOLVED IN CARING FOR MY CHILD

NAME/ROLE	CONTACT PHONE NUMBER
Staff Doctor	Phone
Resident	Phone
Nurse	Phone
Social Woker	Phone
Neurologist	Phone
Intensivist	Phone
Orthopaedic Surgeon	Phone
Neurosurgeon	Phone
Other Doctors	Phone
	Phone
Speech Language Pathologist	Phone
Occupational Therapist	Phone
Physical Therapist	Phone
FACTS Coordinator	Phone
Other Important People	Phone

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

Revised 2004