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# Traumatic Brain Injury: Information for Parents

BY MATTHEW J. HOLCOMB, & ANDREW S. DAVIS, PHD, *Ball State University, Muncie, IN*  
RIK CARL D'AMATO, PHD, *Northern Colorado University, Greeley*

A traumatic brain injury (TBI) is an injury to the brain that was not present at birth. TBIs are defined as either open or closed injuries. An open-head injury typically involves a penetrating object of some sort (e.g., a bullet), while a closed-head injury is usually caused by the child's brain moving within the skull as a result of a fall or crash-type injury (e.g., car accident, abuse, sports). Brain injuries most frequently occur in children and adolescents and are more common in males than females.

More than one million children experience a TBI in the United States annually, with approximately 165,000 requiring hospitalization. About 30,000 children sustain brain injuries that result in lifelong impairments each year. TBIs are the leading cause of death and disability in children and adolescents in the United States, and account for more deaths than any other factor in individuals under the age of 35. The most frequent causes of TBIs are vehicular accidents, sports, falls, and abuse or assault. Repeated TBIs can lead to significantly poorer prognosis for recovery and can actually increase the chance of subsequent TBIs.

This handout is intended to help parents better understand and appreciate the characteristics of TBI, what to expect if their child has sustained a TBI, and what appropriate interventions are available to meet the needs of children with TBIs.

## **IMPACT OF TBI**

TBIs are classified by severity and include mild, moderate, or severe injuries. The vast majority (50–75%) of TBIs fall into the mild category. The Brain Injury Association refers to TBI as “the silent epidemic,” because many children have no visible impairments following a head injury, especially when the TBI is mild. Indeed, in many cases of mild TBI, children are not taken to a hospital or may be sent home without the TBI being fully identified or understood. If the child has experienced a TBI, then symptoms will vary based on the extent of the injury, location of injury, secondary complications, and factors related to risk and resiliency.

Experiencing a TBI may alter how a child acts, thinks, or moves. These changes may cause profound shifts in how the child learns or behaves in school or at home. These transformations can range from mild impairment in one area to broad deficits in global functioning. Some of the changes parents might see in their child include:

- *Cognitive impairments*, which include short- or long-term memory problems, difficulties in concentration, attention problems, deficits in planning and problem solving, impairment of judgment, and difficulties with tasks requiring information processing, such as reading and listening
- *Behavioral changes*, which include improper interpretation of social cues, defiance, lying, restlessness, temper tantrums, changes in sleep patterns, lethargy, fatigue, withdrawal from family/friends, and hyperactivity
- *Physical impairments*, which include speech, vision, or hearing difficulties; other sensory impairments; headaches; paralysis or muscle weakness; seizures; balance problems; gait changes; nausea; need for support devices in standing or walking; and lack of motor coordination
- *Academic difficulties*, which include communication deficits, delayed reading skill acquisition, problems in math, slowed thinking, inconsistent classroom participation, difficulties in sequencing, loss of interest in school, messy handwriting, poor test performance, failure in some subjects with success in others, and grade retention or failure to meet graduation requirements
- *Personality changes*, which include difficulty controlling emotions, irritability, agitation, depression, anxiety, impulsiveness, mood swings, increased use of drugs and/or alcohol, and reduced self-esteem

Regardless of the changes that the child experiences following a TBI, in most cases there will be substantial improvement over time. In fact, much of the recovery from a TBI occurs within the six months immediately following the injury. However, approximately 20–40% of children who experience a TBI will have some type of permanent impairment in at least one area of functioning.

### **EDUCATIONAL SUPPORTS AND SERVICES**

Many education professionals are unaware of the consequences of a TBI. Especially in cases where the TBI was mild, missed, or mislabeled, it is common for the child to be misclassified as having a learning disability, attention deficit hyperactivity disorder (ADHD), or an emotional or behavioral disorder. If the child is misdiagnosed, then he or she may have difficulty in accessing appropriate educational interventions and services.

Children with a TBI require comprehensive evaluations, including assessments of neuropsychological, speech and language, educational, and motor skills. For children who are found eligible for special education services, these evaluations should be used in the development of an appropriate Individualized Educational Program (IEP; the written plan for special services). Some children with mild TBIs, while not meeting state and federal criteria for special education, might nevertheless meet criteria for accommodations and modification under a Section 504 Plan (a service mandated by the Rehabilitation Act) as individuals with disabilities that interfere with everyday activities such as school performance. The IEP or Section 504 Plan will serve as a guide for teachers and other school personnel to best teach and interact with the child.

Whenever possible, the IEP or 504 Plan should be established before the child re-enters the school setting following a TBI. Parents will need to meet with school personnel in order to plan for the child's return to school well before his or her first day back. Parents may need to ask that direct supervision be provided to the child when necessary (e.g., in between class times, before and after school, restroom, lunch). Teachers need to recognize that a child's short-term memory and attention may be impaired. Additionally, inservice training may need to be provided for school personnel who will be working directly with the child. Services from school psychologists, school counselors, and social workers can also assist in supporting the students' social and emotional needs. Other modifications that might be needed to support the child with a TBI include:

- A distraction-free work environment (smaller class setting, quiet work area)
- Simple directive language using concrete vocabulary when providing instruction and directions

- Additional time for task completion
- Teaching of compensatory strategies specific to memory
- Strategies to address increased fatigue and the need for frequent breaks

Parents should not be shy about requesting flexibility and ongoing communication in designing supports for their child with TBI. Neither an IEP nor Section 504 Plan is a permanent document, and can be reviewed upon parent request. Parents and families also need to maintain flexibility and monitor and adjust their expectations regarding the child's academic performance.

### **INTERVENTION STRATEGIES FOR PARENTS**

Having a child with a TBI can be disruptive to the entire family and it may be difficult for siblings and other family members to adjust to needed changes. Yet there are many ways that families can support a child with TBI and in the long run help the family and child return to a more normal life.

#### **Learn More About TBI**

Parents are their child's best advocate. The more parents know and understand about TBI, the better equipped they will be in helping the child navigate the school and community environment. Consult resources and organizations for additional information on medical, educational, social, and family information regarding TBI (see Recommended Resources).

#### **Collaborate With Physicians and School Personnel**

- Be an active participant in understanding the child's injury and treatment plan.
- Ask questions and make sure that your opinions and voices are heard.
- Make suggestions and act as an advocate for your child.
- Communicate with medical and school personnel. It is important that both parents and physicians know how the child is doing at school after a TBI. Stay in contact with educators and find out how your child adjusts to the return to school. It may be helpful to do this in person, but many times a phone call, e-mail, or a progress report/letter sent home with the child will be sufficient for parents to track the progress of the child. Communication will continue to be important long after the initial adjustment period.
- Gather information from the medical professionals who treated your child and share it with school personnel, particularly information about physical limitations that require adjustments in his or her school day.

- Do not assume that school personnel have more information than you do about TBI! Often parents come across new ideas from physicians and their own research as they seek to stay informed. School personnel might benefit from what you learn.

### Keep Organized Records

There will be a large amount of documents and records concerning the treatment and diagnoses of children with TBI. It is not uncommon for parents of children with TBIs to meet with a variety of professionals including doctors, nurses, teachers, special education directors, school specialists, and many others.

- Keep a folder, box, or binder to store important information to help in treatment planning.
- Write down what is said at conferences and take notes about any specific plans for your child.
- Keep track of reports describing the results of assessments and records of your child's progress.
- If medical or school personnel ask for documents, be sure to keep the original and provide others with a copy.

### Meet and Share With Other Parents

Parents may feel like they are the only one going through the recovery from TBI, but this is not the case. Seek out and talk to other parents whose children have TBI. There are parent activist groups all over the United States and Canada that can help by sharing advice and giving parents emotional support. There are many resources, such as the Brain Injury Association of America, that may help parents gain more information and support about TBI (see Recommended Resources).

### Seek Family Resources

Remember that family and friends can be a tremendous source of support. Be aware of your own frustration levels around the child, and ask for help when the situation demands it. Due to the stress that a TBI can create for the whole family, parents and siblings often benefit from talking to a mental health professional.

### Monitor the Child's Performance

- *Monitor homework:* The child's academic performance may change after the TBI. Additionally, many children with TBIs suffer from poor organization, and attention and motivation problems, all skills important for completing and turning in homework. If you notice difficulties, talk to teachers about possibly modifying homework demands or ask for ideas to help support homework completion. Keep in mind that homework

difficulties may be symptoms of more significant difficulties with academic tasks that require assessment and possibly other services.

- *Monitor fatigue:* Children and adolescents who have experienced a TBI commonly report tiring easily and feeling fatigued. Therefore, parents may need to alter the length of their activities, change previously established schedules, or simply monitor the energy level of the child.

## RECOMMENDED RESOURCES

### Print

Brain Injury Association of America. (2007). *Facts about traumatic brain injury* (DHHS Cooperative Agreement U 93 MC 00010-05-03). Washington, DC: U.S. Government Printing Office.

Hibbard, M., Gordon, W., Martin, T., Rashkin, B., & Brown, M. (2001). *Students with traumatic brain injury: Identification, assessment, and classroom accommodations*. New York: Research and Training Center on Community Integration of Individuals with Traumatic Brain Injury.

High, W. M., Sander, A. M., Struchen, M. A., & Hart, K. A. (Eds.). (2005). *Rehabilitation for traumatic brain injury*. New York: Oxford.

Schoenbrodt, L. (2001). *Children with traumatic brain injury: A parent's guide*. Bethesda, MD: Woodbine House.

Semrud-Clikeman, M. (2001). *Traumatic brain injury in children and adolescents*. New York: Guilford Press.

### Online

Head Injury Hotline: <http://www.headinjury.com>

Research and Training Center on Community Integration of Individuals With Traumatic Brain Injury: <http://www.mssm.edu/tbinet>

### Organizations

Brain Injury Association: <http://www.biausa.org>; 1776 Massachusetts Avenue NW, Suite 1000, Washington, DC 20036; (800) 444-6443 (Family Helpline); (202) 296-6443

Epilepsy Foundation of America: <http://www.efa.org>; 4351 Garden City Drive, Suite 406, Landover, MD 20785; (301) 459-3700; (800) 332-1000; (800) 332-2070 (TTY); [postmaster@efa.org](mailto:postmaster@efa.org)

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*Matthew J. Holcomb is a graduate student and Andrew S. Davis, PhD, is an Assistant Professor at Ball State University in Muncie, IN; Rik Carl D'Amato, PhD, is a Professor at the University of Northern Colorado in Greeley, CO.*

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