



Home Care for Patients with Traumatic Brain Injury

What is Traumatic Brain Injury?

Traumatic Brain Injury (TBI) is most often an injury caused by a blow or a jolt to the head or by a penetration to the skull, and disrupts the normal functioning of a healthy brain. However, brain injuries can also be the result of strokes, brain bleeds from ruptured arteries, infections (e.g., meningitis), tumors, or oxygen deprivation.

The degree of injury may range from mild to severe, which will determine the length of time necessary to recover.

Key Demographics and Statistics about TBI

Industry research tells us that currently, approximately 1.7 million Americans sustain some form of TBI every year, and the numbers will continue to climb. These TBIs occur either singularly or in conjunction with other injuries. Additionally:

- Approximately 75% of the TBIs that occur in the United States each year are concussions or other forms of mild TBIs.
- TBI is a factor in approximately 30% of all injury-related deaths in the United States.
- The populations most likely to suffer a TBI include children between the ages of 0 to 4 years old, adolescents between 15 and 19 years old and older adults (65+ years). **Adults 75 years and older have the highest rates of TBI-related hospitalization and death.**
- In sheer numbers, across all age groups, **males are the most likely to sustain a TBI.** Child abuse, warfare, professional sports (football, baseball, boxing, etc.) are major causes of this type of brain damage.

Types of Brain Injuries

There are many degrees of brain injuries—some are mild and an individual can recover with no long-lasting effects, and some are so severe that the individual will require lifelong 24/7 care. Some of the more common brain injuries include the following:

- Aneurysm (a blood-filled sac formed by a disease-related or hereditary condition that weakens and stretches the wall of an artery or blood vessel)
- Anoxic/Hypoxic Encephalopathy (absence or shortage of oxygen in the brain)
- Arterial Dissections (severed or torn arteries in the neck)
- Concussion (injury from a blow or bump to the head)
- Contusion (bruising of the brain tissue)
- Hemorrhage/hematoma (damage to blood vessels in the brain, causing heavy bleeding, seepage or accumulation of blood in the brain)
- Hydrocephalus (excess fluid in the brain)
- Seizures (brain irritation or injury that interferes with communication between parts of the brain)
- Shearing (damage to the tissue and nerve cells of the brain)
- Skull Fracture (penetrating wound to the brain with broken skull bones)
- Stroke (a blood clot blocks the flow of blood to the brain and the brain cannot receive new oxygen or important nutrients)

Assessing the Damage

When a brain injury occurs, especially a severe one, getting medical help *as soon as possible* is vital to lessening further damage to the brain.

Health professionals will first act to maintain an adequate supply of oxygen to the brain, ensure blood pressure is at an acceptable level, obtain all the facts about the injury, and otherwise stabilize the individual.

Various diagnostic tools specific to the brain and its functioning are used to determine the nature and severity of the brain injury. These include x-rays, CT and PET scans, MRIs, EEGs, and other related tests as well as frequent blood and urine testing.

Glasgow Coma Scale

After an individual has been stabilized, transfer to the ICU (intensive care unit) for further treatment and ongoing assessment is usually the next step. Doctors typically use the *Glasgow Coma Scale* to evaluate injuries to the brain and thus to classify them as mild, moderate or severe.

The Scale has three levels of response that indicate the severity of brain impairment:

1. **Eye opening test** reveals the level of functioning of the brain's activity centers.
2. **Best verbal response** test identifies the condition of the central nervous system.
3. **Best motor response** test measures the ability to move arms and legs.

Vital Signs

Continuous monitoring and assessment of vital signs (pulse, blood pressure, temperature, breathing rate, pupil response to light, and grip strength) is an integral part of care for the individual with a brain injury. This is because a change in any one vital sign can be the first indication of a change in the overall condition of the individual. For example, a fever could indicate that an infection may be starting or lack of responsiveness could indicate increasing pressure on the brain.

From Intensive Care to Inpatient Hospitalization to Rehabilitation

Once vital signs are stable for a defined period or time, and there are no risks for other medical problems or surgical needs, the individual is transferred to an acute care setting or to a brain injury rehabilitation setting. At this time, further evaluation and treatment is conducted.

For those who sustained neurological damage from which they have not recovered, the **Rancho Los Amigos Scale of Cognitive Functioning** is used to assist rehabilitation professionals in determining the individual's behavioral and psychological capabilities.

The Scale has eight levels of functioning against which the individual is evaluated, ranging from 'no response' (Level 1) to showing a 'purposeful and appropriate' response to their environment (Level 8).

As the individual shows improvement at every level, the healthcare team (with support from the family) will begin activities and treatment to help the individual develop successive skills and encourage appropriate behavior.

Physical Changes

In addition to the physical injuries that occur at the time of a TBI, there are many physical changes that may result from this type of injury—some temporary, and some permanent and disabling.

Headaches, pain, loss of hearing, speech or vision, recurring seizures, loss of mobility, (e.g., being confined to a wheelchair), paralysis or amputation of a limb—these are examples of the physical changes an individual with a TBI may have to contend with during recovery and beyond, when trying to return to as normal a life as possible.

Behavioral Changes

A brain injury, even a mild one, can bring changes in behavior. While some of these may be temporary, it is very likely that when a serious brain injury occurs, there will be a range of emotional, psychological, and intellectual impairments that are longer term or permanent. For example, inability to reason, memory loss, poor attention span, and difficulty reading, writing, and speaking are all known issues with brain injuries.

However, some of the most difficult issues to address (for the individual *and* their family) are those associated with the **personality changes** that often result from a TBI. For example, an individual who had previously been quiet and calm can become loud, aggressive, and impatient. Conversely, a previously friendly, gregarious individual who suffers a TBI can become withdrawn, sad, and quiet.

Typically, whatever personality changes do occur will become pronounced, and may include mood swings that happen without warning and an inability to control emotions.

Much of this behavior is emotionally fueled by the frustration, worry, and confusion the individual is experiencing, and can result in depression, anxiety, anger, irritability, and restlessness.

Teamwork to Find Answers

Finding solutions to the physical and behavioral issues that confront an individual with a TBI requires the combined efforts and dedicated teamwork of various healthcare professionals working with the individual and their family. It is often a long process and one in which outcomes are measured in small steps rather than larger milestones.

Impact on Family Members

When a loved one suffers a traumatic injury of any kind, understandably, the family is traumatized too. And when the injury involves the brain, the stress and worry are compounded. Depending on the circumstances of the injury, family members may feel a host of emotions: panic, fear, anger, guilt, anxiety, confusion, isolation, fatigue, and hopelessness about the outcome for their loved one. It is an overwhelming situation by any measure.

To help the family through this crisis and beyond, the healthcare team should educate them on what to expect (depending on the diagnosis and condition of their loved one) at every phase of recovery. Some things to consider:

- There will be good days and bad days during the recovery and rehabilitation periods.
- Progress can take the form of 'fits and starts'...of moving forward and taking a step backward.
- The healthcare team should work together to explain what is happening to the individual at any point on the continuum of care.
- Planning for post-discharge care is critical and should begin while the individual is still hospitalized.

Care for the TBI Patient after the Hospital/ Rehabilitation Facility

Once the individual and family know what the expected outcome of the TBI will be, together they can plan for post-discharge care. An in-depth discussion with the doctor/healthcare team should identify the options for the individual.

Whether the team believes that home care is a good next step or if the recommendation is for a long-term care facility, the doctor should initiate the referral and discharge planning process to begin the transition of care.

Home Care for Individuals with TBI

The goal of rehabilitation is to help the individual safely function as independently as possible. A home care program can support the rehabilitation program established by the doctor to help the body and the brain heal, and to (re)learn critical activities.

Recovery from a brain injury is different for everyone—no two brain injuries are exactly alike. It is usually a lengthy process and may take anywhere from several months to several years. The activities of daily living, including a home care program, must be carefully monitored by both professional caregivers as well as family members.

The home care nurse and other members of the home care team (physical, occupational, and speech therapists, as well as behavioral therapists, home health aides, et al) will work with the doctor to develop an appropriate plan of care and implement and monitor the individual's progress.

One very important element will be educating the individual and the family on the home-based rehabilitation process, including the following:

Home Care for Patients with Traumatic Brain Injury

- Teaching healthy habits to establish and maintain as part of the recovery, including:
 - Get enough rest—energy levels are still recovering too, and it is easy to become fatigued.
 - Avoid any activities or behavior that could cause another blow or injury to the head.
 - Discuss with the doctor a timetable for driving a car, riding a bike, playing sports, using any kind of heavy equipment, lawn mowers, etc.
 - Take medication as prescribed.
 - Do not use drugs or alcohol.
 - Keep a list of things to help with memory loss.
 - Discuss with the doctor other rehabilitation services that might help and ask for a referral to receive those services.
- Helping the family understand how the individual's disabilities (short- or long-term) will affect behavior and activities of daily living, and involve them in the day-to-day rehabilitation process whenever possible.
- Suggesting practical ways the family can help the individual compensate for the loss of abilities, whether temporary or permanent.
- Ensuring the individual has a room ready at the time of arrival at home, and that it is arranged so the individual can function as independently as possible. For example, dresser drawers may be labeled to describe the contents (socks, underwear, pajamas, etc.) The nightstand next to the bed may have a tray meant just for eyeglasses, phone, wallet, pens, etc.

Home Care for Patients with Traumatic Brain Injury

- Establishing a consistent home care schedule that encourages as much activity as the individual can manage without becoming fatigued. This schedule will take into account any in-home as well as outpatient rehabilitation activities, doctor's appointments, social contact, etc.
- Addressing (along with the family) any other issues that existed before the injury (e.g., alcohol or drug abuse). While in the rehabilitation phase, this is an excellent time to educate and reinforce to the individual the importance of maintaining good health by avoiding drugs and alcohol, especially if prescription medications are being administered. Mixing alcohol or other drugs with prescription medication is dangerous.
- Teaching the importance of cueing by using lists, notes, cue cards or similar tools to help the individual compensate for memory loss while increasing self-confidence and promoting independence.
- Emphasizing the importance of *consistency* and *structure* in the home environment. This strategy helps provide a sense of security because the individual knows what to expect day in and day out.
- Maintaining ongoing communication with the doctor and with the family—especially if changes in behavior are seen. For example, 'silent' seizures may develop after a TBI, and while the individual may not show any outward signs (i.e., no convulsions) this can create changes in behavior. Other symptoms may include restlessness, pacing, complaining of changes in smell or taste, even hallucinations.
- Monitoring the individual's progress in all aspects of their home care program.

The Role of Family/Friends

When a loved one is recovering from a traumatic injury, the help and support of friends and family can make a significant difference in their rehabilitation.

Here are some suggestions for ways to support a loved one who is in recovery—whether in a facility or at home:

- During visits, especially in the early days of the injury, direct verbal communication may not be possible; sit quietly, hold their hand, let them know you are there. Because other senses (e.g., hearing, smell, taste) may be intact, you might bring a sample of their favorite perfume, or read to them from one of their favorite books, or arrange for them to listen to music they previously enjoyed. If they are able to speak, limit the length of the conversation and discuss topics that will not over-stimulate or stress the individual.
- Use familiar names for things consistently to help orient the individual to their environment.
- Be consistent in your approach during every contact; stay calm during emotional outbursts or behavior that is extreme.
- Give step-by-step directions that the individual can follow when carrying out tasks, especially those associated with their rehabilitation program.
- Don't remind them of their past abilities; they may not be able to do the things they did before the injury.
- Use age appropriate language; don't 'talk down' to the individual, and allow them time to respond; their condition may slow down response times.

Home Care for Patients with Traumatic Brain Injury

- Keep a sense of humor; this can help everyone cope
- Praise the individual as they progress in their recovery and rehabilitation program; this encourages and reinforces the effort they are making.

Tips for Managing Stress

Even as their loved one is undergoing treatment and receiving intensive care for a TBI, family members need care, too. More times than not, the family suffers along with the individual. Some things that may help family members during this very difficult time include:

- Maintain good nutrition; eat well-balanced meals at regular intervals.
- Get as much rest as possible; have family members and friends take turns visiting the individual. Let others help.
- Share your feelings with a professional. This can help relieve feelings of guilt and worry.
- Join a support group. Often hospitals or community organizations sponsor these for family and friends.
- Try to get some regular exercise. See friends, maintain social connections.

Role of Community Resources

As part of an ongoing home care program for the individual with a TBI, a daytime rehabilitation program may be an option.

Day treatment programs may provide rehabilitation activities for partial or full days, and the individual can return to their home later in the day.

Behavior management programs can also be an important part of a rehabilitation plan. These are usually community-based programs that teach techniques for self-control and other socially appropriate behaviors.

The hospital or treatment facility should be able to arrange referrals to these resources.

There are national organizations that also support TBI survivors and their families. Contacting them for information and practical assistance can be very helpful, no matter where the individual is in the treatment or recovery processes. Please see *Additional Resources* at the back of this booklet for more Web sites and contact information.

Research on Traumatic Brain Injury

The **National Institute of Neurological Disorders and Stroke (NINDS)** has long been a major resource for research on TBI. Key findings from their research include the following:

- **One of the most pervasive types of injury is *shearing*—damage to the brain’s tissue and nerve cells.** Shearing sets off a chain reaction of chemicals in the brain that also damages other healthy brain cells and can lead to cell death. This typically occurs within the first 24 – 48 hours after the TBI. Research has demonstrated that:
 - there are **special chemicals** that can be used to **counteract shearing**;
 - using a substance called ***cyclosporin A*** can **protect the nerve cells** in the brain; and
 - inducing a state of low body temperature (**hypothermia**) can **slow down brain cell death**.

Home Care for Patients with Traumatic Brain Injury

- After a TBI **the brain tries to heal itself**. It is a very delicate process and it can be interrupted by any of a number of things, such as low oxygen levels and low blood flow to the brain. Therefore, **researchers are trying to learn more about the brain's natural recovery process and the factors that control it**.
- **Trauma to the frontal lobes of the brain can damage specific chemical messengers in the brain—the dopaminergic system**. This system is a group of nerve cells in the brain that uses **dopamine**, an important chemical messenger. Ongoing research is trying to determine how the dopaminergic system responds after a TBI.
- **Use of stem cells** to repair or replace damaged brain tissue. A *neural stem cell* can normally develop into several different cell types found within the central nervous system. Research is focusing on **the ability of stem cells to develop into neurotransmitter-producing neurons**, specifically dopamine-producing cells.

Clinical Trials Research

In addition to the research described above, the clinical scientific community is also working on a wider variety of TBI research involving actual TBI patients, including:

- **Study of the brain's *plasticity*** (ability to adapt to injury) after a trauma. The brain's plasticity as well as its ability to 'rewire' its nerve connections enables another part of the brain to take on the functions of the damaged area.
- **Creation of new and better rehabilitation programs** for those with disabilities resulting from a TBI.

- **Lowering the body temperature (hypothermia) in TBI patients within 8 hours of the trauma.** Research has already shown that while this treatment did not improve outcome overall, **it did demonstrate that patients younger than 45 years old who were admitted to the hospital already in a hypothermic state fared better if they were kept cool** than if they were brought back to normal body temperature.

Other ongoing clinical trials include the use of hypothermia for severe TBI in children, the use of magnesium sulfate to protect nerve cells after TBI, and the effects of lowering ICP and increasing cerebral blood flow.

Glossary of Terms Associated with TBI

Aneurysm - a blood-filled sac formed by disease-related stretching of an artery or blood vessel

Anoxia – lack of oxygen to an organ's tissues leading to cell death

Aphasia - difficulty understanding and/or producing spoken and written language

Brain death - an irreversible cessation of measurable brain function

Cerebrospinal fluid (CSF) - the fluid that bathes and protects the brain and spinal cord

Chronic Traumatic Encephalopathy – Brain damage caused by repetitive head injury (often associated with professional sports such as boxing, football, baseball, etc.)

Closed head injury - an injury that occurs when the head suddenly and violently hits an object but the object does not break through the skull

Coma - a state of profound unconsciousness caused by disease, injury, or poison

Computed Tomography (CT) - a scan that creates a series of cross-sectional X-rays of the head and brain; also called CAT scan

Concussion - injury to the brain caused by a hard blow or violent shaking, resulting in a sudden and temporary impairment of brain function, such as a loss of consciousness or disturbance of vision and equilibrium

Contusion - distinct area of swollen brain tissue mixed with blood released from broken blood vessels

Deep vein thrombosis - formation of a blood clot deep within a vein

Depressed skull fracture - a fracture occurring when pieces of broken skull press into the tissues of the brain

Hematoma - heavy bleeding into or around the brain caused by damage to a major blood vessel in the head

Hypoxia - decreased oxygen levels in an organ, such as the brain; less severe than anoxia

Immediate seizures - seizures that occur within 24 hours of a traumatic brain injury

Home Care for Patients with Traumatic Brain Injury

Intracranial pressure – build-up of pressure in the brain as a result of injury

Locked-in syndrome - a condition in which an individual is aware and awake, but cannot move or communicate due to complete paralysis of the body

Penetrating head injury - a brain injury in which an object pierces the skull and enters the brain tissue

Persistent vegetative state - an ongoing state of severely impaired consciousness, in which the individual is incapable of voluntary movement

Plasticity - ability of the brain to adapt to injury

Post-concussion syndrome (PCS) - a complex problem that may cause headache after head injury; in most cases, there is no memory of the event that caused the concussion and of the time prior to the injury

Post-traumatic amnesia (PTA) - confusion due to a traumatic brain injury, including difficulty with perception, thinking, remembering, and concentration

Post-traumatic dementia - mental deterioration and emotional apathy following trauma

Shaken Baby Syndrome - a severe form of head injury that occurs when an infant or small child is shaken forcibly enough to cause the brain to bounce against the skull; symptoms include irritability, lethargy, tremors, or vomiting, seizures, coma, stupor, or death

Stupor - a state of impaired consciousness in which the individual is unresponsive but can be aroused briefly by a strong stimulus

Thrombosis or thrombus – the forming of a blood clot at the site of an injury

Vasospasm - exaggerated, persistent contraction of the walls of a blood vessel

Vegetative state - a condition in which individuals are unconscious and unaware of their surroundings, but continue to have a sleep/wake cycle and can have periods of alertness

Ventriculostomy - a surgical procedure that drains cerebrospinal fluid from the brain

Additional Resources

- **Brain Injury Association of America, Inc.**
1608 Spring Hill Road, Suite 110
Vienna, VA 22182
Phone: 703-761-0750 / Fax: 703-761-0755
National Brain Injury Information Center
1-800-444-6443 (Brain Injury Information Only)
<http://www.biausa.org>
- **Brain Trauma Foundation**
7 World Trade Center/34th Floor
250 Greenwich St.
New York, NY 10007
Phone: 212-772-0608
<http://www.braintrauma.org>
- **National Rehabilitation Information Center**
8400 Corporate Drive, Suite 500
Landover, MD 20785
Phone: 800/346-2742 (V)
301/459-5984 (TTY)
301/459-4263 (Fax)
<http://www.naric.com>

