



LOS ANGELES CAREGIVER RESOURCE CENTER

Fact Sheet Traumatic Brain Injury

Introduction

Each year, an estimated 1.5 million people in the U.S. sustain a traumatic brain injury. The impact on their families and caregivers is immense. This fact sheet discusses traumatic brain injury (TBI) and its consequences, and provides information about the helpful resources available to families caring for a loved one affected by TBI.

Definition

Traumatic brain injury, also called brain injury or head injury, occurs when a blow or jolt to the head results in damage to the brain. TBIs range in severity from mild to severe.

Mild TBI occurs when a person has a brief change in mental status or loss of consciousness. The most common type of brain injury, a **concussion**, is classified as a *mild traumatic brain injury*. Mild TBI often goes undiagnosed and consequently the person suffering the injury loses out on the benefits of rehabilitation and medical care.

Severe TBIs may involve loss of consciousness for hours or weeks and can result in permanent disability. Any TBI, whether mild or severe, can result in short- or long-term disability.

There are many different types of traumatic brain injury, including:

- Concussions - the most common type of TBI
- Penetration injury - from bullets or other objects entering the skull
- Contusions - bleeding that results from blows to the head
- Diffuse axonal injury - damage from tearing of the brain tissue (includes shaken baby syndrome and some bicycle, car or motorcycle accident injuries)

Facts

- 5.3 million Americans, approximately 2% of the population, currently live with disabilities related to brain injury.

- Males are more than twice as likely as females to experience a TBI.
- TBI is most common among adolescents (aged 15-24) and older adults (75 and older).
- The most common causes of TBI:
 - Motor vehicle collisions
 - Falls
 - Violence
 - Sports
- Research has shown that approximately 85% of head injuries from bicycle accidents can be prevented with the use of helmets.

Consequences

A TBI may result in mild, moderate or severe changes in one or more areas, including thinking, speech, physical functions and social behavior. The consequences of TBI can be lifelong for some people, while others may be able to recover and resume activities they enjoyed before the injury occurred.

A partial list of **Cognitive Changes** (or **Changes in Thinking**) which can occur due to a brain injury include:

- Shortened attention span
- Memory problems
- Problem-solving difficulties
- Poor judgment
- Partial or complete loss of reading and writing skills
- Language problems, including communication deficits and loss of vocabulary
- Inability to understand abstract concepts
- Difficulty learning new things

Some of the **Physical Changes** that can occur due to a brain injury include:

- Weakness
- Muscle coordination problems
- Full or partial paralysis
- Changes in sexual functioning
- Changes in the senses (hearing, sight, touch, etc.)
- Seizures (also called traumatic epilepsy)
- Sleep problems
- Speech difficulties

Personality and Behavioral Changes may be subtle or severe and include:

- Difficulty with social skills
- Inability to empathize with others
- Tendency to be more self-centered
- Inability to control one's emotions
- Increases in irritability and frustration
- Inappropriate and/or aggressive behavior
- Extreme mood swings
- Depression (individuals with TBI are considered to be at a high risk for depression)

For further information about how to cope with behavior problems that result from a TBI, see the FCA Fact Sheet “*Coping with Behavior Problems after Head Injury.*”

Prognosis (or Chance of Recovery)

It is difficult to predict how well someone who has had a brain injury will recover, partly because there is no test a doctor can use to predict recovery. The Glasgow Coma Scale is used to determine the initial severity of a brain injury. It is often used at the scene of the accident or in the emergency room. This scale uses eye movements and ability to speak and move other parts of the body to determine the seriousness of the injury. Ask your doctor to explain the tests used to determine your loved one’s ability to recover.

Your loved one’s prognosis will depend on many factors, including the severity of the injury, the type of injury, and what parts of the brain have been affected. Prompt diagnosis and treatment will help the recovery process.

Recovery Tips for People Who Have Had a TBI

The recovery process is different for everyone. Just as no two people are alike, no two brain injuries are alike. Recovery is typically lengthy—from months to years—because the brain takes a long time to heal. These tips, directed at the person with a brain injury, will help your loved one improve after the injury:

- Get lots of rest.
- Avoid doing anything that could cause another blow or jolt to the head.
- Ask the doctor when it's safe to drive a car, ride a bike, play sports or use heavy equipment, because reaction time may be slower after a brain injury.
- Take prescription medication according to the doctor’s instructions.
- Do not drink alcohol or use street drugs.
- Write things down to help with memory problems.
- Ask the doctor to recommend rehabilitation services that might help recovery, and follow those recommendations.

Rehabilitation

The goal of rehabilitation is to help your loved one live and function as independently as possible. Rehabilitation helps the body heal and assists the brain in relearning processes so that an individual recovers as quickly and efficiently as possible. Rehabilitation will also help the person with TBI learn new ways to do things if any previous abilities have been lost.

After your loved one’s initial life-saving treatment at the time of the injury, he or she will most likely start a rehabilitation program and will work with a team of specialists. The person with TBI and his or her family are the most important members of the rehabilitation team. Family members should be included in the rehabilitation and treatment as much as possible. Some of the other professionals who may be part of this team include:

- **Physiatrists** - doctors who are experts in rehabilitation medicine who typically oversee the rehabilitation process.

- **Neurologists** - doctors who are trained in the diagnosis and treatment of nervous system disorders, including diseases of the brain, spinal cord, nerves, and muscles.
- **Occupational, physical, speech and language therapists** - therapists that help the person regain thinking skills, communication skills, physical abilities and behavioral skills.
- **Neuropsychologists** - specialized psychologists who focus on thinking skills and behavior problems.
- **Vocational rehabilitation experts** - employment coaches who help with regaining job skills.

It is important to remember that rehabilitation may last years and that your loved one will benefit from the ability to receive rehabilitation services throughout this time. Appropriate programs and treatments will also change as your family member's needs change.

A variety of treatment and rehabilitation programs may help your loved one. Some of the different types of rehabilitation facilities include:

- **Acute rehabilitation** - an intensive rehabilitation program.
- **Coma treatment centers** - provide coma-specific medical care.
- **Transitional living programs** - nonmedical residential programs that teach skills for community living.
- **Long-term care and supervised living programs** - residential facilities that provide care and rehabilitation to people with TBI who are not able to live independently.
- **Behavior management programs** - typically community-based (i.e., not residential) programs that teach self-control and appropriate social behaviors.
- **Day treatment programs** - provide rehabilitation during the day so the person can return home at night.

The Brain Injury Association of America's *Guide to Selecting and Monitoring Brain Injury Rehabilitation Programs* is a good resource for figuring out what questions to ask a rehabilitation provider and can help in choosing a rehabilitation facility. The Brain Injury Association of America also publishes the *National Directory of Brain Injury Rehabilitation Services*, which lists services in each state.

Caregiving

When someone suffers a Traumatic Brain Injury (TBI), the entire family is affected. Studies show that caregivers of people who have suffered a brain injury may experience feelings of burden, distress, anxiety, anger and depression. If you are caring for a partner, spouse, child, relative or close friend with TBI, it is important to recognize how stressful this situation can be and to seek support services.

Services that may be most helpful to you include in-home assistance (home health aides or personal care assistants), respite care to provide breaks from caregiving, brain injury support groups, and ongoing or short-term counseling for caregivers to adjust to the changes that have come as a result of the injury. You also may need to ask your support system of family, friends and community members for help with your loved one's care, so that you don't get burned out. (See Family Caregiver Alliance's Fact Sheet: *Taking Care of YOU: Self-Care for Family Caregivers* for additional tips on taking care of yourself.)

In your role as a caregiver, you will probably find that it can be difficult to find appropriate and adequate services for your loved one. It is important to know that you will most likely need to be persistent in your search for assistance. You should use your network of family and friends, as well as professionals, to get tips about available resources.

Useful Resources & Services for Families Affected by TBI

Protection and Advocacy (P&A) System and Client Assistance Program (CAP)

This nationwide network of congressionally mandated disability rights agencies provides various services to people with disabilities, including TBI. P&A agencies provide information and referral services and help people with disabilities find solutions to problems involving discrimination and employment, education, health care and transportation, personal decision-making, and Social Security disability benefits. These agencies also provide individual and family advocacy. CAP agencies help clients seeking vocational rehabilitation.

For more information on P&A and CAP programs, contact the National Association of Protection and Advocacy Systems, Inc. at: www.napas.org or (202) 408-9514.

Traumatic Brain Injury Model Systems

Funded through the National Institute on Disability and Rehabilitation Research, the TBI Model Systems consist of 16 TBI treatment centers throughout the U.S. The TBI Model Systems have extensive experience treating people with TBI and are linked to well established medical centers which provide high quality trauma care from the onset of head injury through the rehabilitation process.

For more information on the TBI Model Systems, go to www.tbinc.org/main_centers.php or call (800) 248-3221 x4812 to find the center nearest you.

State Brain Injury Programs

Some states have developed programs to assist individuals with TBI. These programs are often called brain injury programs, task forces or advisory councils and are typically part of the state's Department of Rehabilitation or Health Services. To see if your state has any state-funded TBI programs that can be of assistance, check with the Brain Injury Association of America's State Affiliate at www.biausa.org (click on "State Affiliates"), or (800) 444-6443. You can also contact the TBI Technical Assistance Center, which provides information about TBI resources in each state-see www.tbitac.org/site/StateProfile.cfm or call (301) 443-5599.

Social Security Disability Insurance (SSDI) & Supplemental Security Income (SSI)

It is possible that your loved one may be entitled to SSDI and/or SSI. SSDI and SSI eligibility is dependent on a number of factors including the severity of the disability and what assets and income your loved one has. You should contact the Social Security Administration to find out more about these programs and whether your loved one will qualify for these benefits. For more information on SSDI and SSI, contact the Social Security Administration at www.ssa.gov or (800) 772-1213

Centers for Independent Living (CIL)

Some families have found that it is important to encourage their loved one with a TBI to continually learn skills that can allow them to live independently in the community.

The CILs exist nationwide to help people with disabilities live independently in the community and may have resources to help your loved one reach a goal of living alone. CIL services include advocacy, peer counseling, case management, personal assistance and counseling, information and referral, and independent living skills development. For more information on the CIL system, contact the National Council on Independent Living at www.virtualcil.net/cils or (703) 525-3406.

Recommended Readings

Living with Brain Injury: A Guide for Families, Second Edition. Richard Senelick, MD and Karla Dougherty. 2001: HealthSouth Press. ISBN#: 189152509-3

Traumatic Head Injury: Cause, Consequence and Challenge. Dennis P. Swiercinsky, Terrie L. Price and Lief Erick Leaf, 1993, Head Injury Association of Kansas and Greater Kansas City, 1100 Pennsylvania Ave., Suite 305, Kansas City, MO 64105. 1993. Kansas City: Brain Injury Association of Kansas.

Head Injury: Information and Answers to Commonly Asked Questions: A Family's Guide to Coping. Christopher D. Strum, MD, Thomas R. Forget, Jr., MD, and Janet L. Strum, RN. 1998: Quality Medical Publishing, St. Louis, MO. ISBN# 1-57626-096-8

Children with Traumatic Brain Injury: A Parent's Guide. Edited by Lisa Schoenbrodt, Ed. D. 2001: Woodbine House. ISBN#0-933149-99-9.

The HDI Coping Series and the HDI Professional Series on Traumatic Brain Injury, William Burke, Michael Wesolowski and William Blacker, 1996 (revised), HDI Publishers, 10131 Alfred Lane, Houston, TX 77041, (800) 321-7037.

Fact Sheet: Taking Care of YOU: Self-Care for Family Caregivers, Family Caregiver Alliance.
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=847

Fact Sheet: Coping with Behavior Problems After Head Injury, Family Caregiver Alliance.
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=396

Credits

Brain Injury Association of America. *Guide to Selecting and Monitoring Brain Injury Rehabilitation Programs.* (800) 444-6443.

Brain Injury Association of America. (2002). *National Directory of Brain Injury Rehabilitation Services: May 2002 - May 2003.* (800) 444-6443.

Brain Injury Association of America.
What Is Brain Injury? www.biausa.org/Pages/what_is_brain_injury.html

Brain Injury Association of America. Treatment and Rehabilitation.
www.biausa.org/Pages/treatment_and_rehab.html

National Institutes of Health. (1998). *Rehabilitation of Persons with Traumatic Brain Injury.* Consensus, NIH Consensus Statement. October 26-28, 1998.

Centers for Disease Control. Traumatic Brain Injury. *Fact Sheet. National Center for Injury Prevention and Control.* www.cdc.gov/ncipc/factsheets/tbi.htm

Vaughn, S.L. & King, A. (2001). A survey of state programs to finance rehabilitation and community services for individuals with brain injury, *Journal of Head Trauma Rehabilitation*, Vol. 16, 20-33.

Fujii, D., Schaefer Hanes, S., & Kokuni, Y. (1996). Family intervention in the rehabilitation and community reintegration of individuals with brain injury, *The Journal of Cognitive Rehabilitation*, March/April, 6-10.

The National Institute of Neurological Disorders and Stroke. *NINDS Traumatic Brain Injury Information Page*. www.ninds.nih.gov/health_and_medical/disorders/tbi_doc.htm

Resources

Los Angeles Caregiver Resource Center

3715 McClintock Avenue

Los Angeles, CA 90089-0191

(800) 540-4442 (in CA) or (213) 821-7777

Web Site: www.losangelescrc.org

E-mail: lacrc@usc.edu

The Los Angeles Caregiver Resource Center serves family caregivers of a brain impaired or frail, older adult through education, research, services and advocacy.

For residents of the Los Angeles County Area, LACRC provides direct family support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's, ALS, Multiple Sclerosis, Huntington's disease and other debilitating brain disorders that strike adults.

Brain Injury Association of America

8201 Greensboro Drive

Suite 611

McLean, VA 22102

(703) 761-0750

Helpline: (800) 444-6443

Helpline e-mail: familyhelpline@biausa.org

www.biausa.org

The Brain Injury Association of America is a national advocacy and awareness organization which develops and distributes educational information about brain injury and resources, legal rights and services. The Association provides a variety of information regarding brain injury and has state affiliates throughout the U.S.

Traumatic Brain Injury Model System (TBIMS)

www.tbinc.org/main_centers.php

Family Caregiver Alliance

180 Montgomery Street, Suite 1100

San Francisco, CA 94104

(415) 434-3388 or (800) 445-8106

Web Site: www.caregiver.org

E-mail: info@caregiver.org

National Association of Protection and Advocacy Systems, Inc.

900 Second Street, NE, Suite 211

Washington, D.C. 20002

(202) 408-9514

www.napas.org

Social Security Administration

(800) 772-1213

www.ssa.gov

Centers for Independent Living (CIL)

National Council on Independent Living

1916 Wilson Blvd., Suite 209

Arlington, VA 22209

(703) 525-3406

www.virtualcil.net/cils

Tammy Greenspan Head Injury Collection

(877) HEAD-INJ or (877) 432-3465

www.nassaulibrary.org/farmingd/TamaraGreenspanHeadInjuryCollection.htm

This is a free resource library, with many good books on brain injury available through the interlibrary loan system.

TBI Technical Assistance Center

National Association of State Head Injury Administrators

4330 East West Highway, Suite 301

Bethesda, MD 20814

(301) 656-3500

www.tbitac.org

TBI TAC provides information about the TBI State grant programs among other resources.

Head Injury Hotline

212 Pioneer Bldg.

Seattle, WA 98104-2221

(206) 621-8558

www.headinjury.com

This organization provides consultations, research assistance, case management services, and legal services to families and professionals.

Neurotrauma Registry

(800) 373-1166

www.neure.com

A web-based, national directory of brain and spinal cord injury programs and professionals.

This fact sheet was prepared by the National Center on Caregiving at Family Caregiver Alliance and was reviewed by Catherine Sebold, Communications Specialist of the Brain Injury Association of America. Funded by the Archstone Foundation. September 2003. © Family Caregiver Alliance. All rights reserved.