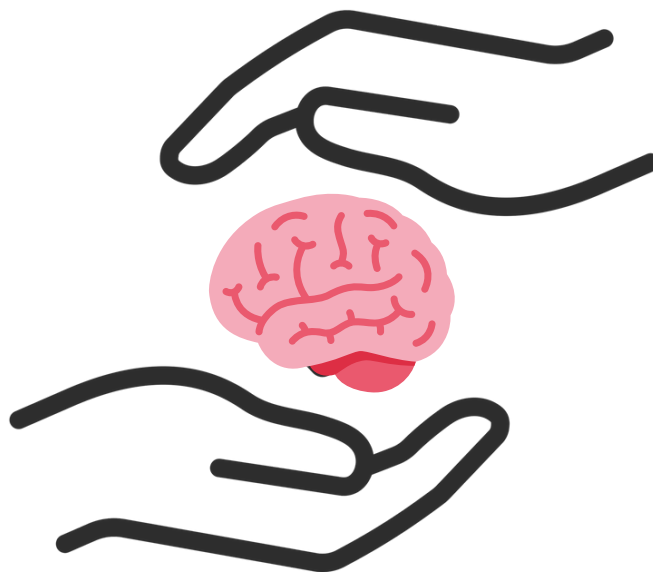


Together in Recovery

Brain Injury Resources for Survivors and Their Families



 **Spaulding-Harvard** 
Traumatic Brain Injury Model System
Serving the New England Region

 Mass General Brigham
Spaulding Rehabilitation

 **HARVARD MEDICAL SCHOOL**
TEACHING HOSPITAL



TBIMS
Traumatic Brain Injury Model System
Since 1987

The Traumatic Brain Injury Model Systems

National Institute on Disability, Independent Living, and Rehabilitation Research

Every year an estimated 2.8 million people in the United States visit an emergency department, are hospitalized or die as a result of a traumatic brain injury. A TBI is defined as damage to the brain caused by an external force as evidenced by altered consciousness and impairment of brain functioning. After the initial medical event, TBI can present significant challenges to the individual, family, and society. An injured person may experience a wide range of physical, cognitive, emotional and behavioral changes that affect everyday function. Financial hardship, reduced physical activity, limited participation in the community, isolation, anxiety and depression are some common problems experienced by individuals following a TBI.

The Traumatic Brain Injury Model System (TBIMS) Program is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) in the U.S. Department of Health and Human Services. The TBIMS began in 1987 and continues its mission to improve care and outcomes for individuals with TBI. Currently there are 16 TBIMS centers, each providing a multidisciplinary system of rehabilitation care, including emergency medical, acute medical, and post-acute services. In addition to providing direct services, these centers play a pivotal role in building the national capacity for high-quality treatment and research serving persons with TBI, their families, and the communities in which they reside.

Some TBIMS accomplishments include:

- Development of practice guidelines in important areas of medical care for people with TBI (e.g., management of post-traumatic seizures, spasticity, post-traumatic agitation, post traumatic headache, and disorders of consciousness).
- Development of innovative approaches and procedures for rehabilitation throughout recovery.
- Creation of new diagnostic procedures and assessment tools that measure recovery and outcome.
- Characterization and improved understanding of the long-term health and societal impacts of TBI across the lifespan.
- Development and dissemination of information for patients/families, professionals, and policy makers on TBI and its consequences.
- Leadership in collaborative efforts among governmental, professional, and advocacy organizations at the state and national level.

Research

More than 100 peer-reviewed publications have resulted from TBIMS-funded research, including 10 special issues of leading journals in the field of rehabilitation. Currently there are 16 active center-specific research projects and 8 multicenter research projects in the TBIMS. Collaboration within the TBIMS and with other research groups has demonstrated the utility of leveraging the infrastructure of the TBIMS.

Each of the 16 centers, as well as previously funded centers, contributes data to the TBIMS National Database, a longitudinal database started in 1988 that currently includes information on more than 19,000 individuals who were admitted for inpatient TBI rehabilitation. This database is the largest longitudinal study of TBI in the world and includes data on pre-injury, acute care, rehabilitation, and outcomes at 1, 2 and 5 years post injury and at every 5 years thereafter. Some participants have been followed for 35 years.

To ensure high data quality in TBIMS research, NIDILRR separately funds the TBIMS National Data and Statistical Center, which manages the TBIMS National Database and other collaborative TBIMS research.

To ensure that research is translated into practice, NIDILRR separately funds a Model Systems Knowledge Translation Center, which promotes the adoption of research findings by stakeholders, including rehabilitation professionals, policy-makers, TBI survivors, and family members of persons with TBI.

Once each 5-year funding cycle, TBIMS Centers may also compete for an additional collaborative grant that supports studies of outcomes, rehabilitation interventions, and service delivery.



National Summary Data on TBI

The TBI Model Systems National Database provides valuable information regarding the short-term consequences of surviving a TBI. It also offers a unique opportunity to study the long-term nature of TBI. The information contained in the National Database largely characterizes moderate to severe TBI, given that persons included in the database were admitted for inpatient rehabilitation.

Recent research co-funded by the Centers for Disease Control and Prevention and NIDILRR has confirmed that the TBIMS National Database is representative of persons receiving inpatient rehabilitation for TBI in the US. The following information is based on weighted, nationally representative data of the TBIMS National Database. For those in the US over the age of 15 with TBI requiring inpatient rehabilitation:

- Demographic characteristics: age 16-25 years (27%), 26-45 years (32%), 46-65 years (25%), age 66+ (16%); male (74%); minority population (34%); high school education or less (60%).
- Cause of injury: vehicular (49%), followed by falls (29%) and violence (11%).
- Employment: 61% employed at time of injury, with 18% retired.
- Level of disability and functional ability: Improvements are most pronounced during inpatient rehabilitation, with continued improvement seen the first year after injury.
- Lifespan: Reduced an average of 9 years.
- Health outcomes at 5 years after injury: 22% have died; 30% have become worse; 22% have stayed the same; 26% have improved.
- Disability and social outcomes at 5 years after injury: Of those still living, 53% are moderately or severely disabled; 15% do not have a job (but were employed at the time of their injury); 21% return to a hospital at least once; 19% rely on others for help with everyday activities; 23% are not satisfied with life; 24% use illicit drugs or misuse alcohol; 9% reside in nursing homes or other institutions.

TBI Partnerships

The TBIMS is engaged in several research initiatives with Federal agencies, including the Department of Veterans Affairs (VA), the Centers for Disease Control and Prevention, the Department of Defense and the National Institutes of Health. For example, the TBIMS functions in close partnership with the 5 Polytrauma Rehabilitation Centers, funded by the VA. Also referred to as the VA TBIMS, these centers collaborate with the NIDILRR-funded TBIMS in research, longitudinal data collection, and development and dissemination of TBI-related information materials to the public. This partnership has increased productivity, decreased redundancy, and strengthened TBI research through leveraging of resources.

For More Information

- Traumatic Brain Injury Model Systems: <http://msktc.org/tbi>
- Model Systems Knowledge Translation Center (MSKTC): <http://msktc.org>
- Traumatic Brain Injury Model Systems National Data and Statistical Center: <http://www.tbindsc.org>
- Center for Outcome Measurement in Brain Injury (COMBI): <http://www.tbims.org/combi/index.html>

Source

The contents of this document were developed under grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90DP0082 and 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). The contents of this document do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

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Community Resources for TBI

New to TBI? Good news! There are lots of resources to help you along your recovery journey.

Learn more about brain injury:

Model Systems Knowledge Translation Center (MSKTC)

The Model Systems Knowledge Translation Center (MSKTC) works closely with researchers in the 16 Traumatic Brain Injury (TBI) Model Systems to develop resources for people living with TBI and their supporters. These evidence-based materials are available in a variety of formats such as printable PDF documents, videos, and slideshows.



Website: <https://msktc.org/TBI>

Resources to get involved:

Brain Injury Association of America (BIAA)

The Brain Injury Association of America is a national organization that provides information, resources, and advocacy about brain injury in the United States. Subscribe to their newsletter for national news on brain injury happenings and browse their website for useful education about brain injury.



Website: <https://biausa.org/>

Brain Injury Association of Massachusetts (BIA-MA)

The Brain Injury Association of Massachusetts is the Massachusetts branch of the BIAA. BIA-MA houses many support groups, both online and in-person. The BIA-MA also participates in many advocacy efforts at the state level, with the state legislature, for example. Check out their website for programs in Massachusetts for survivors, caregivers, and providers.



Website: <https://biama.org/>

Brain Injury Resource Facilitators (BIRF)

Through the BIA-MA, NeuroResource Facilitators (BIA-MA's version of the BIRF national program) can provide individual advice and resource referral for brain injury survivors and families. If you are struggling with meeting your needs after brain injury, reach out to BIA-MA's NeuroResource Facilitators using the QR code here.



Website: <https://biama.org//forcaregiversandsurvivors/>

Brain Injury Association of New Hampshire (BIANH)

Much like BIA-MA, the Brain Injury Association of New Hampshire is the New Hampshire chapter of the BIAA, housing local support groups and resources



Website: <https://bianh.org/>

Brain Injury Association of Rhode Island (BIARI)

Much like BIA-MA, the Brain Injury Association of Rhode Island is the Rhode Island chapter of the BIAA, housing local support groups and resources.



Website: <https://biari.org/>

Brain Injury Alliance of Vermont (BIAVT)

The Brain Injury Alliance of Vermont is an advocacy organization dedicated to serving those who have experienced brain injuries in Vermont. This independent organization houses similar resources to the Brain Injury Association state chapters, but independent from the BIAA.



Website: <https://biavt.org/>

MassAbility

This statewide program assists with empowering people with disabilities to live life on their terms. Many programs and services are available, including career assistance and training, home and community life support, and legal assistance including disability determination for federal programs.



Website: <https://www.mass.gov/orgs/massability>

MassAbility Statewide Head Injury Program (SHIP)

SHIP is a state-funded program that assists people in Massachusetts who have had brain injuries with things like service coordination, family consultation, social and recreational programs, individual skills training, and caregiver placement.



Website: <https://www.mass.gov/statewide-head-injury-program-ship>

Synapse

Synapse is an organization to support individuals with brain injuries by providing powerful social support networks and inspiring new leaders and advocates in the field. Many academic institutions house a Synapse chapter



Website: <https://synapsenational.wixsite.com/synapse>

Boston Acquired Brain Injury Support (BABIS) Group

BABIS is an in-person support group hosted at Spaulding Rehabilitation in Charlestown every first Saturday of the month, from 10AM-12PM. Each meeting, brain injury survivors have the opportunity to build connections with other survivors and their caregivers, and to learn something to help them on their journey from a guest speaker.



Website: <https://biama.org//forcaregiversandsurvivors/>



SPAULDING CHARLESTOWN **INPATIENT** SUPPORT GROUPS

Brain Injury Peer Support Group



Meet others who understand your journey, share experiences, and find resources and encouragement in a safe, welcoming space.

When: Second Sunday of each month

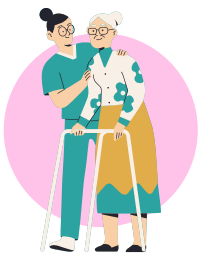
Time: 11 am – 12 pm

Where: SRH 7th Floor Lantern Room

For more information, please contact

Beth Hansen | eahansen@mgb.org

Kasey Noonan | knoonan9@mgb.org



Brain Injury Caregiver Education Group: Life At and After Spaulding

No matter how big or small, we want to hear your brain injury questions. This is a time for getting the answers you need for navigating the rehabilitation process as well as planning for life after Spaulding. We are here to address your concerns.

Topics covered:

- Orientation to the Brain Injury Unit.
- Practical support and brain injury education for caregivers/families.
- Introduction to community resources including the BIA (Brain Injury Association).
- Q&A with representatives from the rehab team.

When: Thursdays 12:15 – 12:45 PM
(Excluding Holidays)

Where:

In Person Location: 7th Floor Patient Education Room

For Virtual Access Contact:

Abigail Spaulding | aspaulding@mgb.org

Kati Paye | kpaye@mgb.org



OUTPATIENT SUPPORT GROUPS

Boston Acquired Brain Injury (BABIS) Support Group

Boston Acquired Brain Injury Support Group (BABIS) is for brain injury survivors, family and friends, this large support group averages 60+ people each month. We also have a facilitated family/caregiver (brain injury-related) support group that meets at the same time.



When: First Saturday of the month

Time: 10:30am – 12pm

Where: Spaulding Rehabilitation Hospital 300 1st Ave, Charlestown, MA 02129
Conference Rooms A and B

For more information, please contact: supportgroups@biama.org

Brain Injury Association of Massachusetts (BIA-MA) Support Groups

BIA-MA sponsors in-person and virtual support groups across the state that provide survivors and their loved ones a forum for sharing information, a compassionate and understanding peer group, and an opportunity to socialize and make new friends.

Scan the QR code or visit <https://biama.org/forcaregiversandsurvivors/> to register for virtual meetings.

For further assistance with support group meetings, please contact
supportgroups@biama.org



Adult Post-Concussion Support Group

This support group meeting is intended for survivors post-concussion. Meet people who share similar experiences, challenges, joys and hopes while we heal together from acquired brain injuries.

When: Third Wednesday of the month

Time: 10:30am – 12:00pm

Where: Spaulding Cape Cod 311 Service Road, East Sandwich, MA 02537
1st Floor Conference Room

Facilitators: Ann Pike-Paris and Gary Brennan, Brain Injury Association-MA

For more information or to receive virtual link via email, please contact
Ann Pike-Paris | apikep2@gmail.com





Explore & Learn About Traumatic Brain Injury

The Model Systems Knowledge Translation Center (MSKTC) works closely with researchers in the 16 Traumatic Brain Injury (TBI) Model Systems to develop resources for people living with TBI and their supporters. These evidence-based materials are available in a variety of formats such as printable PDF documents, videos, and slideshows.

Below is a curated selection of materials from the MSKTC. Simply scan the QR code or manually enter the URL into your browser to access the full resource.

Additional full-length sample factsheets can be found at the end of the packet.



Scan the QR code or visit <https://msktc.org/TBI> to explore the full MSKTC TBI collection



MSKTC Radio



MSKTC Radio features free research-based podcasts to support individuals living with spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury.

Available TBI related topics include:

- Change in Memory after TBI
- Loss of Taste and Smell after TBI
- Relationships after TBI
- Many more!

<https://soundcloud.com/user-744503006>



MSKTCtv



MSKTCtv features free research-based videos to support individuals living with spinal cord injury (SCI), traumatic brain injury (TBI), and burn injury.

Available TBI Topics Include:

- Change in TBI
- TBI and Depression
- Many more!

<https://youtube.com/@msktctv>



Factsheet: Headaches after TBI

Headache is one of the most common symptoms after traumatic brain injury (often called "post-traumatic headache"). Over 30% of people with moderate to severe TBI report having headaches which continue long after injury. An even larger percentage people with mild TBI complain of headache.

<https://msktc.org/tbi/tbi-topics/headaches>



MSKTC HOT TOPICS

The MSKTC TBI hot topic modules consist of a suite of resources such as videos, a factsheet, and a slideshow to support people with traumatic brain injury. Access a hot topic module by scanning the QR Code or entering the URL into your browser.

<https://msktc.org/tbi/Hot-Topics>

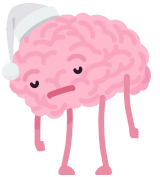


Factsheet: Fatigue and TBI

Fatigue is a feeling of exhaustion, tiredness, weariness, or lack of energy. After TBI, you may have more than one kind of fatigue:

1. **Physical fatigue:** "I'm tired and I need to rest. I'm dragging today."
2. **Psychological fatigue:** "I just can't get motivated to do anything. Being depressed wears me out; I just don't feel like doing anything."
3. **Mental fatigue:** "After a while, I just can't concentrate anymore. It's hard to stay focused. My mind goes blank."

<https://msktc.org/tbi/factsheets/fatigue-and-traumatic-brain-injury>



Factsheet: Driving after TBI



Driving can be an important part of feeling independent. It can improve mental well-being and self-esteem. It also helps you to feel like you are part of a community. It supports activities of daily living such as working and shopping. It also supports access to health care. Driving is a big part of our daily lives, but it is easy to forget that driving is dangerous.

<https://msktc.org/tbi/tbi-topics/driving>



Infocomic: Emotional Changes After TBI

Sometimes, it can be hard for people with TBI to control their feelings. This comic talks about changes in mood or feelings that may happen after a traumatic brain injury.

<https://msktc.org/tbi/infocomics/emotional-changes-after-tbi-infocomic>



Factsheet: Cognitive Problems after TBI

Cognition is the act of knowing or thinking. Some thinking abilities that can be affected by TBI include:

- Attention and concentration
- Processing and understanding information
- Memory
- Planning, organizing, and assembling
- Reasoning, problem-solving, decision-making, and judgment
- Monitoring and watching behavior to ensure that it is socially acceptable
- Communicating thoughts or ideas in ways that others can understand



<https://msktc.org/tbi/tbi-topics/cognitive-problems>



Understanding Traumatic Brain Injury

Part 1: What happens to the brain during injury and in the early stages of recovery from TBI?

March 2019

www.msktc.org/tbi/factsheets

TBI Factsheet

This factsheet explains what happens to the brain during TBI and in the early stages of recovery from TBI.

What is a brain injury?

Traumatic brain injury (TBI) refers to damage to the brain caused by an external physical force such as a car accident, a gunshot wound to the head, or a fall. A TBI is not caused by something internal such as a stroke or tumor and does not include damage to the brain due to prolonged lack of oxygen (anoxic brain injury). It is possible to have a TBI and never lose consciousness. For example, someone with a penetrating gunshot wound to the head may not lose consciousness.

Commonly accepted criteria established by the TBI Model Systems (TBIMS)* to identify the presence and severity of TBI include:

Damage to brain tissue caused by an external force and at least one of the following:

- A documented loss of consciousness
- The person cannot recall the actual traumatic event (amnesia)
- The person has a skull fracture, post-traumatic seizure, or an abnormal brain scan due to the trauma

A TBI can range from mild to severe in effect. The TBI Model System program focuses on those with moderate to severe TBI that requires participation in rehabilitation. Much of the information provided below focuses on those with moderate-severe TBI.

Causes of TBI

Statistics from the Centers for Disease Control and Prevention for 2007 to 2013 indicate that the leading cause of brain injury is falls (47%). This is followed by being hit by or against an object (15%) and car crashes (14%). Many of these injuries are mild. If you focus only on moderate to severe TBI (those injuries that may require admission to a neurointensive care unit), falls are the most common cause of TBI, followed by car crashes and assaults.

Types of injuries

The brain is about 3–4 pounds of extremely delicate soft tissue floating in fluid within the skull. Under the skull there are three layers of membrane that cover and protect the brain. The brain tissue is soft and therefore can be compressed (squeezed), pulled, and stretched. When there is sudden speeding up and slowing down, such as in a car crash or fall, the brain can move around violently inside the skull, resulting in injury.

Closed versus open head injury

Closed means the skull and brain contents have not been penetrated (broken into or through), whereas *open* means the skull and other protective layers are penetrated and exposed to air. A common example of an open head injury is a gunshot wound to the head. A common closed head injury is one that occurs as the result of a motor vehicle crash.

The Traumatic Brain Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/tbi/model-system-centers> for more information).



In a closed head injury, damage occurs because of a blow to the person's head or having the head stop suddenly after moving at high speed. This causes the brain to move forward and back or from side to side, such that it collides with the bony skull around it. This jarring movement bruises brain tissue. When brain injury occurs at high speed, the brain rotates inside the skull. This type of rotational movement damages axons (part of the nerve cells) and blood vessels by stretching and tearing them. After a closed head injury, damage can occur in specific brain areas (localized injury) or throughout the brain (diffuse axonal injury).

Damage following **open head injury** tends to be localized and therefore damage tends to be limited to a specific area of the brain. However, such injuries can be as severe as closed head injuries, depending on the destructive path of the bullet or other invasive object within the brain.

Primary versus secondary injuries

Primary injuries occur at the time of injury and there is nothing that physicians can do to reverse those injuries. Instead, the goal of the treatment team in the hospital is to prevent any further, or secondary, injury to the brain. Below are some primary injuries.

- **Skull fracture** occurs when there is a breaking or denting of the skull. Pieces of bone pressing on the brain can cause injury, often referred to as a depressed skull fracture.
- **Localized injury** means that a particular area of the brain is injured. Injuries can involve bruising (contusions) or bleeding (hemorrhages) on the surface of or within any layer of the brain.
- **Diffuse axonal Injury** (DAI) involves damage throughout the brain and loss of consciousness. DAI is a “stretching” injury to the neurons (the cell bodies of the brain) and axons (fibers that allow for communication from one neuron to another neuron). Everything our brains do for us depends on neurons communicating. When the brain is injured, axons can be pulled, stretched, and torn. If there is too much injury to the axon, the neuron will not survive. In a DAI, this happens to neurons all over the brain. This type of damage is often difficult to detect with routine brain scans like computed tomography (CT scans).

Secondary injuries occur after the initial injury, usually within a few days. Secondary injury may be caused by oxygen not reaching the brain, which can be the result of continued low blood pressure or increased intracranial pressure (pressure inside the skull) from brain tissue swelling.

Measuring the severity of TBI

“Severity of injury” refers to the degree or extent of brain tissue damage. The degree of damage is estimated by measuring the duration of loss of consciousness, the depth of coma and level of amnesia (memory loss), and through brain scans.

The **Glasgow Coma Scale** (GCS) is used to measure the depth of coma. The GCS rates three aspects of functioning:

- Eye opening
- Movement
- Verbal response

Individuals in deep coma score very low on all these aspects of functioning, while those less severely injured or recovering from coma score higher.

- A GCS score of 3 indicates the deepest level of coma, describing a person who is totally unresponsive.
- A score of 9 or more indicates that the person is no longer in a coma.
- The highest score (15) refers to a person who is fully conscious.

A person's first GCS score is often done at the roadside by the emergency response personnel. In many instances, moderately to severely injured people are intubated (a tube is placed down the throat and into the air passage into the lungs) at the scene of the injury to ensure the person gets enough oxygen. To do the intubation the person must be sedated (given medication that makes the person go to sleep). So, by the time the person arrives at the hospital he/she has already received sedating medications and has a breathing tube in place. Under these conditions it is impossible for a person to talk, so the doctors cannot assess the verbal part of the GCS. People in this situation often receive a "T" after the GCS score, indicating that they were intubated when the examination took place, so you might see a score of 5T, for instance.

The GCS is done at intervals in the neurointensive care unit to document a person's recovery.

The duration of a confusional state following injury, often referred to as post-traumatic amnesia (PTA), is another good estimate for severity of a brain injury. Anytime a person has a major blow to the head he or she will not remember the injury and related events for some time afterward. People with these injuries might not recall having spoken to someone just a couple of hours ago and may repeat things they have already said. This is the period of post-traumatic amnesia. The longer the duration of confusion/amnesia, the more severe the brain damage.

CT or MRI Scan Results

The computed tomography (CT) scan is a type of X-ray that shows problems in the brain such as bruises, blood clots, and swelling. CT scans are not painful. People with moderate to severe TBI will have several CT scans while in the hospital to keep track of lesions (damaged areas in the brain). In some cases, a magnetic resonance imaging (MRI) scan may also be performed. This also creates a picture of the brain based on magnetic properties of molecules in tissue. Most people with severe TBI will have an abnormality on a CT scan or MRI scan. These scans cannot detect all types of brain injuries, so it is possible to have a severe TBI and be in coma even though the scan results (particularly CT scans) are normal.

Brain tissue response to injury

Common Problems:

Increased intracranial pressure

The brain is like any other body tissue when it gets injured: it fills with fluid and swells. Because of the hard skull around it, however, the brain has nowhere to expand as it swells. This swelling increases pressure inside the head (intracranial pressure), which can cause further injury to the brain. Decreasing and controlling intracranial pressure is a major focus of medical treatment early after a TBI. If intracranial pressure remains high, it can prevent blood passage to tissue, which results in further brain injury.

Neurochemical problems that disrupt functioning

Our brains operate based on a delicate chemistry. Chemical substances in the brain called neurotransmitters are necessary for communication between neurons, the specialized cells within our central nervous system. When the brain is functioning normally, chemical signals are sent from neuron to neuron, and groups of neurons work together to perform functions.

TBI disturbs the delicate chemistry of the brain so that the neurons cannot function normally. This results in changes in thinking and behavior. It can take weeks and sometimes months for the brain to resolve the chemical imbalance that occurs with TBI. As the chemistry of the brain improves, so can the person's ability to function. This is one reason that someone may make rapid progress in the first few weeks after an injury.

Neural plasticity (ability of change) of the brain

The brain is a dynamic organ that has a natural ability to adapt and change with time. Even after it has been injured, the brain changes by setting up new connections between neurons that carry the messages within our brains. We now know the brain can create new neurons in some parts of the brain, although the extent and purpose of this is still uncertain. Plasticity of the brain occurs at every stage of development throughout the life cycle. Plasticity is more likely to occur when there is stimulation of the neural system, meaning that the brain must be active to adapt. Changes do not occur without exposure to a stimulating environment that prompts the brain to work. These changes do not occur quickly. That is one of the reasons that recovery may go on for months and sometimes years following TBI.

More in the Understanding TBI series

- Understanding TBI, Part 2: Brain injury impact on individuals' functioning
- Understanding TBI, Part 3: The recovery process
- Understanding TBI, Part 4: The impact of a recent TBI on family members and what they can do to help with recovery

Authorship

Understanding TBI was developed by Thomas Novack, PhD and Tamara Bushnik, PhD in collaboration with the University of Washington Model Systems Knowledge Translation Center. Portions of this document were adapted from materials developed by the University of Alabama TBIMS, Baylor Institute for Rehabilitation, New York TBIMS, Mayo Clinic TBIMS, Moss TBIMS, and from Picking up the pieces after TBI: A guide for Family Members, by Angelle M. Sander, PhD, Baylor College of Medicine (2002).

Source: The content is based on research and/or professional consensus. This content has been reviewed and approved by experts from the Traumatic Brain Injury Model Systems (TBIMS), funded by the National Institute of Disability, Independent Living, and Rehabilitation Research, as well as experts from the Polytrauma Rehabilitation Centers (PRC), funded by the U.S. Department of Veterans Affairs.

Disclaimer: The information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. This publication was originally produced by the TBI Model Systems in collaboration with the University of Washington Model Systems Knowledge Translation Center with funding from the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education (grant number H133A060070). It was updated by the TBI Model Systems in collaboration with the Model Systems Knowledge Translation Center at the American Institutes for Research with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR; grant number 90DP0082). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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Understanding Traumatic Brain Injury

Part 2: Brain injury impact on individuals' functioning

March 2019

www.msktc.org/tbi/factsheets

TBI Factsheet

This factsheet explains the impact of TBI on individuals' functioning.

A traumatic brain injury interferes with the way the brain normally works. When nerve cells in the brain are damaged, they can no longer send information to each other in the normal way. This causes changes in the person's behavior and abilities. The injury may cause different problems, depending upon which parts of the brain were damaged most.

There are three general types of problems that can happen after TBI: physical, cognitive and emotional/ behavioral problems. It is impossible to tell early on which specific problems a person will have after a TBI. Problems typically improve as the person recovers, but this may take weeks or months. With some severe injuries changes can take many years.

Structure and function of the brain

The brain is the control center for all human activity, including vital processes (breathing and moving) as well as thinking, judgment, and emotional reactions. Understanding how different parts of the brain work helps us understand how injury affects a person's abilities and behaviors.

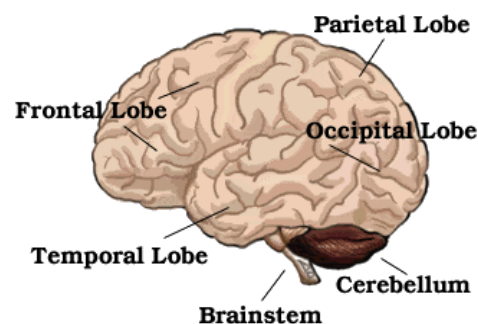
Left vs. Right Brain

- The brain is divided into two halves (hemispheres). The left half controls movement and sensation in the right side of the body, and the right half controls movement and sensation in the left side. Thus, damage to the right side of the brain may cause movement problems or weakness on the body's left side.
- For most people, the left half of the brain is responsible for verbal and logical functions including language (listening, reading, speaking, and writing), thought and memory involving words.
- The right half is responsible for nonverbal and intuitive functions such as putting bits of information together to make up an entire picture, recognizing oral and visual patterns and designs (music and art), and expressing and understanding emotions.

The Traumatic Brain Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. (See <http://www.msktc.org/tbi/model-system-centers> for more information).

Brain Areas & Associated Functions

The brain is made up of six parts that can be injured in a head injury. The effect of a brain injury is partially determined by the location of the injury. Sometimes only a single area is affected, but in most cases of TBI multiple areas have been injured. When all areas of the brain are affected, the injury can be very severe.



<i>Six parts</i>	<i>Functions</i>
Brain Stem	▪ Breathing ▪ Heart Rate ▪ Swallowing ▪ Reflexes for seeing and hearing ▪ Controls sweating, blood pressure, digestion, temperature ▪ Affects level of alertness ▪ Ability to sleep ▪ Sense of balance
Cerebellum	▪ Coordination of voluntary movement ▪ Balance and equilibrium ▪ Some memory for reflex motor acts
Frontal Lobe	▪ How we know what we are doing within our environment ▪ How we initiate activity in response to our environment ▪ Judgments we make about what occurs in our daily activities ▪ Controls our emotional response ▪ Controls our expressive language ▪ Assigns meaning to the words we choose ▪ Involves word associations ▪ Memory for habits and motor activities ▪ Flexibility of thought, planning and organizing ▪ Understanding abstract concepts ▪ Reasoning and problem solving
Parietal Lobe	▪ Visual attention ▪ Touch perception ▪ Goal directed voluntary movements ▪ Manipulation of objects ▪ Integration of different senses
Occipital Lobe	▪ Vision
Temporal Lobe	▪ Hearing ability ▪ Memory acquisition ▪ Some visual perceptions such as face recognition and object identification ▪ Categorization of objects ▪ Understanding or processing verbal information ▪ Emotion

Physical Problems

Most people with TBI are able to walk and use their hands within 6-12 months after injury. In most cases, the physical difficulties do not prevent a return to independent living, including work and driving.

In the long term the TBI may reduce coordination or produce weakness and problems with balance. For example, a person with TBI may have difficulty playing sports as well as they did before the injury. They also may not be able to maintain activity for very long due to fatigue.

Cognitive (Thinking) Problems

- Individuals with a moderate-to-severe brain injury often have problems in basic cognitive (thinking) skills such as paying attention, concentrating, and remembering new information and events.
- They may think slowly, speak slowly and solve problems slowly.
- They may become confused easily when normal routines are changed or when things become too noisy or hectic around them.
- They may stick to a task too long, being unable to switch to different task when having difficulties.
- On the other hand, they may jump at the first “solution” they see without thinking it through.
- They may have speech and language problems, such as trouble finding the right word or understanding others.
- After brain injury, a person may have trouble with all the complex cognitive activities necessary to be independent and competent in our complex world. The brain processes large amounts of complex information all the time that allows us to function independently in our daily lives. This activity is called “executive function” because it means “being the executive” or being in charge of one’s own life.

Emotional/Behavioral Problems

Behavioral and emotional difficulties are common and can be the result of several causes:

- First, the changes can come directly from damage to brain tissue. This is especially true for injuries to the frontal lobe, which controls emotion and behavior.
- Second, cognitive problems may lead to emotional changes or make them worse. For example, a person who cannot pay attention well enough to follow a conversation may become very frustrated and upset in those situations.
- Third, it is understandable for people with TBI to have strong emotional reactions to the major life changes that are caused by the injury. For example, loss of job and income, changes in family roles, and needing supervision for the first time in one’s adult life can cause frustration and depression.

Brain injury can bring on disturbing new behaviors or change a person’s personality. This is very distressing to both the person with the TBI and the family. These behaviors may include:

- Restlessness
- Acting more dependent on others
- Emotional or mood swings
- Lack of motivation
- Irritability
- Aggression
- Lethargy (sluggishness)
- Acting inappropriately in different situations
- Lack of self-awareness. Injured individuals may be unaware that they have changed or have problems. This can be due to the brain damage itself or to a denial of what’s really going on in order to avoid fully facing the seriousness of their condition.

Fortunately, with rehabilitation training, therapy and other supports, the person can learn to manage these emotional and behavioral problems.

More in the Understanding TBI series

- Understanding TBI, Part 1: What happens to the brain during injury and in early stage of recovery from TBI?
- Understanding TBI, Part 3: The recovery process
- Understanding TBI, Part 4: The impact of a recent TBI on family members and what they can do to help with recovery

Authorship

Understanding TBI was developed by Thomas Novack, PhD and Tamara Bushnik, PhD in collaboration with the University of Washington Model Systems Knowledge Translation Center. Portions of this document were adapted from materials developed by the University of Alabama TBIMS, Baylor Institute for Rehabilitation, New York TBIMS, Mayo Clinic TBIMS, Moss TBIMS, and from Picking up the pieces after TBI: A guide for Family Members, by Angelle M. Sander, PhD, Baylor College of Medicine (2002).

Source: The content is based on research and/or professional consensus. This content has been reviewed and approved by experts from the Traumatic Brain Injury Model Systems (TBIMS), funded by the National Institute of Disability, Independent Living, and Rehabilitation Research, as well as experts from the Polytrauma Rehabilitation Centers (PRC), funded by the U.S. Department of Veterans Affairs.

Disclaimer: The information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. This publication was originally produced by the TBI Model Systems in collaboration with the University of Washington Model Systems Knowledge Translation Center with funding from the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education (grant number H133A060070). It was updated by the TBI Model Systems in collaboration with the Model Systems Knowledge Translation Center at the American Institutes for Research with funding from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR; grant number 90DP0082). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

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More from the Understanding TBI Series

Part 3: The Recovery Process

In the first few weeks after a moderate to severe brain injury, swelling, bleeding or changes in brain chemistry often affect the function of healthy brain tissue. The injured person's eyes may remain closed, and the person may not show signs of awareness. As swelling decreases and blood flow and brain chemistry improve, brain function usually improves. With time, the person's eyes may open, sleep-wake cycles may begin, and the injured person may follow commands, respond to family members, and speak.

<https://msktc.org/tbi/factsheets/understanding-tbi-part-3-recovery-process>



Part 4: The Impact of a Recent TBI on Family Members and What They Can Do To Help With Recovery

For most family members, life is not the same after TBI. We want you to know that you are not alone in what you are feeling. While everyone's situation is a bit different, there are some common problems that many family members experience such as less time for yourself, financial difficulties, role changes of family members, problems with communication, and lack of support from other family members and friends. These are just some of the problems that family members may face after injury. Sometimes these problems can seem too much and you may become overwhelmed, not seeing any way out.

<https://msktc.org/tbi/factsheets/understanding-tbi-part-4-impact-recent-tbi-family-members-and-what-they-can-do-help>

