Southern Caregiver Resource Center

Caring for those who care for others

# Fact Sheet: Traumatic Brain Injury

## Introduction

Each year, an estimated 2.5 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:
  - Falls (40.5%)
  - Unintentional blunt trauma (15.5%)
  - Motor vehicle accidents (14.3%)
  - Violence (10%)
- TBI is a contributing factor to a third (30.5%) of all injury-related deaths in the United States.

 The direct medical costs and indirect costs of TBI, such as lost productivity, total an estimated \$60 billion in the United States.

## 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 selfcentered
- 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 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 communitybased (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

## Prevention

TBI's can be life altering, yet many are preventable if the necessary precautions are taken. The following are tips for minimizing the risk of sustaining a TBI:

Drivers and passengers should always:

• Wear lap belts and should harnesses.

- Use properly installed infant and child safety seats. A representative of your local police department or highway patrol can show you the proper method of installation.
- Avoid drinking and driving or driving under the influence of drugs or medications.
- Use helmets for motorcycle and bicycle riding and other recreational sports.

To help prevent falls individuals should:

- Use the rails on stairways
- Install adequate lighting, especially on stairs for people with poor vision or who have difficulty walking.
- Place bars on windows to prevent children from falling
- Do not place obstacles in walking pathways

Research has shown that approximately 85% of head injuries from bicycle accidents can be prevented with the use of helmets.

## 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 shortterm 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 the 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.

## Veteran Affairs Response to TBI

Due to the high incidence of TBI in the military field, Veteran Affairs (VA) and other sectors of the US military health system have become active in addressing the issues surrounding TBI.

Active duty and reserve service members are at an increased risk of sustaining a TBI compared to their civilian peers. This is a result of several factors, including the specific demographics of the military; in general, young men between the ages of 18 to 24 are at the greatest risk for TBI. This is coupled with an increased risk of being deployed to areas where they are at risk for experiencing blast exposures and the potential danger of even the most common operational and training activities, which are common in the military. Research conducted by the Defense and Veterans Brain Center (DVBIC) in 2005 found that blasts in combination with other mechanisms are a leading cause of TBI for active duty military personnel in war zones. The DVBIC also found that service members with previous TBI's had more symptoms in the first three months after a subsequent injury, compared to those with their first TBI, highlighting the significance and implications for treatment, of multiple TBI's.

VA has implemented an integrated nationwide system of care for Veterans and active duty service members recovering from TBI and polytrauma. This system is designed to provide care for persons with TBI as an isolated condition or in the context of polytrauma or other comorbidities. It consists of more than 100 VA medical centers; each offering specialized rehabilitation care by an interdisciplinary team.

Various steps have been taken to improve identification and treatment:

- In 2007, the VA initiated a TBI screening for all Veterans.
- Veterans with a positive TBI screen are referred for a comprehensive evaluation with specialty providers who determine a definitive diagnosis.
- An individualized Rehabilitation and Reintegration Treatment Plan of Care is developed for those Veterans that need ongoing rehabilitation services.

In late 2012, the Department of Veterans Affairs and the Department of Defense announced they were investing more than \$100 million in research to improve diagnosis and treatment of mild TBI and post- traumatic stress disorder (PTSD).

# Useful Resources & Services for Families Affected by TBI

#### **National Disability Rights Network** Protection and Advocacy for Individuals with Disabilities 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 decisionmaking, 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, see the National Disability Rights Network website, www.ndrn.org.

## 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, see www.tbindsc.org.

Brain Injury Association of America (BIAA) Chartered State Affiliates BIAA is a national program with a network of more than 40 chartered state affiliates, as well as hundreds of local chapters providing information, education and support to individuals, families and professionals affected by brain injury. To locate your state's TBI programs that can be of assistance, see the Brain Injury Association of America's online listing of chartered state affiliates at www.biausa.org/state-affiliates.

#### 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, see www.ssa.gov.

#### **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 as possible. 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, see www.virtualcil.net/cils.

### Resources

#### Southern Caregiver Resource Center

891 Kuhn Drive Ste. 200 Chula Vista, CA 91914 (858) 268-4432 | (800) 827-1008 (in CA) Fax: (858) 268-7816 E-mail: scrc@caregivercenter.org Website: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

#### **Family Caregiver Alliance**

(415) 434-3388 | (800) 445-8106 Website: www.caregiver.org E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

## Brain Injury Association of America www.biausa.org

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.

## Defense and Veterans Brain Injury Center

www.dvbic.dcoe.mil

Serves active duty military, their dependents and veterans with traumatic brain injury. Offers evaluation, treatment, follow-up care, educational materials and research.

#### Brainline

www.brainline.org

Brain Injury Resource Center www.headinjury.com

#### **Recommended Readings**

Brainline.org. *Research Update: Traumatic Brain Injury.* www.brainline.org

Center for Disease Control and Protection. *Traumatic Brain Injury.* www.cdc.gov

National Institute of Neurological Disorders and Stroke. *NINDS Traumatic Brain Injury Information Page.* www.ninds.nih.gov

#### **Fact Sheets**

Coping with Behavior Problems After Head Injury

Taking Care of YOU: Self-Care for Family Caregivers

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