

Brain Injury: The Abc Years

Understanding and Preventing Pediatric Brain Injury

Introduction

According to the Centers for Disease Control and Prevention (CDC), **an estimated 5.3 million Americans, a little more than 2 percent of the U.S. population**, currently live with disabilities resulting from brain injuries. The CDC also reports that of the one million people who are treated in and released from hospital emergency rooms each year:

- 230,000 will be hospitalized and survive
- 80,000 will experience an onset of disabilities resulting from their brain injuries
- 50,000 will die

After many years of studies, the following findings have been released about the prevalence of brain injury:

- The risk of having a brain injury is especially high among adolescents and young adults, as well as people older than 75 years (CDC, 1999). In fact, it is males 14 to 24 years of age who are at the highest risk for sustaining a brain injury, followed by infants and the elderly (Kraus, 1993)
- For persons of all ages, the risk of brain injury among males is twice the risk among females, due to differences in risk exposure and lifestyle (CDC, 1999; Kraus, 1993)
- The leading causes of brain injury are motor vehicle crashes, violence and falls (CDC, 1999)
- The leading causes of brain injury vary by age. Falls are the leading cause among persons aged 65 years and older and 5 years of age and under, whereas transportation-related injuries are most frequent among persons ages 5 to 64
- The outcome of these injuries varies greatly depending on the cause: 91% of firearm-related brain injuries resulted in death, but only 11% of fall-related ones proved fatal (CDC, 1999)



What Is Brain Injury?

Traumatic brain injury (TBI) has been defined as a physiological disruption of brain function resulting from trauma both external (an object striking the head or the head striking an object) and/or internal (the rapid acceleration/deceleration of the brain within the skullcap).

There are two basic types of brain injury. Open head injuries are caused by bullets or other penetrating objects. Closed head injuries are the more common of the two and usually are caused by a rapid movement of the head during which the brain is bounced back and forth within the skullcap. Closed head injuries often result from motor vehicle crashes, falls and injuries sustained during sports and other recreational activities (i.e., football, bicycling).

Brain injuries are classified in terms of severity (i.e., mild, moderate, severe):

Mild Brain Injury

Also known as concussion, a mild brain injury is defined as one in which an individual experiences at least one of the following: 1) any period of loss of consciousness; 2) any loss of memory of events immediately preceding and/or following the injury; 3) any alteration in mental state at the time of the injury and 4) focal neurological deficit(s) that may or may not be transient.

The most common symptoms of mild brain injury fall into the following categories:

- **Physical** (headache, dizziness, nausea, sleep problems, fatigue)
- **Cognitive** (decreased attention span, concentration, mental speed and short-term memory)
- **Behavioral** (irritability, emotional lability, depression, anxiety)

The majority of individuals who sustain a mild brain injury will recover spontaneously and with no residual deficits within one to three months, although some individuals may require a longer length of time. Even with a mild brain injury or concussion, a relatively subtle amount of damage occurs and a small subset of people will be left with permanent disability or deficits.



Moderate Brain Injury

Although a mild brain injury can be identified and documented easily, distinctions between moderate and severe brain injury are less clear-cut. Generally, a moderate brain injury is one that results in a loss of consciousness lasting only a few minutes to a few hours, followed by days and/or weeks of confusion. Persons sustaining a moderate brain injury usually have physical, cognitive and/or behavioral impairments which can last for many months and even become permanent. Although to a lesser extent, these impairments are similar to those experienced by individuals with severe brain injury. With treatment, however, individuals with moderate brain injuries usually are able to make a complete recovery or successfully learn to compensate for their deficits. (For more information about deficits after brain injury, see the “Consequences” section on page 7.)

Severe Brain Injury

Severe brain injury almost always results in prolonged unconsciousness or coma lasting days, weeks and even months after the injury. Coma is defined as a state of unconsciousness from which the individual cannot be awakened; in which the individual responds minimally or not at all to stimuli and initiates no voluntary activities. Although persons who sustain a severe brain injury can make significant improvements in the first year after the injury and continue to improve at a much slower rate for many years, these individuals often will be left with permanent physical, cognitive or behavioral impairments.

Brain Injury And Children

Brain injury is the most frequent cause of disability and death among children and adolescents in the United States (CDC, 1999; Lehr, 1990). Each year, more than one million children sustain brain injuries ranging from mild to severe (Eiben et al., 1984). According to the National Pediatric Trauma Registry, approximately one-third of all pediatric injury cases are related to brain injury (1993). As noted previously, the causes and consequences vary with the child’s age.

Causes

Falls—For children under five years of age, falls are the number one cause of brain injury, accounting for more than 50% (Kraus et al., 1984; Ivan et al., 1983). The severity of brain injury is determined by the distance of the fall and the type of landing surface (i.e., concrete pavement, sand). Because falls are associated with a child’s curiosity and development of motor skills, children under age 10 are at the greatest risk for fall-related brain injury and death (National Safe Kids Campaign, 1999a). During a fall, a child’s brain is at special risk because of the size and weight of his/her head in relation to his/her body.



Infants are at greater risk of falls from changing tables, cribs and other pieces of furniture, stairs and baby walkers. Toddlers and school age children are predominantly at risk for falls from windows, balconies, porches, stairs and playground equipment. In children four years of age and under, more than 89% of fall-related injuries occur in the home (National Safe Kids Campaign, 1999a). Children between the ages of 5 and 14 experience 45% percent of fall-related injuries in the home and 23% in school settings (National Safe Kids Campaign, 1999a).

Preventing Falls

The following are tips to help prevent infants and children from sustaining a brain injury in a fall:

- Never leave infants unattended on changing tables or other furniture where there is danger of falling
- Never use baby walkers on wheels. Use alternative products such as stationary activity centers
- Use safety gates at the top and bottom of all stairs
- Lock all unopened windows. Open windows from the top, not the bottom. Move chairs and other furniture away from windows. Consider installing window guards in all windows
- Be sure that children are always supervised and do not allow them to sit on ledges

Motor Vehicle Crashes—The second major cause of pediatric brain injury is motor vehicle crashes with children as passengers. Among children ages 4 to 14, it is the number one cause of brain injury.

Although 85% of infants (children under age one) were restrained while riding in motor vehicles in 1997, only 60% of children ages one to four were restrained (National Safe Kids Campaign, 1999b). As they grow older, the percentage of children being restrained continues to decrease. Unrestrained children of any age are more likely to incur a brain injury and/or die in motor vehicle crashes than children that are restrained. In fact, among children ages 14 and under who were killed as occupants in motor vehicle crashes in 1997, 63% were not using safety restraints at the time of the collision (National Safe Kids Campaign, 1999b). Misuse of child safety seats is rampant and it is estimated that 80% of children who are placed in child safety seats are being improperly restrained (National Safe Kids Campaign, 1999b).

Preventing Motor Vehicle Crashes

Correctly installed child safety seats in passenger cars are extremely effective, reducing the risk of death by 77% for infants and by 54% for children ages one to four (National Safe Kids Campaign, 1999b).



Adult safety seat belts do not adequately protect children ages four to eight from sustaining a brain injury during a motor vehicle crash. Car booster seats combined with proper seat belt usage are the best protection, although it is estimated that only 5% of the children in this age group are properly restrained in booster seats. To further prevent the risk of a child sustaining a brain injury during a motor vehicle crash, follow these simple precautions:

- Always place infants and children under 12 in the back seat of the car
- Infants age one and under or children weighing less than 20 pounds should ride in rear facing child safety seats in the back seat
- Never put an infant in the front seat of a car with passenger side airbags
- Children weighing 20 to 40 pounds should ride in approved car seats, facing forward in the back seat
- Children weighing 40 to 80 pounds should ride in approved car booster seats in the back seat

Pedestrian—Each year, approximately 50,000 children are hit by motor vehicles, often receiving serious brain injuries (Child Pedestrian Safety Program, Harborview Injury Prevention and Research Center, 1995). Children are particularly vulnerable to pedestrian brain injury and death because they are exposed to traffic threats that exceed their cognitive, developmental, behavioral and physical abilities.

Preventing Pedestrian Injuries

- When crossing the street, children should hold an adult's hand and cross at designated crossing areas
- Children should never cross between parked cars
- Children should be taught to look left-right-left when crossing and watch for cars that are turning
- Children should always walk on the sidewalk. When there is no sidewalk, children should walk facing traffic
- When outside after dark, children should always wear reflective materials

Abuse—Abuse is another leading cause of serious brain injury in children. Approximately two-thirds (64%) of children under one year of age that are physically abused sustain brain injuries (Billmire & Myers, 1985). An outcome study of children younger than six years found that cognitive and motor abilities were more damaged in children who had been abused versus children who had sustained accidental brain injuries (Kriel et al., 1989).

Shaken Baby Syndrome—is a disturbing and serious cause of brain injury caused by a vigorous shaking of an infant or child by the arms, chest or shoulders. This forceful shaking can result in brain injury leading to cognitive, physical and behavioral impairments and even death.



Head trauma is the most frequent cause of permanent damage or death among abused infants and children, and shaking accounts for a significant amount of these cases (Showers, 1999).

The potential outcome of shaken baby syndrome is generally severe brain injury or even death. Approximately 75-90% of these cases exhibit retinal hemorrhages, a symptom almost never seen with accidental brain injuries (The National Conference on Shaken Baby Syndrome, 1996). Males are the predominant perpetrators, involved in between 65-90% of the cases, followed by female babysitters or childcare providers. The number one cause of Shaken Baby Syndrome and other forms of child abuse is inconsolable crying.

Preventing Abuse

Any parent or caregiver who fears they may injure a child should follow three simple steps:

- **Stop:** Put the child in a safe place and leave the room for a few minutes
- **Calm Down:** Call a friend or neighbor. Take 10 deep breaths. Change the activity. Sit down, close your eyes and think of a pleasant memory
- **Try Again:** Go back to your child and try again to deal with the problems at hand

Firearms—Every two hours in the United States someone's child is killed with a loaded gun (American Academy of Pediatrics, 1994). It is estimated that half of all American households have firearms. In 1992, firearms surpassed motor vehicles as the number one cause of brain injury fatalities in the United States (Sosin et al., 1995).

Firearm violence is a uniquely American problem, with a rate approximately 90 times greater than any other similar country (Martin, 1998). In 1992, handguns were used to murder 13 people in Australia, 33 in Great Britain, 36 in Sweden, 60 in Japan, 97 in Switzerland, 128 in Canada and 13,495 in the United States (Think First Foundation, 1999).

Exposure to guns and access to a loaded firearm increase the risk of unintentional brain injury and death in a child. The unintentional death rate among children 14 years of age and younger is nine times higher than in 25 other industrialized countries combined (National Safe Kids Campaign, 1999c). Nearly all unintentional shootings occur in or around the home. Most unintentional shooting deaths involve guns that have been kept loaded and accessible to children and occur when children play with loaded guns (National Safe Kids Campaign, 1999c).



Preventing Firearm Injuries

An estimated 30% of all unintentional shootings could be prevented by the presence of safety features such as trigger locks and loading indicators, but American-made guns are not subject to federal safety standards like other consumer products. To help protect a child from sustaining a brain injury from firearms, follow these simple steps:

- Always keep guns unloaded and locked up. Lock and store bullets in a separate location and make sure children do not have access to the keys
- Explain to children that guns are dangerous and that they never should touch guns or remain in a home where a gun is accessible
- Tell children that gun violence in the media is not real — in real life children are hurt and killed with guns
- Talk with children about ways to solve arguments and fights without guns or violence
- The best way to reduce gun risks is to remove the gun from your home

Consequences

Impairments from brain injury can be divided into three major categories: physical, cognitive and behavioral.

Physical Impairments

- Speech, vision, hearing and other sensory impairments
- Headaches
- Lack of coordination
- Muscle spasticity (A condition that causes stiff, tight muscles, especially in the arms and legs, making movements stiff, jerky or uncontrollable)
- Paralysis
- Seizure disorders
- Problems with sleep
- Dysphagia (a disorder of swallowing)
- Dysarthria (a disorder of articulation and the muscular/motor control of speech)

Cognitive Impairments

- Short- and long-term memory deficits
- Slowness of thinking
- Problems with reading and writing skills
- Difficulty maintaining attention and concentration



- Impairments of perception, communication, reasoning, problem solving, planning, sequencing and judgment
- Lack of motivation or inability to initiate activities

Behavioral Impairments

- Mood swings
- Denial
- Depression and/or anxiety
- Lowered self esteem
- Sexual dysfunction

- Restlessness and/or impatience
- Inability to self-monitor, inappropriate social responses
- Difficulty with emotional control and anger management
- Inability to cope
- Excessive laughing or crying
- Difficulty relating to others
- Irritability and/or anger
- Agitation
- Abrupt and unexpected acts of violence
- Delusions, paranoia, mania

Outcome After Pediatric Brain Injury

When dealing with pediatric brain injury, it is important to recognize that children are not simply smaller versions of adults. When infants and toddlers sustain traumatic brain injuries, many people cite the adage that the younger the child, the better they will do. The assumption is made that because the very young child has yet to use many parts of his/her brain, there is ample room for a good outcome (Wedel-Sellars & Hill-Vegter, 1997).

Further studies seem to cast doubt on this theory when the causes of injury and the outcome of the young child are examined (Wedel-Sellars & Hill-Vegter, 1997). In any case, the child's cognitive, personality and psychosocial development need to be considered in the assessment and treatment of a brain injury. Unlike adults, the effects of brain injury on brain function interact with the maturation or development of the child. Skills that are emerging or developing may be affected differently by brain injury than skills that are already established.



The child with a brain injury is unique not only in comparison with peers of the same age, but also to other children with brain injuries. Each child's recovery process, outcome and family are different and unique. Although this is true for any man, woman or child who sustains a brain injury, nowhere is it more different than in the very young child (Wedel-Sellars & Hill-Vegter, 1997).

Return To School After A Brain Injury

The education of a student with brain injury becomes more complex over time, as schoolwork gradually becomes more difficult with each grade level entered. Outcomes from pediatric brain injury are rarely predictable and neither is the student's progress in school.

The pattern of quicker physical recovery among children and the emergence of cognitive and behavioral impairments over time make accurate assessments much more complicated. As the child's brain is still maturing, the full impact of a brain injury may not become evident for many months or even years. This time delay makes it even more difficult for parents, educators and clinicians to establish the relationship between an earlier injury and altered abilities to learn and function in the classroom and school environment.

Before the child returns to school, it is necessary for the student, parents, rehabilitation and educational professionals to sit down and complete an Individualized Educational Plan (IEP). An IEP is an educational plan designed by the public school system outlining the special learning needs of a child, including:

- The amount of special education or resources which needs to be provided
- The educational and learning goals
- The frequency of the interventions within the school (usually revised yearly)

Although it can be extremely challenging for parents and educators to work together to develop and continue supporting an IEP for a student with such unique and complex needs, it is essential to the successful return to school of a child with a brain injury.



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National Safe Kids Campaign. *Fact Sheet on Falls*. Washington, DC, 1999a.

National Safe Kids Campaign. *Fact Sheet on Motor Vehicle Occupant Injury*. Washington, DC, 1999b.

National Safe Kids Campaign. *Fact Sheet on Unintentional Firearm Injury*. Washington, DC, 1999c.



Research and Training Center in Rehabilitation and Childhood Trauma: Injuries among children. In: *The Pediatric Trauma Registry*. Boston: Tufts University School of Medicine, New England Medical Center, 1993.

Showers J: Shaken baby syndrome: A major cause of traumatic brain injury. *Brain Injury Source*. 3(2):28-30.

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The National Conference on Shaken Baby Syndrome. Keynote Addresses. December, 1996. Salt Lake City, Utah.

THINK FIRST Foundation. *Fact Sheet on Firearms*. Park Ridge, IL. 1999.

Wedel-Sellars C & Hill-Vegter C: *Pediatric Brain Injury*. Houston: HDI Publishers, 1997.

For more information about any topic covered in this educational pamphlet, contact the Brain Injury Association's (BIA's) Family Helpline at (800) 444-6443, visit its web site at <http://www.biausa.org> or write to BIA, Information and Resources Department, 105 North Alfred Street, Alexandria, VA 22314.

Additional Resources

American Academy of Pediatrics
141 Northwest Point Blvd.
Elk Grove Village, IL 60007-1098
Phone: (847) 228-5005
Fax: (847) 228-5097
Web site: <http://www.aap.org>

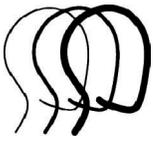
National Safe Kids Campaign
1301 Pennsylvania Ave., NW
Suite 1000
Washington, DC 20004-1707
Phone: (202) 662-0600
Website: <http://www.safekids.org>

American Academy of Neurology
1080 Montreal Avenue
St. Paul, MN 55116
Phone: (800) 879-1960
Fax: (612) 695-2791
Web site: <http://www.aan.com>

National Highway Traffic Safety Administration (NHTSA)
National Organizations for Youth Safety
400 7th Street
Washington, DC 20590
Phone: (800) 424-9393
Web site: <http://www.nhtsa.dot.gov>

Lash & Associates Publishing and Training
708 Young Forest Drive
Wake Forest, NC 27587
Phone: (919) 562-0015
Web site: <http://www.lapublishing.com>





Falls

Falls are a major cause of brain injuries.

Playground Safety



- Brain injury is one of the top 10 diagnoses in emergency departments for playground-related injuries.¹
- The estimated cost of playground-related injuries to children under the age of 15 was \$1.2 billion in 1995.²
- Nearly 20 children die each year from playground-related injuries. More than half of these deaths result from strangulation and about one-third result from falls.²
- Most injuries occur on the swings, monkey bars or climbers, and slides.²
- Falls off playground equipment to the ground account for more than 60 percent of all playground-related injuries.²
- Public playground equipment accounts for approximately 70 percent of all playground equipment injuries.²



Prevention of Playground Injuries

- Since more than 60 percent of all playground injuries are caused by falls to the ground, protective surfacing under and around all playground equipment can reduce the risk of serious head injury.³
- Make sure surfaces around playground equipment have at least 12 inches of wood chips, mulch, sand, pea gravel, or mats made of safety-tested rubber or rubber-like materials.⁴
- Adult presence is needed to watch for potential hazards, observe, intercede and facilitate play when necessary. Strings on clothing or ropes used for play can cause accidental strangulation if caught on equipment.⁵
- Make sure play structures more than 30 inches high are spaced at least nine feet apart. Also check that protective surfacing extends at least six feet in all directions from play equipment.⁴



Falls and the Elderly

- People ages 75 years and older represent the highest rate of traumatic brain injury (TBI) fatality. Falls are the leading cause of TBI among the elderly.⁶
- Of all fall-related deaths, more than 60 percent involve people who are 75 years or older.⁷
- Factors that contribute to falls include problems with gait and balance, neurological and musculoskeletal disabilities, psychoactive medication use, dementia and visual impairment.⁷
- Environmental hazards such as slippery surfaces, uneven floors, poor lighting, loose rugs, unstable furniture and objects on floors may also play a role in falls.⁷

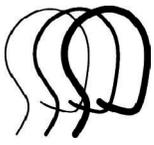
Preventing Falls for the Elderly

- Exercise regularly - regular physical activity is one of the best ways to reduce your chances of falling.
- Home safety check - Remove things that might be tripped over, store items that are used often in cabinets that can be reached easily without a step stool, install grab bars in the tub or shower, use non-slip mats on the bathtubs and shower floors and install handrails and lights on all stairs and outside.
- Have your health care provider review medicines. A doctor, pharmacist or your healthcare professional should look at all the medicines taken (including over-the-counter medicines)
- Wear safe shoes. Wear sturdy shoes with thin, non-slip soles.



Sources:

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2. National Center for Injury Prevention and Control, "Playground Injuries." <http://www.cdc.gov/ncipc/factsheets/playgr.htm>. (February 2, 2001)
3. Consumer Product Safety Commission, "Home Playground Safety Tips." <http://www.cpsc.gov/cpscpub/pubs/323.html>. (February 2, 2001)
4. Consumer Product Safety Commission, "Public Playground Safety Checklist." <http://www.cpsc.gov/cpscpub/pubs/327.html>. (February 2, 2001)
5. National Program for Playground Safety, "Keep Your Children Safe." <http://www.uni.edu/playground/tips/general/checklist.html> (February 2, 2001)
6. Centers for Disease Control, "Traumatic Brain Injury in the United States: A Report to Congress." <http://www.cdc.gov/ncipc/pub-res/tbicongress.htm> (February 2, 2001)
7. National Center for Injury Prevention and Control, "Falls and Hip Fractures Among Older Adults." <http://www.cdc.gov/ncipc/factsheets/falls.htm> (February 2, 2001)



Brain Injury

An Estimated 5.3 Million Americans - a little more than 2 percent of the U.S. population - currently live with disabilities resulting from traumatic brain injury.¹



Every 21 Seconds, One Person in the U.S. Sustains a Traumatic Brain Injury

Traumatic brain injury (TBI) Definition:

An insult to the brain, not of degenerative or congenital nature caused by an external physical force that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning.

Acquired brain injury (ABI) Definition:

Injury to the brain which is not hereditary, congenital or degenerative that has occurred after birth. (Includes anoxia, aneurysms, infections to the brain and stroke.)

- 1.5 Million Americans sustain a traumatic brain injury each year¹
- Each year, 80,000 Americans experience the onset of long-term disability following TBI.¹
- More than 50,000 people die every year as a result of TBI.¹
- The risk of TBI is highest among adolescents, young adults and those older than 75.²
- After one brain injury, the risk for a second injury is three times greater; after the second injury, the risk for a third injury is eight times greater.³

The Cost of Brain Injury



The cost of traumatic brain injury in the United States is estimated to be \$48.3 billion annually. Hospitalization accounts for \$31.7 billion, and fatal brain injuries cost the nation \$16.6 billion each year.⁴

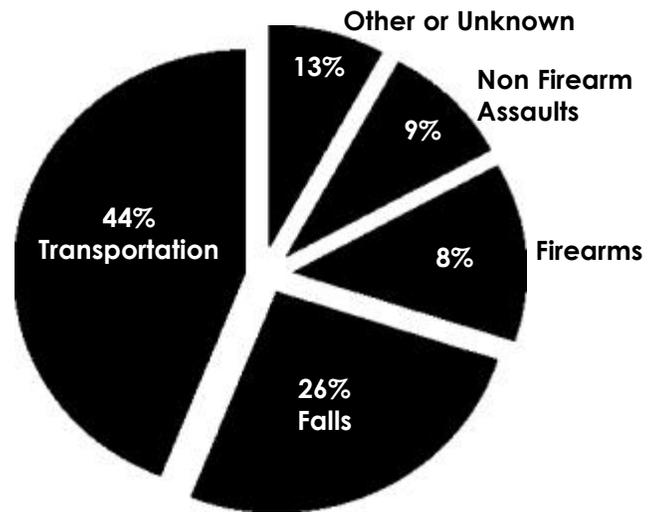
Creating a better future through brain injury prevention, research, education and advocacy

Percentage of TBI Causes⁵

1995-1996 -14 States*

* Rhode Island, New York, Maryland, South Carolina, Minnesota, Louisiana, Nebraska, Oklahoma, Utah, Alaska and California (Sacramento County Only)

Vehicle Crashes are the **leading cause** of brain injury. **Falls** are the **second leading cause**, and the leading cause of brain injury in the elderly.



The Consequences of Brain Injury

Cognitive Consequences Can Include:

- Short-term memory loss; long-term memory loss
- Slowed ability to process information
- Trouble concentrating or paying attention for periods of time
- Difficulty keeping up with a conversation; other communication difficulties such as word finding problems
- Spatial disorientation
- Organizational problems and impaired judgement
- Unable to do more than one thing at a time
- A lack of initiating activities, or once started, difficulty in completing tasks without reminders

Physical Consequences Can Include:

- Seizures of all types
- Muscle spasticity
- Double vision or low vision, even blindness
- Loss of smell or taste
- Speech impairments such as slow or slurred speech
- Headaches or migraines
- Fatigue, increased need for sleep
- Balance problems

Emotional Consequences Can Include:

- Increased anxiety
- Depression and mood swings
- Impulsive behavior
- More easily agitated
- Egocentric behaviors; difficulty seeing how behaviors can affect others

Sources:

1. Centers for Disease Control. "Traumatic Brain Injury in the United States: A Report to Congress." www: Centers for Disease Control, (January 16, 2001) <http://www.cdc.gov/ncipc/pub-res/tbicongress.htm>.
2. Analysis by the CDC National Center for Injury Prevention and Control, using data obtained from state health departments in Alaska, Arizona, California, Colorado, Louisiana, Maryland, Missouri, New York, Oklahoma, Rhode Island, South Carolina and Utah.
3. Annegers JF, Garbow JD, Kurtland LT et al. The Incidence, Causes and Secular Trends of Head Trauma in Olstead County, Minnesota 1935- 1974. Neurology. 1980; 30:912-919.
4. Lewin -ICF. The Cost of Disorders of the Brain Washington, DC: The National Foundation for the Brain, 1992.
5. Personal Communications with Dr. David Thurman, CDC - National Center for Injury Prevention and Control, June 29, 1999.

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 Management

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
518-473-1890

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

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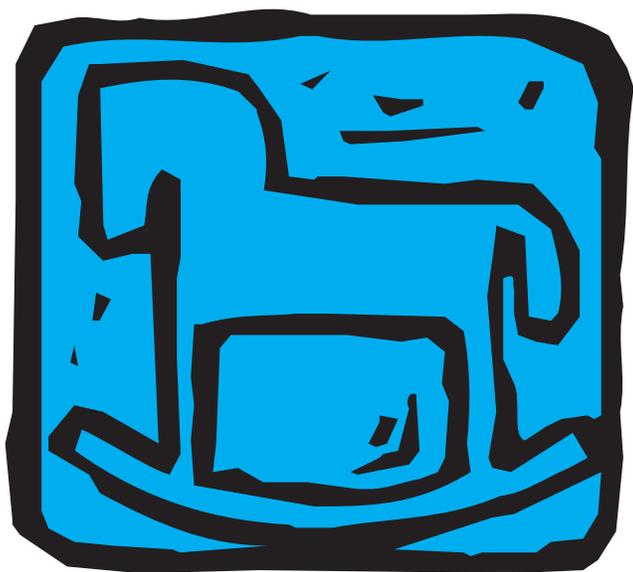
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MY CHILD'S BRAIN INJURY....



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 knowledgeable 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 IN 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.

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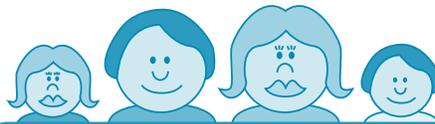
Causes of an acquired brain injury include:

- ★ car crash
- ★ sports injury
- ★ fall
- ★ physical fight
- ★ bicycle crash
- ★ being shaken by someone
- ★ abuse
- ★ 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-traumatic 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

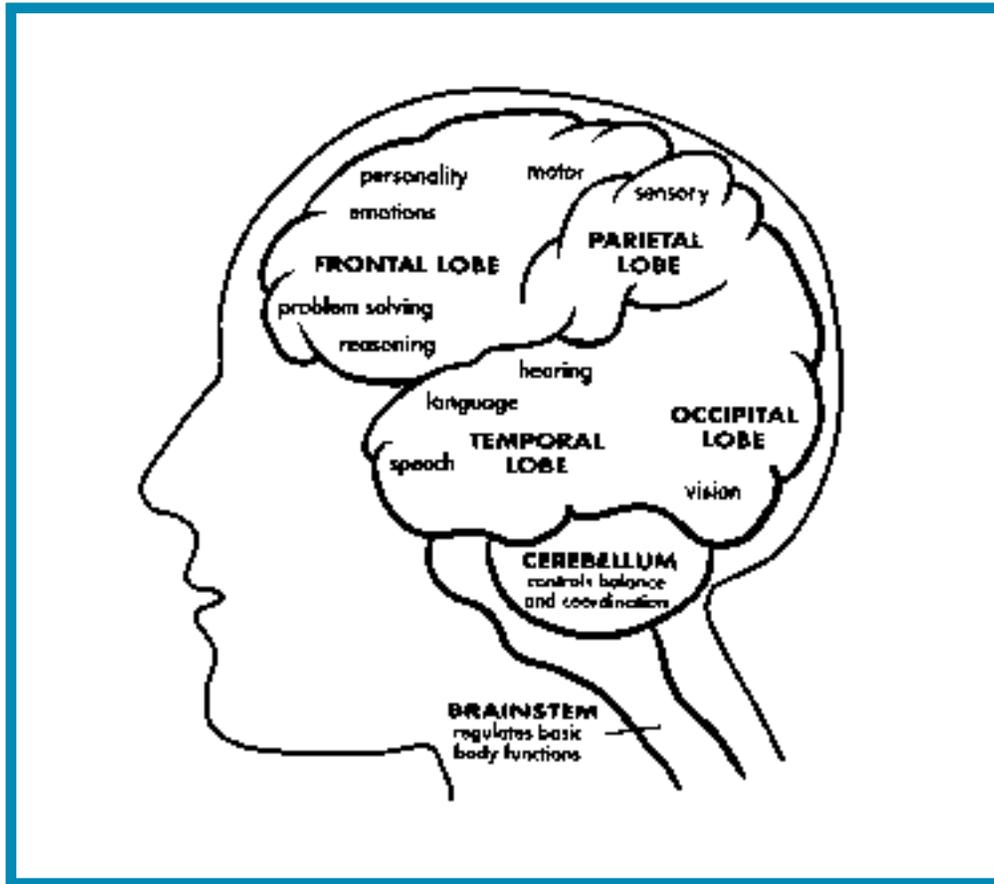
Changes occur in how a child does everyday things such as:

- 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
- ★ Slurring 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 as 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.



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 you 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?
- ★ 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?



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

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 TBI. 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.

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.

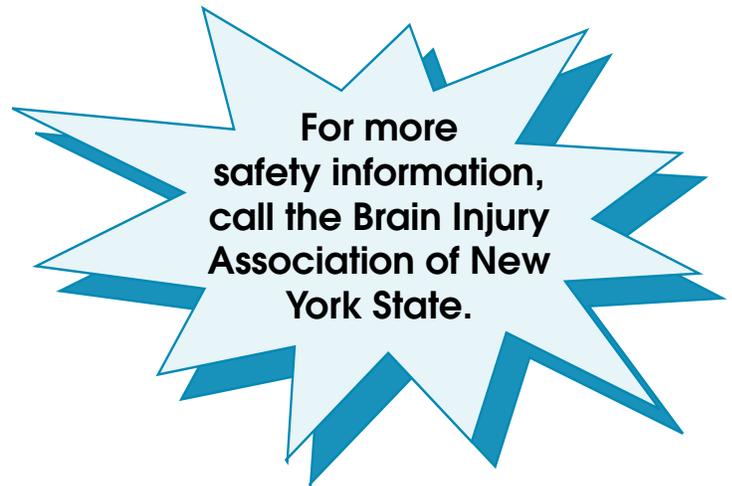
It is important that you talk to your child's teacher to find out how your child is doing at school and if there are any problems.

How can I prevent another traumatic brain injury?

Your child 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 a helmet, knee and elbow pads, and mouth guards.

- ★ Your child should always use car seats and seat belts.
- ★ You should 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.



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) program 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 TBI

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 knowledgeable 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, tinnitus, 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, feed 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.

Brainstem: the lower portion of the brain, which connects it to the spinal cord. The brainstem 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 pressure 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 Management

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
518-473-1890

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: nichcy@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 Worker	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

Traumatic Brain Injury (TBI)

- An injury caused by an external force
- Event results in a definitive loss of consciousness or a period of feeling dazed or confused
- Changes in physical, cognitive and emotional/behavioral functioning secondary to the event

Mechanism of Injuries

- Impact: Coup injury
- Inertial: Contre - coup injury

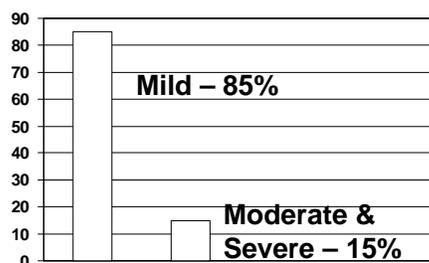
Effects of Trauma to the Brain

- Primary
 - Damage to the brain 2° to impact force

Effects of Trauma to the Brain

- Secondary
 - Diffuse axon injury
 - Edema
 - Infection
 - Ischemia
 - Bleeding
 - Seizures

Levels of TBI Severity:



Moderate-Severe TBI

- Blow to head/medical event
- Loss of consciousness > 20 minutes
- Cognitive/physical and behavioral consequences
- Damage visualized on CT or MRI scans
- Causal link well established

Moderate-Severe TBI

- Hospitalized
- Rehabilitation
- Known to the medical community

Mild TBI

- Blow to the head
- Altered mental status/brief loss of consciousness
- Cognitive/behavioral/physical consequences
- Damage frequently not visualized on CT or MRI
- Confirm with neuropsychological testing

Mild TBI

- Seen in ER/ MD office
 - Frequently unreported or undiagnosed
 - Causal link behavior change and TBI not made

Warning Signs

- Increased Lethargy
- Nausea/Vomiting
- Bleeding from Ears
- Difficulty Arousing from Sleep

Frequency of TBI

- 1,000,000 children to suffer brain injury each year
- Of those, 30,000 will be permanently disabled
- Risk highest in adolescents, young children under the age of 5, Risk of 2nd TBI is 3x greater; 8x greater after 2nd TBI

Frequency of TBI in Children

- Leading cause of death in children under the age of 5
- 75% more ER visits of children with TBI than adults with TBI
- There are more identified and unidentified children with TBI than adults

Each year, TBI in Children Results in...

- 4500 deaths
- 145,000 hospital discharges
- 685,000 medically attended head injuries in children under 18

Child's Anatomy & Risk

- Proportion of Head Size
- Growing Physical Agility
- Brain Not Totally Formed/Fontanel
- Natural Curiosity & Fearlessness

Typical Causes of TBI

- 44% transportation (MVA, pedestrian)
- 26% falls
- 9% assaults (includes domestic violence)
- 8% firearms
- 13% other (includes shaken baby syndrome)

Causes of TBI

- Falls
 - Leading cause of brain injury in children under 5
 - Account for more than 50% of injuries
 - 89% falls occur in home

Causes of TBI

- **Playground Injuries**
 - Brain injury is one of top ten reasons for ER visits
 - 20 children die each year from playground related injuries:
 - 1/2 of injuries due to strangulation
 - 1/3 of injuries from falls
 - 60% of all injuries due to falls from playground equipment

Causes of TBI

- **Pedestrian Accidents**
 - 50,000 children struck by vehicles each year 4,906 pedestrians killed in traffic crashes in the US
 - 1/3 of 5 to 9 year olds killed by vehicles are on foot.
- **Scooter/Bike Injuries**
 - 40,000 ER visits to treat scooter/bike related injuries
 - 90% of injuries occur in children under the age of 15

Causes of TBI

- **Violence**
 - Violence involving guns and other weapons results in penetrating brain injuries
 - Firearms and non-firearm assaults constitute 17% of all brain injuries
 - Every 2 hours, a child is killed with a gun; for every child killed, four are wounded
 - Firearms are the leading cause of death from brain injury

Causes of TBI

- **Shaken Baby Syndrome**
 - One million children severely abused annually
 - Leading cause of morbidity and mortality in infants
 - Annual incidence between 750-3,750 children
 - 1/3 suffer few or no consequences
 - 1/3 suffer permanent injury
 - 1/3 die

Common Causes of TBI in Older Children

- **Baseball**
- **Skateboards**
- **Football**
- **Soccer**
- **Skiing/snowboarding**

Failing to Identify TBI

- 83% of the children admitted to hospitals in NYS in 1996-7 with a diagnosis of shaken baby syndrome also had a TBI (Santilli & Thoburn, NYSDOH, undated)
- In children seen in ER for abuse, TBI of 1/3 remained undiagnosed (Jenny et al, 1999)

Children With TBI and School

- USDOE: Only 9,500 children with TBI were receiving special education in 1996
- Many states report no students with TBI in their special education systems

Typical Misclassification of BI

- **Learning disability**
- **Emotional disability**
- **“Late” onset attention deficit**
- **No classification**

Low “Incidence” of BI in Schools?

- Majority of students (85%) have mild BIs which often remain unidentified
- Children “fall through the cracks” due to lag onset of academic difficulties
- Parents are unaware of long term and developmental nature of TBI symptoms
- Many schools do not have personnel trained to identify BI

Delayed Consequences of BI

- Minimized by professionals
- Unknown to parents
- Not causally linked to future academic failures
- Not causally linked to future behavioral problems
- Misattributed to other etiologies

Negative Consequences of Misclassification

- Eroding academic performance
- Inappropriate classroom accommodations and placements
- Increasing conflict between parents and school
- Increasing demoralization of the student
- School failure/drop out

Children with Moderate-Severe BI

- Are more likely to be classified in the schools
- School often ill equipped to implement accommodations needed
- School fails to monitor and shift accommodations as emerging educational challenges arise
- Increased risk of school failure as the student ages in the system

Physical Changes:

- Seizures
- Paralysis/spasticity
- Chronic pain
- Sleep disorders
- Fatigue
- Appetite changes
- Regulation of body temperature
- Headaches

Changes in Sensory Functions:

- Vision
- Hearing
- Smell
- Taste
- Touch
- Balance

Changes in Thinking Skills

- Attention
- Concentration
- Memory
- Speed of processing
- Impulsiveness
- Language processing
- “Executive” functions

Changes in Social-Emotional Functions:

- Dependent/regressive behaviors
- Mood swings
- Depression or anger
- Irritability / aggression
- Dis-inhibition / risk taking behaviors

Key TBI Screening Questions

- Known event(s) in which the child has experienced a significant blow to the head
- Blow to head accompanied by altered mental state or loss of consciousness
- Physical, thinking, and emotional/behavioral changes after the event

Neuropsychological Assessment

- Child may have had a prior TBI, and is now experiencing declines in grades
- Child with potential BI exhibits increased behavioral symptoms
- Child with potential BI has significant difficulty in transitions to new school environment

Services Provided

- Information and Outreach
- Services to Individuals and Families
- Advocacy
- Prevention

Information & Outreach

- Brain Injury Information and Resource Clearinghouse
 - Community Outreach/Family Help Line
 - Chapters and Support Groups
 - Library
 - Publications
 - Art Show
 - Brain Injury Awareness Month
 - Regional Networks
- Annual Conferences
- Professional Conferences

Services to Individuals & Families

- Family Advocacy, Counseling and Training Services Program (FACTS)
- Adolescent Peer Support Network
- Mentoring Partnership Program
- Building Rural Capacity
- Emergency Medical Services Demonstration Program

Advocacy Services

- Legislative Advocacy
- Involvement with Policy Makers
- Skills Development

Prevention Services

- Kids on the Block
- Saved by the Helmet Club
- Get the Helmet Habit

FACTS Program

- Individuals injured before age 22
- Supportive Counseling
- Service Coordination
- Advocacy
- Education and Training
- Prevention

Does Your Child Have...

- Headaches or seizures
- Changes in physical health
- Changes in mood, personality or behavior
- Problems communicating, paying attention or thinking
- Any other problems that concern you

What To Do

- Ask your child's doctor to recommend an expert in brain injury
- Evaluation by a pediatric physiatrist
- Evaluation of behavior, thinking and communicating by a neuropsychologist
- Call the Brain Injury Association of New York State

Preventing Falls

- Provide supervision
- Never leave infant unattended on changing table or other furniture where there is danger of a fall
- Never use a baby walker on wheels.
- Use safety gates at top & bottom of stairs
- Lock all unopened windows
- Open windows from top, not bottom
- Consider installing window guards
- Don't allow children to sit on ledges

Prevention Motor Vehicle Injury

- Use properly installed child safety seats.
 - Children under 12 always in back seat
 - Children > 20 lbs rear-facing car seat
 - Never put an infant in front seat with side or passenger side air bag
 - Children 21- 40 lbs in forward-facing car seats
 - Children 41- 80 lbs in car booster seat

Preventing Pedestrian Injury

- Hold child's hand when crossing street
- Never let children cross between parked cars
- Always have children walk on sidewalks, facing traffic & not on the shoulder of road
- Teach children to look from left to right when crossing streets & watch for turning cars
- Wear reflective clothing after dark

Preventing Injuries

- Never shake an infant or small child
- Wear helmets when playing sports
- Secure and unload firearms
- Engage in non-violent conflict resolution

Contacting BIANYS

(800) 228-8201 (HELP LINE)

Email: info@bianys.org

Website: www.bianys.org

Next In Safe Baby Series

Reducing Risk of Sudden Infant Death Syndrome

March 25, 2003

1:30 pm – 2:30 pm

**To Obtain A Copy of
This Program**

Contact

Susan.Avery@dfa.state.ny.us