LIVING WITH BRAIN INJURY:

A Guide for the Family of a Child with a Traumatic Brain Injury

2006 Edition

Brain Injury
Association
of America

www.biausa.org

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Address reprint requests to:
Brain Injury Association of America
703-761-0750
www.biausa.org

Brain Injury Association of America

Founded in 1980, Brain Injury Association of America (BIAA) is the nation's leading organization serving and representing individuals, families, and professionals who are touched by a life-altering, often devastating, traumatic brain injury (TBI). Encompassing a network of more than 40 state affiliates, BIAA remains steadfast in its mission to create a better future through brain injury prevention, research, education, and advocacy.

The Association envisions a world where all preventable brain injuries are prevented, all unpreventable brain injuries are minimized, and all individuals who have experienced brain injury maximize their quality of life.

By disseminating service information and resources, participating in legislative advocacy, facilitating prevention awareness, hosting educational programs and encouraging research, the Brain Injury Association of America and its affiliates work to reach the millions of individuals living with the "silent epidemic" of brain injury.

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Disclaimer

Brain Injury Association of America (BIAA) does not endorse or recommend any methods, treatments, or programs which may be referenced in this publication. The Brain Injury Association of America disclaims any liability arising from use of information in this booklet. The Association recommends that individuals with brain injury and their families use this booklet as a resource and adapt the information to their specific needs. BIAA recommends that persons with brain injury, their family members, and other care-givers consult with professionals to determine the best options to meet their individual needs.Living with Brain Injury

A Guide for the Family of a Child with a Traumatic Brain Injury

Contents

Introduction

Brain Injury Association of America created this guide to provide basic information for families who have a child with a brain injury, caregivers, educators, professionals, friends, and associates.

The guide defines brain injury and addresses the causes and consequences of brain injury. The guide also outlines the rehabilitation and community support options that may be available to families of children in the post-acute phase of recovery (that is, after the child's discharge from the hospital).

The term brain injury is used throughout this publication for both acquired brain injury and traumatic brain injury. When references are made specifically to injury caused by trauma due to external physical force, the term traumatic brain injury is used.

Chapter 1: **What is a Brain Injury**

- Definition of Brain Injury
- Signs of Brain Injury

Definition of Brain Injury

A traumatic brain injury (TBI) is defined as a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Not all blows or jolts to the head result in TBI. Brain injuries range from mild (resulting in a brief change in mental status or consciousness) to severe (resulting in an extended period of unconsciousness or loss of memory, called amnesia). TBI can result in short- or long-term problems with a child's ability to function on his or her own, and the child may require help from others.

The Individual with Disabilities Education Act (IDEA) defines TBI as follows:

A TBI is an acquired injury to the brain caused by an external physical force that adversely affects a child's educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.

Source:

Fact Sheet 18 (FS18): Traumatic Brain Injury adapted and reprinted with permission from:
National Dissemination Center for Children with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013
800-695-0285
202-884-8441 (fax)
nichcy@aed.org
www.nichcy.org

Signs of Brain Injury

The signs of brain injury can be very different depending on which part of the brain is injured and how severely. A child with a brain injury may have one or more difficulties, including:

Physical disabilities

Children with brain injury may exhibit physical problems such as:

- Difficulty in speaking, seeing, hearing, and using other senses
- Headaches
- Fatigue or lethargy
- Trouble with skills such as writing or drawing
- Spasticity: The child's muscles may suddenly contract or tighten.
- Seizures
- Impaired balance and ability to walk
- Partial or complete paralysis on one or both sides of the body
- Aphasia (impaired ability to speak or comprehend words)
- Ataxia (loss of muscle coordination)
- Impaired or limited sight and/or hearing

Difficulties in thinking

Because the brain has been injured, it is common that the child's ability to use the brain changes. A child with a brain injury may experience trouble in the following areas:

- Short-term memory (being able to remember something from one minute to the next)
- Long-term memory (being able to remember information from a while ago, such as facts learned last month)
- Concentration: The child may only be able to focus his or her attention for a short time.
- Talking and listening to others
- Reading and writing
- Planning and sequencing (understanding the order in which events happen)
- Judgment: The injury may impair the child's ability to think before acting and to make the correct decisions.

Social, behavioral, or emotional problems

The child may demonstrate:

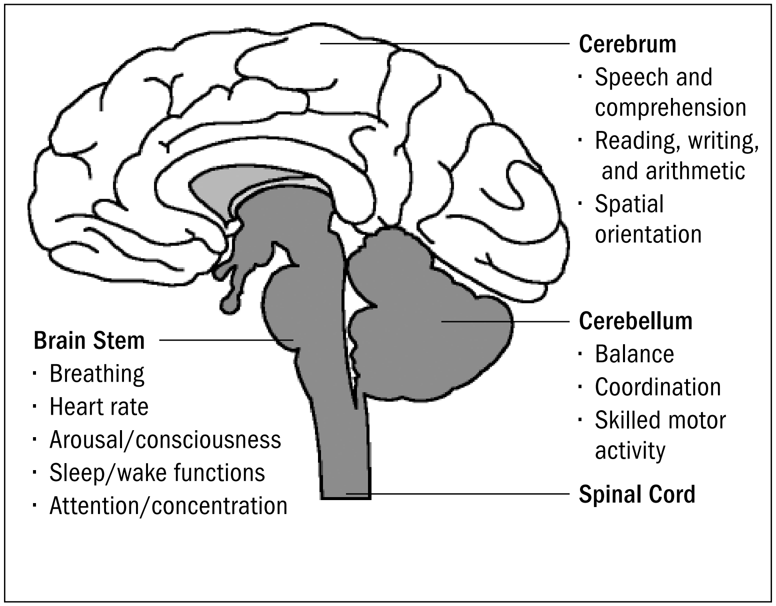
- Sudden changes in mood
- Increased irritability, anger, and temper tantrums
- Impulsive or inappropriate behavior and lack of inhibition
- Trouble relating to others
- Restlessness
- Excessive laughter or crying
- Anxiety: The child may fear that the traumatic event will happen again, feel uneasy about facing new challenges with family, friends, and teachers, or worry about how the injury will affect his or her future.
- Depression: The child may be saddened about impairments that affect his or her participation in the classroom or on the playground, or feel depressed about how the injury affects his or her status among family members and peers (friends may shy away).

Chapter 2: **How the Brain Works**

- The Brain and Its Functions
- Brain-Behavior Relationships

The Brain and Its Functions

The brain is only the size of a grapefruit and weighs about three pounds, yet it controls all functions of the body, including walking, talking, and eating. It controls functions that occur naturally, such as breathing and circulation, as well as the senses, such as sight, smell, and touch. The brain also performs more complex, higher-level functions such as thinking, learning, reading, and remembering.



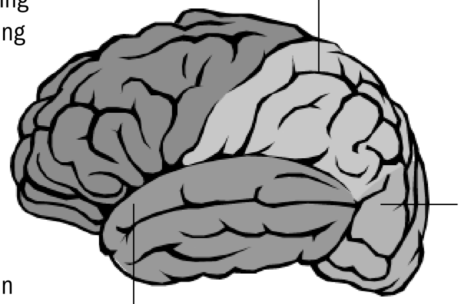
The brain has three main regions: the cerebellum, brain stem, and cerebrum (which itself has two halves). All three regions work together, yet each has its own special functions. Most brain injuries affect several areas of the brain.

Brain Stem: The brain stem is about the size of a little finger. It sits at the base of the brain, and extends from the spinal cord; 12 cranial nerves run from it through the brain. It governs two main arenas: basic life functions (respiratory and cardiac) and arousal (alerting the thinking part of the brain). Damage to the brain stem may cause reduced arousal and alertness and impairment in breathing, heart rate, and sensation of touch.

Cerebellum: The cerebellum lies under the lower back of the skull, has a right and a left side, and is about the size of two large plums. It has two main functions: balance of the body and coordination of the body's movements. Damage to this area may cause difficulties in coordination and difficulties with balance (for walking and standing).

Cerebrum: The cerebrum is the largest part of the brain. It has two regions (or halves): left and right. The left side generally controls movement and receives messages from the right side of the body. The right side controls movement and receives messages from the left side of the body. The dominant side, which is usually on the left (for right-handed people), controls speech, understanding, reading, writing, arithmetic, and other language functions. The nondominant side, usually the right hemisphere, is involved in processing information that is not verbal. This includes spatial orientation, relationships of objects to each other, and recognition of shapes, forms and faces. The cerebral hemispheres are further developed into four sections: parietal, frontal, temporal, and occipital.

Brain – Behavior Relationships



Frontal Lobe
- Initiation
- Problem solving
- Judgment
- Inhibition of behavior
- Planning/anticipation
- Self-monitoring
- Motor planning
- Personality/ emotions
- Awareness of abilities/ limitations
- Organization
- Attention/ concentration
- Mental flexibility
- Speaking (expressive language)

Parietal Lobe
- perception of spatial relationships
- Sense of touch
- Perception and interpretation of sensory input

Occipital Lobe
- Vision

Temporal Lobe
- Memory
- Hearing
- Understanding language (receptive language)
- Organization and ordering of thoughts or events

Chapter 3: **Facts About Brain Injury**

- Brain Injury Statistics in Children
- Causes of Brain Injury

Brain Injury Statistics in Children

Each year in the United States, 1.4 million people sustain a traumatic brain injury; of these, 475,000 are children. TBI is the leading cause of death and disability among children ages 14 and under in the United States. Each year, about one in 500 children sustains an injury to the brain serious enough to require hospitalization. Young people between the ages of 15 and 19 are the group most likely to sustain a TBI. Boys are twice as likely as girls to sustain a TBI, due to a variety of possible factors: They spend more time playing sports, have more exposure to traffic, and generally engage in more risk-taking behavior.

- An estimated 3,000 children and youth die from TBI each year.
- 29,000 children and young people are hospitalized due to TBI each year.
- 400,000 children and youth are treated for TBI-related injuries in hospital emergency departments each year.

By age 16, about four out of every 100 boys and 2.5 out of every 100 girls have sustained a TBI.

Causes of Brain Injury

Falls are the leading cause of TBI across all age ranges. Other causes include motor vehicle accidents, sports-related injuries, gunshot wounds, and physical abuse including Shaken Baby Sudden Impact Syndrome.

- Children four years old and younger are most likely to be injured in falls.
- Five- to 19-year-olds are most likely to be injured in transportation-related accidents.
- 15- to 19-year-olds have the highest rate of firearm-related injuries

Children may experience an acquired brain injury (ABI) as the result of tumors, strokes, infections, illness, or loss of oxygen. Traumatic brain injuries are a subset of acquired brain injuries.

Chapter 4: **Home from the Hospital: The Transition Process**

- Intervention Strategies
- Types of Strategies

Intervention Strategies

Brain injuries can range from mild to severe, and so can the changes that result from the injury. This makes it hard to predict how a child will recover from the injury. Early and ongoing help can make a big difference in how the child recovers. A variety of intervention strategies can aid the child during recovery. Parents can talk to a clinical psychologist about choosing the right strategies for their child.

As the child develops, parents may notice new problems. This is because as children grow, they are expected to use their brain in new and different ways. The damage to the brain from the injury, as well as injuries that have occurred since the original traumatic event, can make it hard for children to learn new skills they need as they grow older. New and unexpected problems may also become evident during the hormonal changes of puberty and adolescence. In all of these cases, intervention strategies can help.

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Types of Strategies

Memory Strategies

- Break down new information into smaller units or individual steps.
- Repeat new material to aid acquisition.
- Rehearse and visualize through active instruction.
- Errorless Learning: When an error occurs, the child is given nonjudgmental corrective feedback, reducing the number of incorrect answers.

Attention Strategies

- Use a small, self-contained setting.
- Reduce distractions.
- Structure and maintain a routine.
- Keep instructions simple and clear.

Visual Processing Strategies

- Have an ophthalmologist conduct an eye examination following the injury and annually thereafter.
- Simplify the visual environment to reduce visual distractions.
- Use computers and other assistive technology.
- Remind and supervise.

Executive Functions Strategies

- Provide choices; for example: “Do you want to go outside to play or stay inside to play?”
- Model goal-setting and problem-solving by thinking out loud with the child.
- Break large tasks into a series of smaller, more manageable tasks.
- Encourage self-monitoring of tasks and/or behaviors.
- Use notes and lists as memory aids. Model this list-making behavior for your child.

Language Strategies

- Monitor the quality of the child’s conversations.
- Provide instructions and directions that the child can comprehend.
- Organize and sequence information.
- Teach the child to be aware of other people’s reactions and/or breakdowns in communication.

Behavior Strategies

- Look out for the conditions that can trigger behavioral problems (such as fatigue or over-stimulation).
- Establish clear rules and make sure the child understands the rewards for following them and the consequences of breaking them. Give praise for correct behavior.
- Set limits: Acknowledge the child’s feelings, clearly communicate boundaries, and define acceptable alternatives.
- Have calming activities ready or a quiet place for the child to go when he or she becomes frustrated or distressed.
- Stay calm and try not become angry with the child. Yelling is counter-productive.

These strategies are adapted from Lisa Schoenbrodt, ed., *Children with Traumatic Brain Injury: A Parent’s Guide* (Bethesda: Woodbine House, 2001).

Chapter 5: **Returning to School: The Transition Process**

- Individual with Disabilities Education Act (IDEA)
- Education Implications
- The Individual Education Plan (IEP)
- An Ever-Changing Process

Individual with Disabilities Education Act (IDEA)

In October 1990, the Individual with Disabilities Education Act (IDEA) was amended to include traumatic brain injury as a disability category for students requiring special education services.

Education Implications

Although brain injury is very common, many health care and education professionals may not realize that some difficulties can be caused by a childhood brain injury. When a child with a brain injury returns to school, his or her educational and emotional needs are often very different from what they were before the injury. Often, students with brain injuries are thought to have learning disabilities, emotional disturbances, or mental retardation. As a result, they don't receive the educational help and support they need.

Planning for the child's return to school should begin immediately after the child is injured. Hospital and/or rehabilitation staff should immediately inform the school that the student has sustained a brain injury. The family and/or attending physician should formally request that a representative from the child's school come to the hospital and evaluate the child. Under the IDEA, any one of three individuals — the parent, the child's physician, or one of the child's teachers — can refer a student for an evaluation to determine the need for special education services.

The Individual Education Plan (IEP)

After determining that the child has a traumatic brain injury and needs special education services, the school can begin to develop the Individual Education Plan (IEP).

The IEP is the written contract between the student's family and the school system designating the kinds and extent of services the student needs. It outlines an instruction program for the student and can be reviewed and revised annually.

In the case of the child with a mild brain injury, a full-fledged special education plan may not be necessary. The student may need to be monitored and have his or her schedules modified for a time to insure that no new neurological signs are demonstrated in the classroom.

For a child with a more severe brain injury, the medical and educational systems need to work closely together and ease the transition from hospital to school. To aid the school reentry process, everyone involved — teachers, classmates, and administrative and support staff — needs to be prepared for potential behavioral, emotional, and cognitive changes in the child.

Parents will want to find out ahead of time about special education services at the school. This information is usually available from the school's principal or special education teacher. Special education eligibility varies from state to state. Parents can sometimes work with the school on coordinating a "homebound program," in which children can receive tutoring at home during extended absences from school.

A key part of the IEP process is the duration and timeliness of the educational plan. A child with a brain injury will have changing needs over the school year. Therefore, the IEP needs to demonstrate changing goals and timelines as the child changes and improves.

It's important to remember that the IEP is a flexible plan. It can be changed as the parents, the school, and the student learn more about what the student needs at school. The IEP should explain and describe:

- the student's current performance level
- his or her annual goals
- the means by which the student will meet these goals
- special-education needs and related service needs
- τransition service needs

An Ever-Changing Process

As the child develops, so do the challenges, demands, and experiences in school. These new demands and challenges will affect each child differently, depending on the severity of the injury and the school demands placed on the child. As the child's brain is continually developing, the effect of the injury will most likely continue to change for years.

Parents indicate that a child's success in coping and progressing with a TBI is often dependent on his or her teachers: their understanding of the brain injury and its impact on learning; their collaboration with parents in addressing problems; and their commitment to accommodate the child's injury.

It is important for parents, teachers, and physicians to keep the lines of communication open and monitor progress, particularly if new behaviors emerge. The student's family and school need to be prepared to meet new challenges as the transition process continues:

- Teachers may need to reconfigure classrooms to meet the student's learning needs.
- The school may need to set up counseling supports to help the student discuss his or her feelings and learn ways to fit in socially. Teachers must be vigilant about teasing and bullying and must make sure that classroom activities are as inclusive as possible.
- The student may require additional occupational, speech, and physical therapy to be integrated into his or her school schedule.
- Teachers may need to provide additional study guides and additional time for assignments. They may need to use specific cognitive and behavioral strategies to enable the student to learn better.

As the child progresses through adolescence, it is important to collaborate with vocational services, independent living centers, community advocacy programs, and other support systems. The support systems for a smooth transition into the community need to be established prior to graduation from high school.

For more information on life after high school, please refer to: Donald R. Hood, Bonnie Todis, and Ann Glang, *Preparing for Life after High School: The Next Steps* (McLean, VA: Brain Injury Association of America, 2006).

Chapter 6: **How Parents and Teachers Can Help**

- Tips for Parents
- Tips for Teachers

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Tips for Parents

- Learn about TBI. The more you know, the more you can help yourself and your child. See the list of resources and organizations at the end of this publication.
- Work with the medical team to understand your child's injury and treatment plan. Don't be shy about asking questions. Tell them what you know or think. Make suggestions.
- Keep track of your child's treatment. A three-ring binder or a box can help you store this history. As your child recovers, you may meet with many doctors, nurses, and others. Write down what they say. Put any paperwork they give you in the binder or box. You can't remember everything! If you need to share paperwork, make a copy — don't give away your original.

- Talk to other parents whose children have TBI. They can share practical advice and emotional support. Contact your state Brain Injury Association to locate the parents' group nearest you. For a list and contact information, visit BIAA's Web site at www.biausa.org.
- If your child was in school before the injury, plan for his or her return to school. Ask the school to test your child as soon as possible to identify his or her special education needs. Ask the principal about special education services. Have the medical team share information with the school. Meet with the school and help develop your child's Individualized EducationProgram (IEP).
- Be your child's advocate. Keep in touch with your child's teacher and make sure the school staff understands the child's needs. Meet in person at the school. Tell the teacher how your child is doing at home. Ask how your child is doing in school. Work with your child's teacher to address learning and behavioral issues.

Tips for Teachers

- Find out more about TBI. Learn as much as you can about the child's injury and his or her present needs. See the list of resources and organizations at the end of this publication.
- Give the student more time to finish schoolwork and tests.
- Give directions one step at a time. For tasks with many steps, it helps to give the student written directions.
- Show the student how to perform new tasks. Demonstrate, if possible. Give examples to go with new ideas and concepts.
- Have consistent routines. This helps the student know what to expect. If the routine is going to change, let the student know ahead of time.
- Check to make sure that the student has actually learned the new skill. Give the student lots of opportunities to practice the new skill.
- Show the student how to use an assignment book and a daily schedule. This helps the student get organized.
- Realize that the student may get tired quickly. Let him or her rest as needed.
- Reduce distractions.
- Keep in touch with the student's parents. Share information about how the student is doing at home and at school.
- Be patient with the student and with his or her parents as well, as everyone is learning about TBI and how it affects learning and behavior. Be flexible about what is expected of the student, but also keep in mind that many children exceed expectations. Maximize the student's chances for success.

Chapter 7: **Resources and Organizations**

Resources

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Organizations

Brain Injury Association of America
8201 Greensboro Drive, Suite 611
McLean, VA 22102
Telephone: 703-761-0750; 800-444-6443 (Family Helpline)
E-mail: FamilyHelpline@biausa.org
Web site: www.biausa.org

Emergency Medical Services for Children — National Resource Center
111 Michigan Avenue N.W.
Washington, DC 20010
Telephone: 202-884-4927
E-mail: information@emscnrc.com
Web site: www.ems-c.org/

Epilepsy Foundation — National Office
4351 Garden City Drive, Suite 500
Landover, MD 20785-7223
Telephone: 301-459-3700; 800-332-1000
Web site: www.epilepsyfoundation.org

Family Caregiver Alliance
180 Montgomery St., Suite 1100
San Francisco, CA 94104
Telephone: 415-434-3388; 800-445-8106
E-mail: info@caregiver.org
Web site: www.caregiver.org

Family Voices
2340 Alamo SE, Suite 102
Albuquerque, NM 87106
Telephone: 505-872-4774; 888-835-5669
E-mail: kidshealth@familyvoices.org
Web site: www.familyvoices.org

U.S. Department of Health and Human Services
Health Resources and Services Administration
Maternal and Child Health Bureau
Parklawn Building Room 18-05
5600 Fishers Lane, Rockville, Maryland 20857
Web site: www.mchb.hrsa.gov

National Association of State Head Injury Administrators
4330 East West Highway, Suite 301
Bethesda, MD 20814
Telephone: 301-656-3500
E-mail: nashia@nashia.org
Web site: www.nashia.org

National Dissemination Center for Children with Disabilities
P.O. Box 1492
Washington, DC 20013
Telephone: 800-695-0285
Web site: **nichcy@aed.org**

Oregon Center for Applied Science, Inc. (ORCAS)
260 E 11th Ave.
Eugene, OR 97401
Telephone: 888.349.5472
E-mail: info@orcasinc.com
Web site: www.orcasinc.com

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