

TRAUMATIC BRAIN INJURY

STRATEGIES FOR
SURVIVING AND THRIVING



SPRING 2009



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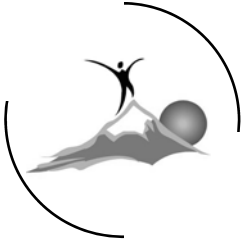
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INTRODUCTION

TRAUMATIC BRAIN INJURY CAREGIVERS' CURRICULUM

This course was developed for caregivers who provide care and services to adults affected by a Traumatic Brain Injury (TBI). This course will help you better understand and work effectively with adults with TBI.

Aging and Disability Services Administration (ADSA) developed this course with the participation of people living with a TBI, families, advocates, and professionals. The project was funded through Grant Number H21MC0062 of the Federal TBI Implementation program.

This course has been designed for both formal and informal caregivers:

- Formal caregivers are paid caregivers of adults who live in their own homes or in other settings such as adult family homes, assisted living facilities, or nursing facilities.
- Informal caregivers are people, such as family members or friends, who are helping to provide unpaid care to the person with a TBI. Informal caregivers have firsthand knowledge and experience at every level with the person whose life changed in the blink of an eye.

Whether you are a formal or informal caregiver, it is critical for you to always be mindful that a person who has a brain injury is first and foremost, a person.

Because there may be many things that the person with a TBI can no longer do, or needs help, guidance, and support to accomplish, it is very easy to focus on the changes, or deficits, only.

It is important to remember that the person who has the brain injury is establishing a new self, or identity, which integrates both who he or she was and who he or she is now.

You have made a commitment to assist people with TBI to receive the care required. In doing so, you are also:

1. Helping them strive for goals and accomplishments they define.
2. Supporting as much independence as possible.
3. Providing choices. These approaches embrace components that adults with brain injury and their advocates have expressed in the development of this curriculum ... the right to self-determination.

INTRODUCTION

CAREGIVING AND TBI

*A person who has
a brain injury is
first and foremost,
a person.*



WHAT YOU WILL LEARN

One of the most important things to understand is that there is no “cookie cutter” approach in working with people with a TBI. The nature and location of the brain injury is unique to each person.

However, through increased knowledge about TBI and the affects that adults may experience as a result of their injury, you will further develop your understanding about TBI and your skills in providing care. This will benefit both the adult(s) you work with as well as you as a caregiver.

COURSE PROCESS

The course is presented in five modules. Each module can be taken one at a time or in a single caregiver training.

The training also includes a DVD with TBI survivors and their caregivers sharing their experiences with you. These stories help to reinforce key information from the modules and highlight strategies for working with TBI.

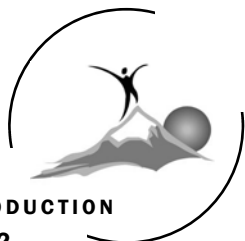
Watch the DVD at the end of each module. The DVD directs you back to the manual to read the next module at the end of each segment.

MODULE 1 – OVERVIEW OF TBI

- How traumatic brain injury (TBI) is different from other kinds of brain disease.
- Why there is growing recognition of TBI as a major problem in our communities.
- Factors that affect recovery and why there is new hope for survivors of TBI and their families.

MODULE 2 – THE BRAIN: BEFORE AND AFTER A TBI

- The major parts and functions of the brain and why no two people with a brain injury are the same.
- How a brain injury to each part of the brain may affect a person.
- Strategies for dealing with the changes that may be a result of a brain injury.



MODULE 3 – PHYSICAL AND COGNITIVE CHANGES AND TBI: HOW TO HELP

- Physical changes that may result from a brain injury, including motor skills, communication, the senses, pain, seizures, and sleep.
- Cognitive changes that may result from a brain injury, including memory, processing information, attention and concentration, reasoning, planning, and initiating actions.
- Specific ways to help with common physical, sensory, and thinking problems that may occur with TBI.
- How to help and tips on caregiving.

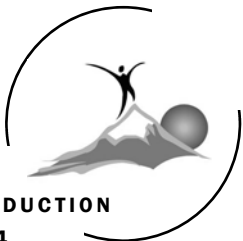
MODULE 4 – CHALLENGES IN CAREGIVING: EMOTIONAL AND BEHAVIORAL CHANGES AND TBI

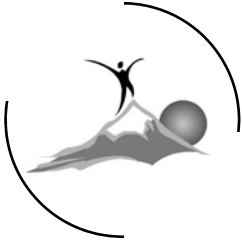
- Emotional and behavioral changes that may be a result of TBI.
- The A-B-C technique for helping with challenging behavior.
- When it's more than the TBI, including conditions before and following the TBI.
- How to help and tips that address strategies for dealing with challenging behaviors that supports the person's strengths.

MODULE 5 – SUPPORTING RECOVERY

- Four general guidelines that support any adult who is recovering from a TBI.
- Strategies that help to create a supportive, safe environment.
- Tips that apply to caregiving, managing stress, and making health a priority for both the adult with a TBI and the caregiver.

This training also addresses caregiver issues that may affect both you as the caregiver and the person who has a TBI. It is important for you to monitor how you are doing as a caregiver, to identify stress, and to recognize when support will help you to stay healthy and be a successful caregiver.





MODULE 1 – OVERVIEW OF TBI

MODULE GOALS

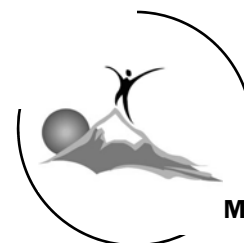
- Learn how traumatic brain injury (TBI) is different from other kinds of brain disease.
- Understand why there is growing recognition of TBI as a major problem in our communities.
- Learn why there is new hope for survivors of TBI and their families.

Brain injury is damage to the brain that causes death of brain cells and loss of function.

- **TBI** is caused by a blow to the head or violent movement of the head.
 - TBI may happen during falls, car wrecks, nearby explosions or assaults, while playing contact sports, or by being shaken very hard.
 - TBI may or may not include loss of consciousness, an open wound, or a skull fracture.
- **Acquired brain injury (ABI)** refers to any kind of damage to the brain that occurs after birth.
 - ABIs include TBIs, but also may be caused by stroke, lack of oxygen to the brain during near-drowning or suffocation, tumors, or an infection in the brain.
 - The terms ABI and TBI are not used for a person who has brain damage before birth or whose brain is injured during birth.
- Some of the information in this module might apply to acquired brain injury (ABI). However, our main focus is traumatic brain injury (TBI).

BRAIN INJURIES DEFINED

Brain injury is damage to the brain that causes death of brain cells and loss of function.



There are over 1.4 million new cases of brain injury in the U.S. each year.

HOW MANY PEOPLE HAVE TBI?

The U.S. Centers for Disease Control (CDC) estimates there are over 1.4 million new cases of brain injury in the U.S. each year.

- That's about eight times the number of people newly diagnosed with breast cancer and 34 times the number of new cases of HIV/AIDS.
- Over 50,000 people in the U.S. and over 1,000 people in Washington State die each year from TBI.
- TBI causes over 200,000 hospitalizations and over one million visits to emergency departments in the U.S. each year.
- Many people sustain a TBI but do not die and do not seek care in a hospital, so they are not counted. The exact number of persons with TBI is much larger than we really know.
- At least 5.3 million Americans, or about two percent of the U.S. population, have a long-term need for help with daily activities because of a TBI.
- Among American children between ages birth to 14 years, TBI causes about 2,700 deaths, 37,000 hospitalizations, and 435,000 emergency department visits a year.

The cost of TBI in the U.S. is estimated at over \$56 billion a year in medical costs and lost work.

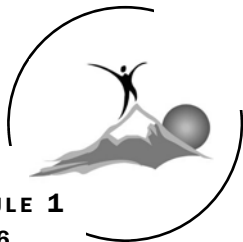
WHY ARE WE HEARING MORE ABOUT TBI NOW?

There is a growing awareness of TBI as a "hidden" or "silent" epidemic.

- A TBI often is not apparent from looking at the person who has it. In the past, many of the problems of TBI were wrongly attributed to other causes, such as mental health conditions.
- Health care professionals, community service workers, and the general public are becoming more aware of the short-term and long-term effects of a TBI.
- In the past, concussions often were not thought of as brain injuries. There is growing awareness that they are.

More people are now surviving TBI than ever before because of:

- Better emergency response systems, such as expanded use of "911" and faster transport to trauma centers.
- Improved safety technology, such as airbags, infant and child car seats, seat belts, sports helmets, and military body armor.



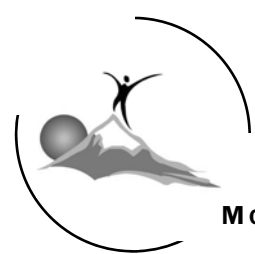
MYTHS AND FACTS ABOUT TBI	
MYTH: If you weren't knocked unconscious, then you didn't really hurt your brain.	FACT: Some recent research studies have found that one-third or more of people who were eventually diagnosed with a TBI did not lose consciousness.
MYTH: If your doctor says you have a "mild" brain injury, it means you don't have a significant problem.	FACT: Many people with "mild" or "minor" brain injury—also referred to as concussion—do recover within a few weeks or months. But others have major, long-term damage to mental functions and quality of life.
MYTH: For your brain to be damaged, your head has to actually strike another hard object.	FACT: TBI is often caused by the brain bouncing off the inside surfaces of the skull—which can happen without the head being hit on the outside.
MYTH: A brain injury is not serious if it is only "psychological."	FACT: The psychological effects of TBI may be more debilitating and long-lasting than the physical effects.

WHO IS MOST AT RISK?

Anyone can get a TBI, but some people have a higher risk.

- About twice as many males as females have a TBI.
- Risk is highest for young people up to 19 years of age and people over 65 years old. However, people of all ages have TBIs.
- There is a higher incidence of TBI in Native American and Alaskan Native communities than in the general population. Nationally, African Americans have the highest death rate from TBI.
- People who have had a TBI before are at higher risk of having another.

People who have had a TBI before are at higher risk of having another.



TBI is the signature injury of the Iraq and Afghanistan Wars.

Some activities place people at higher risk for a TBI. According to the Centers for Disease Control, the main causes of TBI are:

- Falls.
- Motor vehicle crashes.
- Events that cause the head or body to be struck, including many kinds of sports.
- Violent assaults.
- Military duties. Blasts now are a leading cause of TBI for active military personnel in war zones.

The Signature Injury of the Iraq and Afghanistan Wars is TBI. TBI now affects more than one-fourth of the survivors of bomb blasts in war zones. Were it not for advances in body armor, helmets, and battlefield medicine, most military victims of TBI would not have survived as recently as 15 years ago.

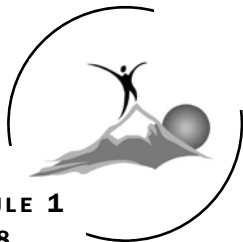
Medical, behavioral and social problems following TBI may lead to failed relationships and careers, substance abuse, and inability to re-adapt to civilian life. Many military survivors of TBI also suffer from post traumatic stress disorder (PTSD).

WHAT HAPPENS WHEN A TBI OCCURS?

With a TBI, there is a **primary event** or initial injury. Then there may be a **secondary event**, or further injury from the body's and brain's responses.

For example, a person striking his or her head very hard causes immediate bruising and tearing of brain tissue—a **primary event**. Then a reaction by the brain, such as swelling, puts pressure on brain tissue and causes more damage—a **secondary event**.

Damage from a secondary event can be more severe than damage from the primary event.



PRIMARY EVENTS—WHAT MAY HAPPEN DURING TRAUMA

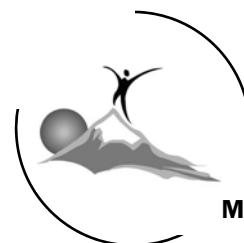
- **Tearing of brain cells (axonal shearing)**—When the head is hit or jerked, the brain can slam back and forth inside the skull. Because the brain is soft and jello-like, it is pressed and stretched inside the skull. The fragile brain cells may be stretched to a point of tearing. This is known as axonal shearing. When this happens, the damaged brain cells die.
- **Bruising and bleeding (contusion)**—When the brain slams against the inside of the skull, small blood vessels can be torn. Bruising and bleeding can cause death of brain cells.
- **Skull fracture**—When skull bones are cracked or broken, they may press on the brain or penetrate it with pieces of bone.
- **Coup-contracoup (pronounced *coo-contracoo*)**—Damage can occur both at the spot where the head is struck (coup) and directly opposite (contracoup), due to the forward and backward motion of the brain inside the skull.

For more information, look up:

www.tbi.org/html/coup_contracoup.html

SECONDARY EVENTS—THE BODY'S RESPONSE TO TRAUMA

- **Brain swelling (edema)**—After an injury, the brain swells just like any other injured body part. Swelling inside the skull can cause damage by squeezing brain cells or interrupting flow of blood and oxygen to brain tissue. Severe swelling can press on the brain stem and cause death.
- **Blood pooling (hematoma)**—If damaged blood vessels are large, they may make a pool of blood inside the skull and increase pressure on the brain. Surgery may be needed to drain blood out of the skull.
- **Shock**—Loss of blood to the brain, due to the body's shock response, may injure brain tissue.



MEASURES OF SEVERITY OF TBI

Medical professionals use some common severity scales to describe TBIs. Because you may hear these, it is important for you to understand what they are and what they are not.

- **What they are**—A rating of severity is necessary for medical professionals to record the injury right after it happens, decide on medical treatments, track changes following treatments, and get paid for medical services.
- **What they are not**—Early severity ratings have been found NOT to be very good at predicting problems that may develop later or how much time or what the path will be to recovery.

Over time, a TBI survivor may do better or worse than predicted at first. Some reasons include:

- The problems (symptoms) will be different depending on whether damage is focal (focused in one or a few limited areas), or diffuse (spread throughout the brain).
- Complicated interactions take place among different parts of the brain. Parts of the brain that have less damage, or that recover quickly, may try to take over for a more damaged part with unpredictable results.

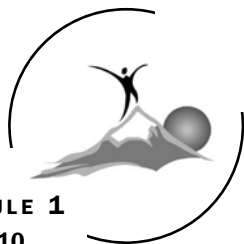
♥ CAREGIVER TIP

The truth is, there is much we still don't know about the brain and its ability to recover after injury. The best attitude toward recovery is hope, balanced with realism.

COMMON RATINGS OF SEVERITY

Medical professionals may rate a TBI as “**mild**,” “**moderate**,” or “**severe**” based on whether the person lost consciousness and for how long.

- **Mild TBI** is defined as loss of consciousness for 15 minutes or less, any loss of memory surrounding the trauma event, or an altered mental state such as feeling dazed, disoriented, or confused. It may also be referred to as a “concussion.” It is estimated that up to 75% of TBIs are initially rated as mild.
- **Moderate TBI** is defined as loss of consciousness lasting between 15 minutes and a few hours, followed by a few days or weeks of mental confusion. About 10-25% of TBIs are rated moderate.



- **Severe TBI** is defined as loss of consciousness for six hours or longer, either immediately after the injury or following a period of clarity. Less than 10% of all TBIs are rated severe. People who remain unconscious for a very long time may be described as in a **coma** or **permanent vegetative state**.

Common scales for rating TBI include:

- **The Glasgow Coma Scale (GCS)**—Used to measure different states of alertness following a brain injury. The lowest possible GCS score is three for a person in a deep coma. The highest score of 15 is for a fully awake person.
- **The Rancho Los Amigos Scale**—Used to track progress of a TBI survivor during rehabilitation.

♥ CAREGIVER TIP

In planning and providing care, try to get current information about the person's condition and abilities. Do not rely too much on ratings of severity done right after the injury.

FACTORS THAT AFFECT RECOVERY

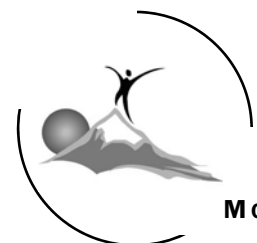
It is hard to know exactly what will happen following a TBI because:

- Early rating of the brain injury may not tell you much about what can happen in the long run.
- It is impossible to predict all possible effects of damage because interactions within the brain and body are so complex and change over time.

To complicate matters further, there are several more factors unique to each person that affect the recovery process:

- Amount of time that has passed since the injury and the amount of time between the injury and when it was accurately diagnosed and treated.
- Personality type and learning style, before and after injury.
- General physical and mental health, before and after injury.
 - Poor physical health and co-existing mental health or substance abuse problems usually make it more difficult to recover from TBI.
 - Chances of recovery are worse for adults who have had more than one brain injury, including childhood brain injuries.

It is hard to know exactly what will happen after a TBI.



- Psychological reactions to the trauma event, to injury, and to having a new disability.
- Influences in the person's environment that help or hinder the recovery, including the person's support system.

Given this complexity, how can you know how to help? That is what the rest of this training is about.

For now, keep in mind that **research on TBI is giving us new reasons for hope.**

- Because we now know recovery is unpredictable and takes longer than formerly believed, and because new treatments constantly are being discovered, **an early diagnosis of brain damage does not have to be a life sentence.**
- Research is proving that things we can control, such as the kind of care we give, can make a big difference.

♥ CAREGIVER TIP

A TBI survivor is likely to experience changes, for better or for worse, over weeks, months, or even years. Recovery may be a lifelong process.

TO LEARN MORE

TBI FACTS

From The National Center for Injury Prevention and Control, U.S. Centers for Disease Control:

www.cdc.gov/ncipc/tbi/FactSheets/Facts_About_TBI.pdf

From the Department of Health, State of Washington:

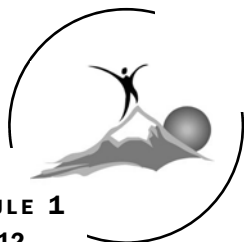
www.doh.wa.gov/HWS/doc/IV/IV_TBI2004.doc

From the Brain Injury Association of America:

www.biausa.org/word.files.to.pdf/good.pdfs/2002FactSheetBrainInjury.pdf

From the Defense and Veterans Brain Injury Center, Walter Reed Medical Center:

www.dvbic.org/pdfs/DVBIC_Fact_Sheet_2006.pdf



About brain injuries for military personnel in war zones:

www.usatoday.com/news/nation/2005-03-03-brain-trauma-lede_x.htm

www.msnbc.msn.com/id/11882164/site/newsweek/

Problems caring for military TBI survivors:

[www.washingtonpost.com/wp-dyn/content/article/2007/02/17/](http://www.washingtonpost.com/wp-dyn/content/article/2007/02/17/AR2007021701172.html)

[AR2007021701172.html](http://www.washingtonpost.com/wp-dyn/content/article/2007/02/17/AR2007021701172.html)

ABOUT THE BRAIN

Interactive brain map, and brain functions:

www.bbc.co.uk/science/humanbody/body/interactives/organs/brainmap/

SOME NEW RESEARCH ON TBI

“Long-term effect of head trauma on intellectual abilities: a 16-year outcome study.” The Journal of Neurology, Neurosurgery, and Psychiatry, Oct 2006

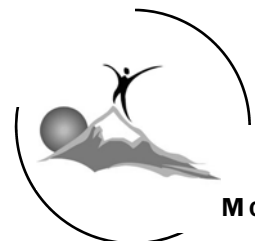
jnnp.bmj.com/cgi/content/abstract/77/1/71

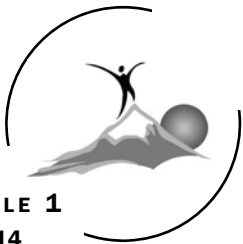
After 16 years, the long-term adjustment of people with severe head injuries was better than predicted from early ratings of severity.

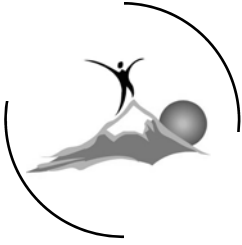
“Life satisfaction after traumatic brain injury and the World Health Organization model of disability.” The American Journal of Physical Medicine & Rehabilitation, Nov 2006.

www.amjphysmedrehab.com/pt/re/ajpmr/issuelist.htm

When considering various aspects of disabling conditions on life satisfaction of individuals with TBI, removal of barriers to participation in life activities was found to have the greatest impact. This is something caregivers can help with!







MODULE 2 – THE BRAIN: BEFORE AND AFTER A TBI

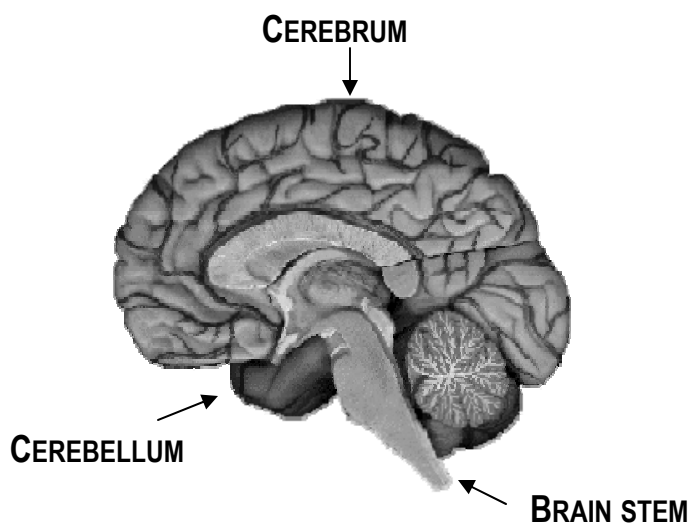
MODULE GOALS

- Learn possible effects of injuries on different parts of the brain.
- Understand ways that a TBI commonly affects the person who is injured.
- Gain knowledge about strategies for dealing with the changes that may be a result of a brain injury.

A TBI often involves damage to more than one area of the brain. Damage may be focused or spread throughout the brain, causing a variety of symptoms. **Knowing what each part of the brain does can be helpful in understanding people with brain injury.**

The brain is made up of many parts, each having different functions. It helps to think of the brain in three major areas:

- Cerebrum
- Cerebellum
- Brain stem/Midbrain

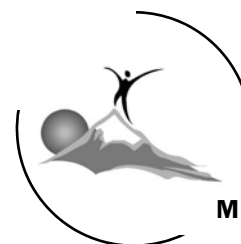


CEREBRUM

The cerebrum is the largest part of the brain. It sits on top of the rest of the brain and has a folded surface called the **cerebral cortex**. The cerebral cortex contains major nerve centers that are involved in:

- Thinking
- Personality and awareness
- Senses
- Voluntary movement

MAJOR AREAS OF THE BRAIN

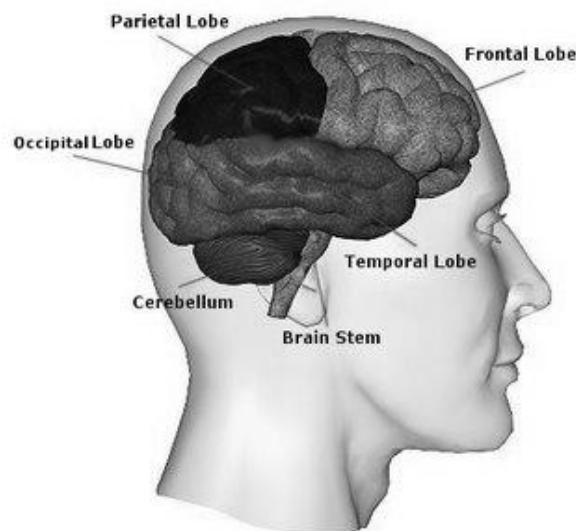


The two hemispheres of the brain produce different modes of thinking in most people.

The cerebrum is split into two halves, called hemispheres, that communicate with each other. Each hemisphere is made up of **frontal**, **parietal**, **occipital**, and **temporal lobes**, each having different functions.

In most people, the two hemispheres produce different modes of thinking.

- The left hemisphere is associated with logical thinking, analysis, accuracy, and breaking things down into parts.
- The right hemisphere is associated with feeling, creativity, and looking at things as a whole rather than in parts.



CEREBELLUM

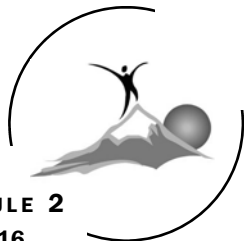
The cerebellum is the second largest area of the brain, and is located under the back of the cerebrum. It is mainly involved in:

- Coordinating muscles to allow precise movements.
- Controlling balance and posture.

BRAIN STEM

The brain stem connects the brain to the spine and is responsible for regulating many life support mechanisms, including:

- Heart rate
- Digestion
- Breathing
- Sleeping and waking



MIDBRAIN

The midbrain is the area in the deep center of the brain located under the cerebrum and above the brain stem. It is made up of several structures with important functions, including:

- Acting as the relay station for incoming nerve impulses, and sending them to appropriate regions of the brain for processing.
- Controlling survival instincts including “fight or flight” reactions, drives and emotions.
- Mediating effects of mood or behavior.
- Keeping conditions in the body constant by regulating body temperature, thirst and hunger, and controlling the release of hormones.

A general understanding of the major parts of the brain and their functions can help you understand changes and behaviors of people who have had a TBI. A person may experience different problems or changes depending upon the area of the brain that has been damaged.

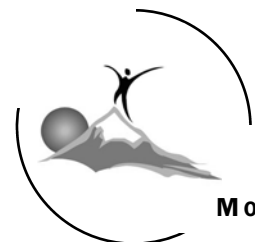
As you learned earlier, the **cerebrum** is made up of two hemispheres, and each hemisphere is made up of **frontal, parietal, occipital, and temporal lobes**. Damage to any of these specific lobes, or to the **cerebellum**, or **brain stem** will affect an individual in different ways.

In the following pages, you will learn about some of the specific changes that may occur as a result of damage to one or more areas of the brain.

COMMON PROBLEMS FROM INJURY TO THE BRAIN’S LEFT HEMISPHERE

- Difficulties in understanding spoken and written language—referred to as “receptive” language ability
- Difficulties in producing language, such as through speaking or writing—referred to as “expressive” language ability
- Difficulties remembering language
- Anxiety or depression
- Decreased control over the right side of the body
- Impaired logic and judgment
- Problems with sequencing (understanding and carrying out step-by-step actions in the right order)

HOW TBI AFFECTS THE BRAIN



COMMON PROBLEMS FROM INJURY TO THE BRAIN'S RIGHT HEMISPHERE

- Difficulty locating where objects are in space through vision
- Lack of attention to the left side of the body (“left neglect”)
- Decreased awareness of one’s own challenges
- Altered creativity or music perception
- Loss of the “big picture”
- Visual memory problems such as not remembering a friend’s face
- Decreased control over the left side of the body

COMMON PROBLEMS FROM DIFFUSE INJURY (INJURY SCATTERED THROUGHOUT BOTH HEMISPHERES OF THE BRAIN)

- Reduced thinking speed
- Confusion
- Reduced attention and concentration
- Fatigue
- Impaired thinking (cognitive skills) in all areas

♥ CAREGIVER TIP

Remember, if a preferred area of the brain is damaged, the person’s mode of thinking may change.

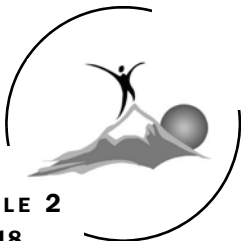
COMMON PROBLEMS FROM INJURY TO THE FRONTAL LOBE OF THE BRAIN

Organizing and doing (executive functions)

- Difficulty initiating activity—not “self-starting”
- Becoming disorganized
- Unable to monitor one’s own actions or progress

Thinking (cognitive functions)

- Poor ability to solve problems
- Lack of good judgment
- Lack of normal inhibitions about behavior—for example, not knowing when to “keep your mouth shut”



Thinking (cognitive functions) continued

- Problems with planning and anticipating consequences of one's actions
- Problems with planning body movements
- Changes in personality and problems with emotional control
- Lack of awareness of one's limitations
- Lack of ability to pay attention or concentrate
- Lack of mental flexibility
- Problems with speech (expressive language)

COMMON PROBLEMS FROM INJURY TO THE PARIETAL LOBE

Senses

- Changes in perception of touch
- Difficulty perceiving size, shape, and color
- Problems with spatial perception (not being able to tell where parts of the body are at within space)
- Problems with visual perception that can cause:
 - Poor hand-eye coordination
 - Difficulty with drawing pictures

COMMON PROBLEMS FROM INJURY TO THE OCCIPITAL LOBE

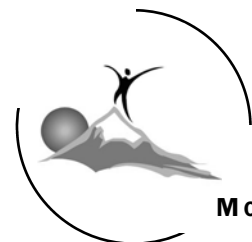
Senses

- Visual perception
 - Blindness
 - Difficulty interpreting visual images
 - Words look meaningless
 - Visual illusions, or seeing things that others do not

COMMON PROBLEMS FROM INJURY TO THE TEMPORAL LOBE

Thinking (cognitive functions)

- Memory problems
- Difficulty understanding language (receptive language)



Organizing and doing (executive functions)

- Problems with organizing and knowing what order to do things in (sequencing)

Senses

- Hearing problems

COMMON PROBLEMS FROM INJURY TO THE CEREBELLUM

Body movements (motor functions)

- Problems maintaining physical balance
- Lack of coordination of physical movements
- Problems with skilled motor activity, such as finger movements, using tools

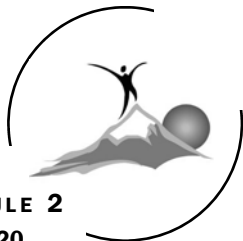
COMMON PROBLEMS FROM INJURY TO THE BRAIN STEM

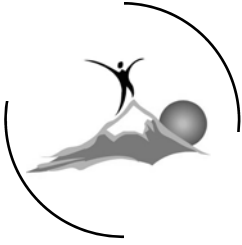
Basic life processes (regulatory functions)

- Breathing problems
- Problems with heart rate
- Problems with waking and maintaining consciousness
- Changes in sleep and waking patterns
- Difficulties with attention and concentration

TO LEARN MORE

Link to “What is a Brain Injury” at <http://biawa.org/whatis.htm>





MODULE 3 – PHYSICAL AND COGNITIVE CHANGES AND TBI: HOW TO HELP

MODULE GOALS

- Increase understanding of the physical changes that may result from a TBI.
- Understand cognitive changes that may result from a TBI.
- Learn specific ways to help with some common physical, sensory, and thinking problems that come from TBI.

MOTOR IMPAIRMENT

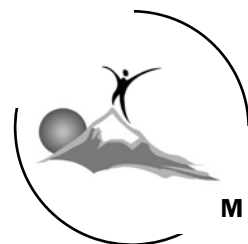
While not all brain injuries involve visible physical injuries, there often is some impact on physical functions. Adults with TBI may have problems with body movement, also known as **motor impairment**. Those impairments can include:

- Weakness on one or both sides of the body.
- Poor balance.
- Less endurance and strength than before TBI.
- Inability to coordinate muscle movements.
- Out-of-control movements such as jerks, shaking or tremors.

HOW TO HELP

- Encourage the person to take time and move slowly.
- Help the person regularly to do any kind of exercise he or she is able to do.
 - Any gentle and safe activity the person is still able to do at some level is beneficial physically and emotionally.
 - Physical conditioning and endurance may be low, so don't overdo it. Modify to current abilities, take it easy, and increase activity gradually.
- The person may benefit from working with a **physical therapist**.
 - Help the person get a referral and appointment.
 - Encourage the person to follow the physical therapist's instructions.

CHANGES IN PHYSICAL ABILITIES



A person who has seizures may have an attack at any time.

Motor coordination—it's harder than you think!

Try this exercise to get a feel for how hard everyday movements can be for a person with a brain injury.

- *Slightly lift your right foot off the floor.*
- *Begin circling your right foot clockwise.*
- *While continuing to circle your foot, try to write your whole name.*

If you thought that was difficult, imagine how frustrated you would be if every task, all day long, was this hard to complete.

SEIZURES

Only a few people with TBI will have a seizure. It is important to know what to do in case it happens.

Seizures, sometimes called convulsions, are when a person's body shakes in a rapid, out-of-control way. During a seizure, the person may lose consciousness and may fall down.

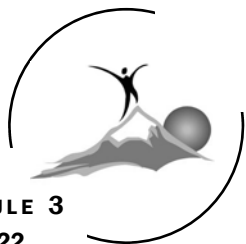
A person who has seizures may have an attack at any time. Seizures of all types are caused by sudden, disorganized electrical activity in the brain.

In spite of their appearance, most seizures are relatively harmless. Usually, they last from 30 seconds to two minutes.

Treat it as a medical emergency if a seizure lasts much longer than two minutes or if there are multiple seizures and the person does not wake up in between. In these situations, call 911 or get other emergency assistance.

HOW TO HELP

- Turn the person on his or her side, and remove any hard or sharp objects from the area.
- Loosen restrictive clothing, such as a collar or belt.
- Place something soft and flat under the person's head.
- Never force anything into the person's mouth, especially your fingers.
- Ask onlookers to leave the area.
- Call 911 if the seizure lasts more than two minutes, if there have been multiple seizures, or you suspect the person has swallowed his or her own vomit.



- Allow the person to lie quietly for five or more minutes following the seizure.
- Gently call the person by name and re-orient him or her to the surroundings and recent events as he or she awakens.
- Watch the person carefully as he or she gets up, and support him or her if he or she starts to fall.
- Take the person to a doctor's office or emergency room if he or she has an injury, such as a badly bleeding tongue.

♥ CAREGIVER TIP

Following a seizure, write down a description of what you observed as soon as you can. Emergency medical workers or the person's doctor may need to know how long the seizure lasted, what the person was doing immediately before it, and what happened afterward.

SWALLOWING

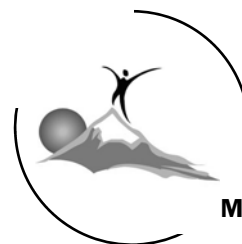
People who have had TBIs may have difficulties with swallowing, especially while eating or drinking. Be alert to risks of choking.

HOW TO HELP

- Encourage the person to take his or her time when eating, drinking, or speaking.
- Help the person sit upright while drinking or eating.
- Learn ahead of time what to do if choking occurs. Take first aid and cardiopulmonary (CPR) training.

♥ CAREGIVER TIP

If you are a paid in-home caregiver, you may take first aid and CPR training as continuing education. Talk to your supervisor or case manager to find out where training is offered in your community. If you are an unpaid caregiver, check with first aid and rescue organizations, community centers, or schools in your area.



CHANGES IN SPEECH AND COMMUNICATION

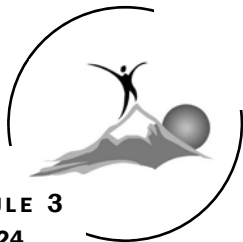
TBI may affect a person's abilities to speak, understand others, and make themselves understood.

The ability to communicate is extremely important for psychological and social well-being. TBI may affect a person's abilities to speak, understand others, and make themselves understood. Stay alert and help with any problems such as:

- Slow speech.
- Slurred speech.
- Difficulty understanding spoken or written instructions.
- Difficulty holding a conversation or finding the right word.
- Disorganized communication, rambling off the topic.
- Increased difficulty when trying to talk with more than one person at a time.

HOW TO HELP

- If the person's speech is very hard to understand, help the individual write down what he or she wants to say.
- Allow plenty of time for communication.
- Use short, simple sentences instead of long, complicated ones.
- Use simple gestures, such as pointing at an object, to support spoken messages.
- Encourage the person to ask for statements to be repeated or clarified as often as necessary for him or her to understand. Be patient.
- Ask, "Did I make sense?" instead of "Did you get that?"
- Don't yell or raise your voice if the person doesn't understand. If the person is hard of hearing, help him or her make an appointment with an **audiologist**.
- Agree with the person on a discreet cue you will give if he or she starts wandering off the topic of conversation.
- Encourage one-to-one conversations instead of trying to talk with several people at once.
- If the person has a hard time finding words or finishing sentences, don't finish sentences for him or her. Instead, ask the person to describe the word or what it sounds like. Only provide the word yourself if the person becomes frustrated and asks for your help.
- Explore using assistive devices such as communication boards, voice boxes, or picture boards, if that might be of help. Work with the person to develop or use a tool that works for his or her needs.
- The person might be helped by a **speech or language therapist**. Help the person to get a referral and appointment. Then encourage the person to follow the therapist's instructions.



CHANGES IN SENSES

VISION

Although vision problems are very common following a TBI, they are often one of the last symptoms to be identified and treated properly. Vision problems can limit the person's ability to safely perform everyday activities and to successfully return to work or school. Mild vision changes may improve on their own, but problems that do not improve within a few weeks should be evaluated by a vision professional.

Problems may include:

- Double vision (seeing two images of a single object).
- Blurred vision caused by inability of the eyes and brain to quickly and accurately change and hold focus.
- Abnormal movements of the eye, resulting in skipped lines or words when reading—causing poor comprehension or errors.
- Over-sensitivity to light, resulting in pain or headache.
- “Shimmering” appearance at the edge of vision, or “shimmering” or “floating” appearance of objects or words on a page.
- Narrowing of field of vision.
- Fatigue caused by eye strain.

HOW TO HELP

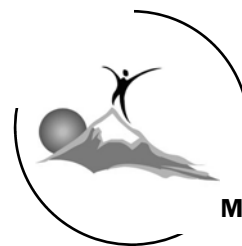
- Encourage the person to turn his or her head to compensate for reduced field of vision.
- Assist the person in seeing an **ophthalmologist** or **neuro-ophthalmologist** with training and experience in brain injury. This is especially important if vision problems are severe or do not improve in a few weeks or if they interfere with safety. Note that standard vision exams may fail to accurately identify vision problems caused by brain injury.

♥ CAREGIVER TIP

If the person you are caring for likes to read, find library books with large print or order books on tape. Reading to the person may be another way to share an activity together.

If the person enjoys working on the computer but can no longer read the small print, use the control panel to increase the size of the fonts on the screen.

Vision problems are very common following a TBI.



♥ CAREGIVER TIP

Eye-glasses or contact lenses worn before the injury may no longer adjust vision properly following a TBI. If eye-glasses or contacts do not seem to work to correct vision, encourage the person to get an examination by a professional who has experience working with TBI.

HEARING

Hearing problems following a TBI may include:

- Loss of hearing associated with injury to the **body's balance system**, which includes the inner ears, eyes, and brain.
- Persistent “ringing” or “buzzing” (tinnitus).
- Increased sensitivity to noise.

HOW TO HELP

- Talk with the person about hearing issues and ask what you can do to help him or her understand or hear you.
- Check with the person to see if he or she is comfortable with the amount of surrounding noise. Make adjustments as needed.
- Assist the person in being seen by an **audiologist** who has training and experience with brain injury if hearing problems interfere with the person's ability to understand others or does not improve over time.

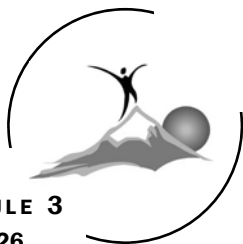
TASTE AND SMELL

Changes in smell and taste are common following a TBI. These senses are important to know what is safe to eat or drink. They also affect whether the person enjoys eating. This can affect the person's nutritional health and enjoyment of social activities that include eating with others.

Be alert to signs of problems with taste or smell, including:

- Eating more or less food than usual.
- Adding extra salt or spices to food.

Changes in hearing, taste, and smell are common following a TBI.



HOW TO HELP

- Watch out for safety risks. A person with TBI may not be able to smell something burning or to tell that food is spoiled by its smell or taste.
- If the problem is severe or poses a safety risk, encourage the person to talk with a physician about testing for loss of smell and taste related to brain damage.
- Pay attention to textures and colors when preparing food to make eating more enjoyable.

Adults with TBIs often have headaches and other kinds of pain long after the injury. Pain can affect every aspect of a person's life, including:

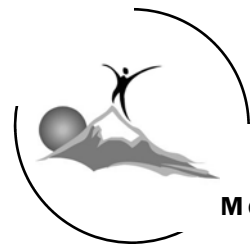
- The ability to participate in daily activities.
- The person's moods, which may affect behavior and/or interfere with relationships.
- Taking an enormous amount of energy and contributing to being overwhelmed and depressed.

HOW TO HELP

- Be alert for nonverbal signs of pain. This is especially important if the person with a TBI is not able to say he or she is in pain. Signs to look for include:
 - Agitation and restlessness.
 - Aggressive behavior, such as yelling or striking out when touched.
 - Inability to sleep.
- Assist the person in getting plenty of rest and doing gentle exercise, if he or she is capable. Monitor the intensity and duration of exercise to help the person avoid overdoing it. This can cause more pain.
- Massage, acupuncture, or medication may be helpful for some kinds of pain.
- Learn about and help the person practice relaxation techniques and deal with emotional reactions such as anxiety, anger, sadness, and depression.

PAIN

Adults with TBIs often have headaches and other kinds of pain long after the injury.



- A **pain management program** designed by a medical professional may help. Help the person get a referral and appointment and follow the pain management program.
- Ask the person about the severity of pain by using the scale below:



CHANGES IN SLEEP

Early identification and treatment of sleep problems can help the person function better on all levels.

In the days immediately after injury, adults with TBIs often need extra sleep. Even years later, an adult with a TBI may tire easily and continue to have changes in sleep patterns.

Lack of sleep interferes with recovery and rehabilitation. Early identification and treatment of sleep problems can help the person function better on all levels.

Problems caused by changes in sleep and energy include:

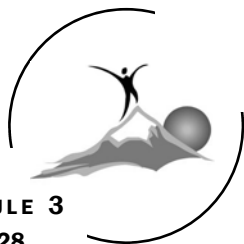
- Constant lack of energy; becoming easily “worn out”.
- Sleepiness most of the day.
- Not being able to fall asleep or stay asleep at night (insomnia).

♥ CAREGIVER TIP

Some medications may cause sleep problems for people with TBI even if they do not have that affect on other people. Be aware that there could be differences.

HOW TO HELP

- Help the person follow regular patterns of sleeping, waking and activity, including whatever exercise he or she is able to do safely.
- Help the person to eat healthy food, drink plenty of water, and avoid foods and drinks that contain caffeine, alcohol, and sugar.
- Help the person monitor his or her physical and mental activity, and take breaks to prevent getting over-tired.



- Help the person see a doctor if the person is not getting enough sleep. He or she should discuss medication or other therapy with a doctor. Do not let the person go without enough sleep for more than a few days before seeking help.
- If the problem is severe, a doctor might recommend a **sleep study** to identify causes and treatments.

♥ CAREGIVER TIP

After TBI, a person may have recurring nightmares, “night terrors” (waking dreams, or hallucinations when half awake), or flashbacks (re-experiencing the traumatic event) that repeatedly awaken them from sleep.

These may be symptoms of post-traumatic stress disorder (PTSD) or other problems adjusting to the trauma event. PTSD will be discussed in more detail in Module 4.

TBI can alter the way people experience and express their sexuality. Common problems include:

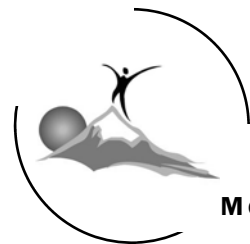
- Reduced sex drive—About half of adults with TBI have a drop in sex drive. Others have an increase or no change.
- Difficulties with sexual functioning—Around half of male TBI survivors have erectile problems. About half of both men and women with TBI have difficulties reaching orgasm.
- Reduced frequency of sex—People with TBI may have sex less often due to social reasons, such as break-up of relationships, or the physical and emotional changes caused by TBI.
- Behaving sexually at inappropriate times—For example, a person who has judgment or memory problems because of a TBI may masturbate in front of other people.

How to help

- Talk about sexual issues with the person if they arise.
- Encourage and assist the adult with TBI to bring up any concerns about sexuality with a medical provider or therapist.
- Encourage and assist partners in getting help from a couples’ therapist with experience working with people with disabilities if the person you are caring for is in a relationship and there appear to be problems related to sexuality.

CHANGES IN SEXUALITY

TBI can alter the way people experience and express their sexuality.



CHANGES IN COGNITIVE FUNCTIONING

- Remain calm if the adult with a TBI behaves inappropriately in a sexual way. If you appear shocked or distressed, it could make the person feel there is something wrong with his or her sexuality.

Tell the person when a behavior is inappropriate and offer alternatives—for example, suggest that the person masturbate in a private area and not in front of others.

- Set firm boundaries on sexual behavior.

♥ CAREGIVER TIP

Although talking about sex can be embarrassing, it is important for the person with a TBI and their loved ones to address sexual issues. Everyone is entitled to express sexuality. Encourage this discussion.

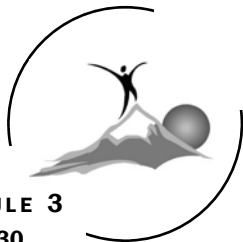
TBI is often followed by one or more changes in thinking (cognitive) processes, including:

- Memory problems.
- Slower speed in processing information.
- Problems with paying attention and maintaining concentration.
- Problems with abstract reasoning—not understanding words with multiple meanings, not understanding examples, taking things too literally.
- Problems with planning, problem-solving and sequencing (doing things in the right order).
- Problems with initiating actions (being self-starting).

It is very important to understand these problems when trying to help a person with a TBI. Each cognitive process will be discussed in more detail in the following sections of this module.

♥ CAREGIVER TIP

At times, it may appear that the person is refusing to cooperate when actually he or she is having trouble understanding what needs to be done or needs more time to respond.



MEMORY

Memory is the process of organizing, keeping, and recalling information that is recent (short-term memory) or from the distant past (long-term memory).

People with a TBI might have:

- Less ability to store and retrieve new information.
- Difficulty remembering details.
- Confusion or no memory of past events—especially, events that occurred around the time of the injury.

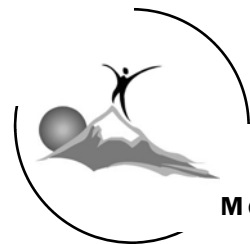
♥ CAREGIVER TIP

A person with memory problems may make up stories or events to fill in gaps in his or her memory. This is called “confabulation”. It can be confused with lying. In fact, confabulation is due to memory problems and the feeling of pressure to have an answer to something.

To a person with TBI who has memory problems, the confabulated story may seem very true. There is no need to insist the person is making the story up. If the confabulation causes the individual stress, help him or her to move on to a different topic or help the person to fill in gaps in memory by what you know to be true about a situation.

HOW TO HELP

- Help and encourage the person to do the activity at his or her pace. Stress or rushing can make memory problems worse.
- Help the person learn and use memory aids, such as notes, lists, a tape recorder, paper, or computer planners.
- Introduce new information or skills one at a time rather than teaching several new things at once.
- Use repetition to help the person learn new tasks and information, if appropriate.
- Provide reminder calls for important events or tasks.
- Develop and maintain regular routines.
- Write directions for how to use appliances, when garbage is picked up, and other parts of the daily routine. Clear an area where the person with a TBI can post this information in a way that can help him or her participate in the daily routine of the household.



A person with a TBI may have trouble processing information in the same way he or she did prior to the TBI.

- Put a clipboard on the wall to make notes on items needed at the store or goals for a particular day. This will remind the person without having to hold the information in his or her memory.
- When it's appropriate, add "brain games" when you interact together such as mind bender puzzles, scrabble, or cross word puzzles. Another good memory game is to learn the names of local birds, trees, or streets and practice these on walks around the neighborhood.

SPEED OF THOUGHT PROCESSES

Because of damage to parts of the brain that help a person to make decisions or think through situations, a person with a TBI may have trouble processing information in the same way he or she did prior to the TBI. Possible symptoms include slow reaction time or slow decision-making.

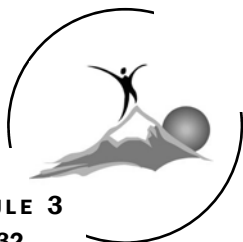
HOW TO HELP

- Allow plenty of time for the person to respond to questions, problems, or new situations.
- Do not jump in and make statements or decisions for the person. Whenever possible, allow him or her as much time as needed to respond or to make a decision.
- If the person asks the same questions repeatedly or asks you to do something you've already done, it likely means that he or she does not remember asking or does not remember your answer. It may help to write down the question and your answer so that he or she can look at the note and know that the question or request has been answered.

♥ CAREGIVER TIP

Some people with TBI may also have problems with judgment due to the new ways their brains process information. It may become important to listen when the person answers the phone to make sure he or she doesn't give out personal information to strangers.

One way to problem solve this situation is to create a "personal code" of rings for when family or friends call so that the person only answers those calls. You may want to let the phone ring until a voice-mail system picks up. That way, the person with a TBI can screen all phone calls.



ATTENTION AND CONCENTRATION

To complete the many simple and complex tasks that fill our day, we must be able to screen out information that is not relevant and stay focused on each task until it is finished. People with TBIs may have problems completing even simple tasks, like brushing their teeth or complex tasks such as balancing a checkbook.

Common problems include being:

- Unable to remember to return to a task or activity if interrupted.
- Unable to pay attention long enough to learn something new.
- Easily distracted.
- Unable to do two or more things at once.
- Unable to filter out things that are not related to the task at hand.

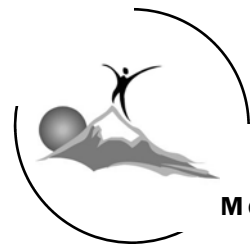
HOW TO HELP

- Keep the space around the person free of noise, clutter, and other unnecessary distractions.
- Help the person create a daily chore calendar. This can include times that things should be done. For example, when to take a shower or when to eat lunch. Make the calendar on a dry erase board so it can be used over and over.
- Encourage the person to use notes and lists to hold his or her place when shifting between tasks.
- Avoid exposing the person to too much stimulation or information at once (“overload”).
- Use a timer to cue the person when it’s time to begin a different task.
- Encourage the person to see a doctor if problems with attention and concentration are severe.
- Explore resources such as **occupational therapy** that might help evaluate problem areas and train the person to function better in everyday life and work.

♥ CAREGIVER TIP

Fatigue and sleep disturbances can reduce a person’s ability to pay attention and concentrate. To improve concentration, help the person maintain a regular sleep schedule, and encourage him or her to rest if he or she begins having extra difficulty in paying attention. The person might want to schedule a daily nap along with regular light exercise if appropriate.

*People with TBI
may have trouble
completing simple
tasks.*



ABSTRACT REASONING

Abstract reasoning allows us to understand language at more than one level at a time. It is a complex thought process, and one of the last abilities we develop as we mature. It is easily lost through brain injury.

Possible symptoms include:

- Difficulty understanding double meanings, sarcasm, or humor.
- Getting “stuck” on one view, not being able to consider different options.
- Taking things too literally.
- Difficulty understanding concepts and ideas.

HOW TO HELP

- Speak in plain words and give practical examples.
- Suggest other ways of looking at a situation or idea.
- Avoid, or else explain, double meanings and jokes.

♥ CAREGIVER TIP

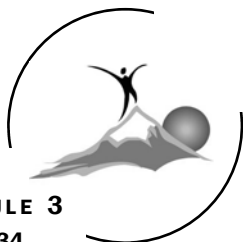
A word of caution

In trying to cheer up a person who was in a trauma unit with a broken hip and several other major injuries due to a car accident, a doctor said jokingly, “You’ll do great! You’ll be skiing two months from now.”

Unfortunately, the person also suffered a brain injury during the car accident and lost abstract reasoning ability. She took the doctor’s comment literally. Two months later, she became depressed when she had not recovered enough to go skiing.

PLANNING AND PROBLEM SOLVING

Attention, concentration, memory, planning, and sequencing (knowing the proper steps in which to perform an activity) all come into play in solving a problem. Problem solving is a very complex activity that may become extremely challenging for an adult following a TBI.



Common problems include:

- Being too rigid in planning or carrying out activities.
- Thinking there is only one right way to do things.
- Difficulty understanding consequences of one's actions or words.
- Difficulty knowing which step in a process comes first (for example, putting shoes on before putting on socks).
- Difficulty organizing tasks and daily schedules.

HOW TO HELP

- Be patient. Allow the person time to work through difficult situations on his or her own. Step in only if the person becomes too frustrated to solve the problem, or he or she asks for help.
- Help the person break down large or complex tasks into small, simple ones and do each step in the right order.
- Suggest and explain other solutions.
- Help the person to establish and maintain routines for everyday tasks.
- Help the person to identify and use assistive tools such as white boards, sticky notes, calendars, a tape recorder, an affordable palm pilot, and/or color-coded systems.

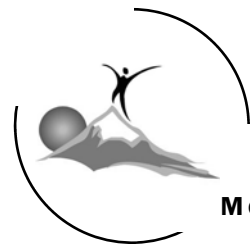
INITIATIVE

After a TBI, some people may no longer be able to start or follow through on tasks by themselves. They may seem to lack facial expression, inner drive, or motivation.

Common problems include:

- No forward action on tasks.
- Needing constant prompts or directions to do things.
- Sitting in front of television all day, or otherwise having problems changing from one activity to another without prompting.
- Not performing activities of daily living (ADLs) or not taking good care of himself or herself.

After a TBI, a person may no longer be able to start a task on their own.



HOW TO HELP

- Understand that the change in motivation and activity is due to changes in the brain. Do not accuse the person of being lazy, lecture, or punish him or her for not doing tasks, or tell the person to “just get over it.”
- Assist the person to make checklists to cue tasks, and to break tasks into simple steps that seem more “do-able.”
- Help the person learn to use a timer as a cue to begin routine tasks.
- Provide verbal cues or reminders only as needed and appropriate.

♥ CAREGIVER TIP

Lack of interest or motivation, especially about activities the person used to enjoy, may be a sign of depression. Reminding the person of successes or how far he or she has come in the past week, days, months can help the person feel there is hope and that he or she has value.

If the person expresses feelings of worthlessness, hopelessness, constant sadness, or a desire to “end it all,” call a medical or mental health professional immediately for screening and possible treatment for depression.

TO LEARN MORE

COMMON PHYSICAL, SENSORY, AND THINKING PROBLEMS

Seizures and TBI:

www.nlm.nih.gov/medlineplus/ency/article/000021.htm

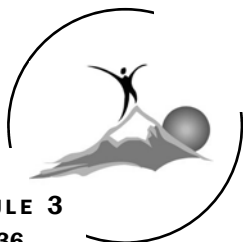
Sexual issues and TBI:

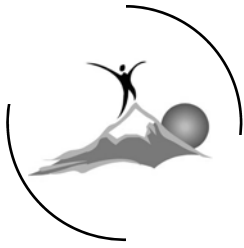
From the Brain Injury Association of America:

www.biausa.org/publications/sexualityisafamily.htm

Fact sheet from Better Health Channel:

www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Traumatic_brain_injury_and_sexual_issues?OpenDocument





MODULE 4 – CHALLENGES OF CAREGIVING: EMOTIONAL AND BEHAVIOR CHANGES AND TBI

MODULE GOALS

- Understand how some emotions and behaviors may be reactions to changes caused by TBI, rather than directly caused by brain damage.
- Learn the A-B-C method for helping with challenging behaviors.
- Learn what to do when there are other physical, mental, or addiction issues in addition to TBI.

In Module 2, you learned that damage to certain parts of the brain can cause changes in the person's ability to control emotions. As a result of the trauma, the person may feel emotions such as anxiety, fear, rage, or sadness.

In this module, you will learn how psychological reactions to TBI can also trigger emotions and behaviors in adults living with TBI.

Sometimes a person with a TBI will express a variety of emotional and behavioral reactions because he or she is overwhelmed. After awhile, reactions may become automatic and block progress to further stages of recovery. Automatic emotions and behaviors can be difficult for a person with a TBI to change without help from you and others.

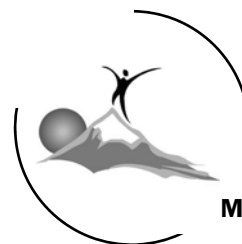
HOW TO HELP

Most people with TBI want to resume active social lives, including rewarding work and relationships. To do so, they may have to re-learn and practice controlling their emotions and behaviors. You can help by following these guidelines:

- Be consistent.
- Model calm and controlled behavior. **Remember not to take the behavior personally.**
- Redirect challenging behavior.
- Be an advocate in obtaining professional help.
- Strive to maintain compassion and a sense of humor. Remember that it's the TBI, not the person, causing the challenging behavior.
- Help the person set realistic goals.
- Expect that both you and the person with a TBI may have ups and downs.
- Recall and focus on successes to remain hopeful about progress in the long run.
- Use the caregiver stress checklist in Module 5 to monitor your own emotions and behaviors. Take breaks from caregiving responsibilities as needed to protect your own physical and emotional health.

REACTIONS TO CHANGES CAUSED BY A TBI

A person with a TBI may have to re-learn and practice controlling their emotions and behaviors.



THE A-B-C METHOD FOR HELPING TO UNDERSTAND CHALLENGING BEHAVIOR

KEEP IN MIND...

- If the person is endangering his or her safety or that of others, call 911 or the crisis line in your area immediately.

♥ CAREGIVER TIP

Following a brain injury, a person's behavior and emotions may change so much that he or she does not seem like the same person as before the TBI—even to himself or herself. You can help the person find the positive aspects of this "new" self by following some of the tips in the rest of this module.

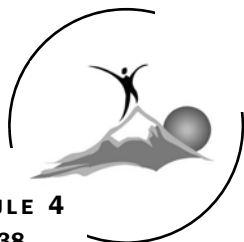
As you observe behaviors of the adult with a TBI, both positive and negative, try to understand what contributes to or may be causing them. Look at what's happening both before and after the behavior for clues about how to change challenging behavior. The A-B-C method will help you do this.

A—Antecedents: What was happening right before the behavior?

B—Behavior: What is the behavior?

C—Consequences: What happens as a result of the behavior?

- By noticing what was happening right before a challenging behavior (the antecedent), you may be able to identify what triggered the behavior. Then you can change or avoid these triggers in the future.
- Chart the ups and downs (noting the hour, the day of the week, and the date). The person you are caring for may have a particular time or day that is particularly stressful.
- Make sure your own behavior is not an antecedent for negative behavior!
- If you are stressed about finances, family or other personal matters, try not to show your own stress to the person with a TBI. Often this can trigger stress that may overwhelm the individual and lead to anger or frustration.
- Take notice of behavior that brings about consequences that work for the person with a TBI and for others around him or her. Notice especially what happens right before the behavior. Repeat or reinforce antecedents that trigger the desired consequences.



HOW THE A-B-C METHOD WORKS

- If a consequence or result of a behavior is what the person wants, the behavior is likely to be repeated.

Example—

Antecedent (or trigger): Sam's caregiver is preoccupied and is not paying as much attention to Sam as he wants.

Behavior: Sam begins yelling and throwing things.

Consequence: His caregiver stops what she is doing to see what is wrong and gives Sam lots of attention.

Because the result of Sam's behavior is positive for him, he is more likely to yell and throw things the next time he wants attention.

- If the behavior leads to results that the person does not want, it is less likely to occur again.

Example—

Antecedent: Sam's caregiver is preoccupied and is not paying as much attention to Sam as he wants.

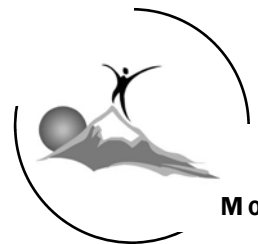
Behavior: Sam begins yelling and throwing things.

Consequence: This time his caregiver ignores him until he asks her politely for help.

Because yelling and throwing things no longer works, Sam is less likely to use this behavior in the future to get attention.

***NOTE:** This method can work best with someone who is able to take control of his or her own behavior. If the person is unable to control his or her behavior, you may need to work out a method where the person with a TBI will take time to "cool off".*

Once he or she is better able to control emotions or outbursts, the person can then work on asking for help in a more polite manner.



- If the consequence or result helps the person to get out of an unpleasant situation or helps to avoid the situation altogether, the behavior is likely to be repeated.

Example—

Antecedent: Cheryl is afraid she will be embarrassed by saying or doing the wrong thing if she goes to a social event. She is invited to a party by a friend who knew her before her TBI.

Behavior: Cheryl calls the host at the last minute and says she is sick.

Consequence: Cheryl stays home and watches television by herself. She is glad she didn't embarrass herself.

Because Cheryl avoided being embarrassed, the next time she is invited to a social event, she comes up with another excuse and stays home.

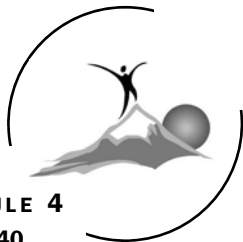
HOW TO HELP

- Understanding the reasons why people act as they do is difficult. Human behavior is complicated. When a person has a TBI, understanding behavior may be even harder.
- Be patient with the person you are caring for, as well as with yourself.
- Use the A-B-C method to try to discover what is causing or leads up to poor behavior.
- Use the A-B-C method to look at consequences, and whether the person is reacting to things you are saying and doing. If so, being aware of your own behavior and changing it may be all that is needed to change the problem behavior of the person with TBI.

There are other factors that reduce the ability of the person with a TBI to behave appropriately or maintain emotional control. Consider these when you are exploring possible reasons for a behavior. The first four bullets outlined below were discussed in more detail in Module 3. You will learn more about the others in this module.

- Not getting enough or getting irregular sleep
- Problems related to sexuality
- Seizures
- Pain
- Anger

When a person has a TBI, understanding behavior may be even harder.



- Anxiety and/or Post Traumatic Stress Disorder (PTSD)
- Depression
- Other psychological reactions to a TBI
- Impaired abilities
- Relationship issues
- Substance abuse, addictions
- Other physical, developmental, or mental health disabilities

♥ CAREGIVER TIP

Some people with TBI may experience emotional and behavior issues that require professional attention. People with symptoms of depression, constant anxiety, paranoia (unjustified suspicions or fear) or mania (over-active, out-of-control thinking and behavior) might benefit from seeing a mental health professional. It is important to select a professional with training and experience in treating traumatic brain injury.

ANGER

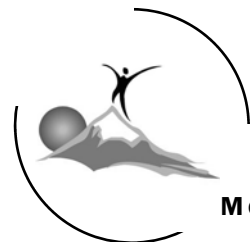
Problems with anger following a TBI often are due to a combination of causes.

- Physiological damage to certain parts of the brain can cause anger.
- Anger is a normal part of a **grief reaction**. A person may be grieving and is angry about all the losses that came with the brain injury, such as loss of physical or mental abilities, or the loss of a job, friends, money, and the control over his or her life.
- Some people may have been angry people before their injuries and still have that problem.
- The person with a brain injury is, in some ways, a different person. What makes the person angry now may be different from what made him or her angry before.

The following are some ways to tell that anger is at least partly caused by damage to the brain:

- Angry feelings come and go suddenly.
- Extreme anger or rage is triggered by minor events—the amount of anger is out of proportion to what caused it.
- The person having the angry episodes is surprised, embarrassed or distressed by them.
- The anger is made worse by fatigue, pain, or low blood sugar.

SPECIFIC GUIDELINES FOR HELPING WITH EMOTIONS



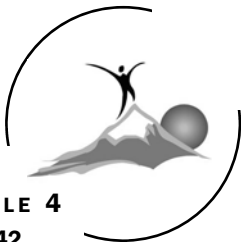
♥ CAREGIVER TIP

Behaviors that are very unpleasant for other people to deal with are also great opportunities to make a difference in recovery. You can play a crucial role by understanding and guiding changes in behaviors and emotional patterns that are getting in the way of recovery.

One way to do this is to ask the person to give you examples of how he or she is feeling. Allow the person a safe place to express emotions that are triggered by these feelings, and reassure the person that the feelings are okay.

♥ CAREGIVER TIP

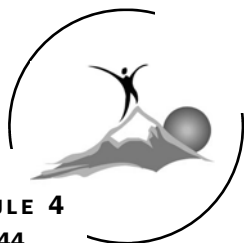
The most important thing you can do is to STAY SAFE yourself. Learn what triggers the person's anger. Watch the person's body language. If necessary, walk away and let the person cool down before you try to help him or her through the episode.



POSSIBLE REASONS FOR ANGER FOLLOWING A TBI AND HELPFUL CAREGIVER RESPONSES

REASON	WHAT TO DO
<p>ANGER AT THE CAUSE OF INJURY</p> <p>The person with TBI might be angry at the cause of the injury such as a drunk driver, an assailant, etc.</p>	<ul style="list-style-type: none"> • Allow the person to talk about the anger or encourage the person to talk with a trusted family member or friend. • Help the person find effective and satisfying ways to express the anger. • Help the person find a local brain injury support group.
<p>GRIEF REACTION</p> <p>One part of a grief reaction may be anger. The person with a TBI might be having a grief reaction over all of the losses the person experienced.</p>	<ul style="list-style-type: none"> • Allow the person to talk about his or her anger over his or her losses and/or encourage the person to talk with a trusted family member or friend. • Remember that poor memory, poor judgment, or emotional or personality problems can complicate grief reactions. Sometimes, professional counseling can help.
<p>FRUSTRATION</p> <p>Sometimes anger can be a sign of frustration. The person may no longer be able to do the things he or she was able to do before the brain injury or may need extra time or help in getting things done. This change in ability can cause frustration.</p>	<ul style="list-style-type: none"> • When frustration contributes to angry reactions, help the person find a way to break tasks into easier steps. • Help the person prepare before difficult tasks. For example, “Now it’s time to go shopping. I know this is sometimes frustrating for you. How will you know if you are starting to get frustrated? What will you do about it? How can I help?”
<p>NORMAL, LEGITIMATE ANGER</p> <p>A person with a brain injury still will have legitimate reasons to get angry. If his or her legitimate anger is discounted or ignored, the person may get angrier.</p>	<ul style="list-style-type: none"> • Find out why the person is angry and try to help him or her work out solutions. • If the person expresses anger in a way that seems inappropriate, help the person to practice appropriate ways to express the anger. Some ideas include: hitting a couch with a big pillow or drawing a picture using colors and strokes that express the anger. • Help the person find solutions to what caused the anger in the first place.

REASON	WHAT TO DO
<p>IMPAIRED JUDGMENT</p> <p>A person may misjudge a harmless situation and become angry about something that is not really happening.</p>	<ul style="list-style-type: none"> • Encourage the person to check his or her judgment with you or others. • Be willing to let the person know if you think he or she is misunderstanding a situation. • Support the person in getting help. Cognitive rehabilitation for judgment might be helpful.
<p>NOT TAKING PRESCRIBED MEDICATIONS</p> <p>Medications are sometime prescribed to control a person’s hormonal levels or to keep other physical or psychological functions in balance.</p> <p>By not taking medications as prescribed, the person may cause an imbalance in body chemistry that contributes to anger.</p>	<ul style="list-style-type: none"> • Let the person’s doctor know if prescribed medications have not been taken as directed and if there have been any problems.
<p>ABUSE OR MISUSE OF ALCOHOL AND DRUGS</p> <p>Alcohol and drugs can interfere with the body’s normal healing responses and can change the way a person is able to respond to stress.</p> <p>The person may get angry quicker or respond with more anger than he or she would if not abusing alcohol or drugs.</p> <p>Heavy use of drugs or alcohol also change the way medications affect the body.</p>	<ul style="list-style-type: none"> • Remind the person that alcohol and drugs can make the effects of a TBI worse. • Encourage the person to avoid drinking or taking drugs. • If the person has problems avoiding alcohol or drugs, call a local chemical dependency center for help in making a referral.



ANGER SELF-CONTROL STRATEGY: BACK OFF, CALM DOWN, TRY AGAIN

If the person with a TBI has recovered enough to be aware of his or her behavior and is able to work on emotional control, the “Back Off, Calm Down, Try Again” strategy can be very effective.

Encourage the person to put the strategy in his or her own words, such as “retreat, relax, return” or “take a break” or “time out.”

- **Back Off:** When warning signs appear, the person should leave the situation and go to a safe place. Others may have to cue the person to leave. If he or she will not leave, the other people present should leave instead, if possible. The person with a TBI should be encouraged to practice backing off when not angry (like a fire drill) so this will go more smoothly when it is really needed.
- **Calm Down:** When the person has backed off to a safe place, he or she should work on calming down. There are many techniques people use to calm themselves, including deep breathing, soft music, meditation, prayer, closed eyes, or physical exercise.
- **Prepare to Return:** Once calm, the person may need to rethink the situation and prepare to return. Reviewing a list of questions is a possible preparation: Do I need to apologize? Do I need to explain why I left? Do I need to tell anyone my feelings? What can I do to avoid this the next time?
- **Try Again:** When the person returns, he or she may need to apologize, talk through the issue, explain what happened, share his or her feelings, or just return to what he or she was doing before.

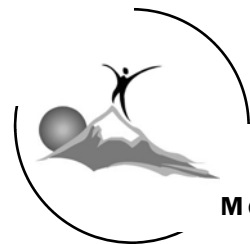
Once a person has learned to back off, calm down and try again successfully, he or she can work on calming down in the situation without leaving.

Anger cue cards can be used to remind the person of his or her warning signs such as “Loud Voice”, “Tense Muscles”, “Confusion”, or “Thoughts of Hitting”. These cards should be carried by the person with a TBI, and copies can be placed where anger incidents often happen or where backing off takes place.

A Back Off card might say “I’m feeling angry, I need to back off,” or “I need to leave the room,” or “I need to take a deep breath and relax my muscles.”

The person who has trouble with self-control should decide on what Back Off cards will work best.

Anger cue cards can be used to remind the person with a TBI of warning signs of anger.



ANXIETY AND POST-TRAUMATIC STRESS DISORDER (PTSD)

Some people with a TBI also have post-traumatic stress disorder (PTSD).

Anxiety is an unpleasant combination of emotions that includes fear, apprehension, and worry. It may include physical sensations such as:

- Rapid or “skipping” heartbeat (palpitations)
- Chest pain
- Shortness of breath
- Headache
- Extra difficulties in concentrating
- Wanting to sleep more often
- Being too agitated to sleep

Some people with a TBI also have **post-traumatic stress disorder (PTSD)**, as a result of the event that caused their injury such as an explosion on a battlefield, a violent attack, or a horrifying car accident.

PTSD is an anxiety reaction in which people have flashbacks or re-experience a traumatic event that was life-threatening or caused the person to feel intense fear, horror, or a sense of helplessness. PTSD can seriously interfere with recovery from a TBI, relationships, and returning to work.

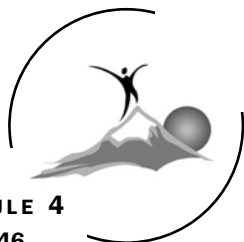
People with PTSD may:

- Have frequent nightmares that prevent them from sleeping well.
- Feel emotionally numb, and have problems relating to other people.
- Constantly try to avoid things that could trigger a flashback. This can cause people with PTSD to limit life activities.
- Try to self-medicate with alcohol or drugs, further complicating recovery.

HOW TO HELP

- If the person you are caring for has signs of severe anxiety or PTSD, encourage and assist the person to get help from a medical or psychological professional. This is especially important if he or she is turning to drinking or drugs to feel better.
- Encourage and support the person in participating in therapy and following medical advice.

People with TBI are about twice as likely as other people to suffer from anxiety. This is due both to physiological changes in the brain and to many problems that come with living with a TBI.



DEPRESSION

There are several factors that cause or contribute to depression, including:

- Physiological changes in the brain due to injury.
- A grief reaction to losses that often follow a TBI.
- The person was depressed prior to the TBI.

In just a few seconds, a brain injury can change everything about a person's life. Here are a few of the losses a person with a TBI may encounter:

- Loss of major physical and mental abilities.
- Loss of independence.
- Loss of employment.
- Loss of financial stability.
- Loss of important relationships.
- Loss of a sense of time, making it difficult to imagine or hope for a better future.
- In addition to losses any person may experience across a lifetime, many survivors of TBI have the unique experience of losing their own identity—losing themselves.

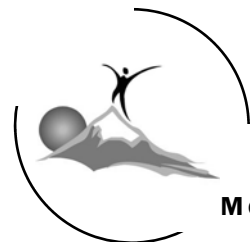
Recognizing depression can be difficult with a person with a TBI.

♥ CAREGIVER STORY

"I have known clients with severe short-term memory loss to grieve and re-grieve over and over again. One gentleman was only able to remember an event for 3 minutes or less and he often would talk about losses that we had discussed in therapy the day before as if he had never processed the issue before."

If you are helping a person who has severe short-term memory loss, you may need to help the person talk about the same loss every day. The best thing you can do is practice patience with the person.

It can be difficult to recognize symptoms of depression in a person with a TBI. He or she may express emotional distress in terms of physical symptoms or cover up feelings of depression. Sometimes it may be hard to tell the difference between symptoms that are caused by the TBI, such as memory loss or lack of initiative, and depression.



The Depression Checklist can be a useful tool to help determine if the person with a TBI needs additional support.

DEPRESSION CHECKLIST

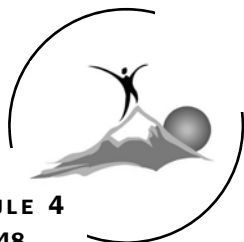
Depression can continue over a period of time and have different signs and symptoms. The following checklist may help you determine if the person needs additional mental health support. The more items checked, the more likely the person needs to be seen by a medical or mental health professional who specializes in working with people with a TBI.

- Aches, pains, or other physical complaints that seem to have no physical basis.
- Marked change in appetite (weight loss or weight gain).
- Changes in sleep patterns: lack of sleep (insomnia), sleeping all the time, or waking and sleeping at unusual times.
- Fatigue, lack of energy, constantly worn out.
- Constant sadness, anxiety, or “empty” mood.
- Apathy (lack of feeling anything at all).
- Lack of pleasure or interest in activities the person previously enjoyed.
- Crying for no apparent reason, with no relief.
- Hopelessness, pessimism.
- Feelings of worthlessness, inadequacy, helplessness.
- Inappropriate or excessive guilt.
- Recurrent thoughts or statements about death or suicide.

In the general population, six out of every 100 people experience significant depression in the course of their lives. However, according to one recent study, people with a TBI, have a rate of severe depression ten times that rate following injury.

HOW TO HELP

- Know the signs of depression and help the person get professional help if needed.
- Help the person identify a special activity he or she enjoyed before the injury that may be possible to regain. Modify the activity or break it down into smaller goals to make it “do-able.” Then help the person work toward regaining the ability or activity. Even small victories can spark hope and reduce depression.
- Encourage the person to explore self-care through support groups, counseling, and social networks.
- Help the person celebrate all victories – no matter how small.



♥ CAREGIVER TIP

Having little or no hope contributes to depression. Having a sense of control over one's life can enhance feelings of well-being and self-esteem and give a person a sense of HOPE.

Giving a person with a TBI a sense of control can be as simple as honoring his or her choices.

♥ CAREGIVER TIP

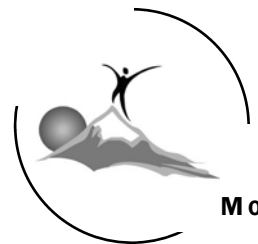
SUICIDE RISK: KNOW THE SIGNS AND WHAT TO DO

Many people with TBI are at risk for a suicide attempt due to depression or anxiety combined with poor impulse control.

Treat all threats as serious threats. Call 911 or a suicide prevention hotline if the person:

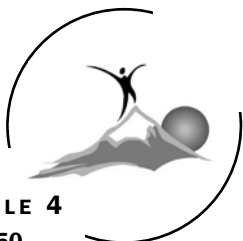
- Says he or she wants to or should die.
- Has a plan for taking his or her own life.
- Has the means to carry out the plan, such as a gun or a supply of medication that could be used to overdose.

If possible, take the means away from the person and stay with the person until help arrives.



OTHER PSYCHOLOGICAL REACTIONS TO TBI AND HOW TO HELP

REACTION	WHAT YOU MIGHT SEE	HOW TO HELP
DENIAL, DEFENSIVENESS, LACK OF RECOGNITION OF TBI	<ul style="list-style-type: none"> • Denies any changes to self since brain injury. • Does not recognize that abilities have changed. • Resists participating in new or different activities or programs. 	<ul style="list-style-type: none"> • Be Patient. • Remember that denial is a defense mechanism against psychological pain. • Encourage the person to attend a support group at least two times in order to meet other people with the same challenges. • Encourage psychological testing or counseling if behaviors are extreme. • Be aware of increased risk for suicide.
DEPENDENCY OR REGRESSION	<ul style="list-style-type: none"> • Inability to do tasks independently that he or she really can do alone. • Does not ask questions if help is needed. • Acts “like a child” to get others to take care of him or her. 	<ul style="list-style-type: none"> • Consider whether helplessness is being reinforced by other people taking over and not allowing independence. • Prompt the person to do activities independently. • Gradually remove assistance. • Ask the person to try three times before asking for help, and reward efforts the person makes no matter how small. • Help the person practice problem-solving exercises.
INFLEXIBILITY OR RIGIDITY	<ul style="list-style-type: none"> • Resists change, increases under stress. • Unable to compromise. 	<ul style="list-style-type: none"> • Acknowledge what the person is experiencing. • Reinforce only positive actions, ignore inappropriate responses.



IMPAIRED ABILITIES

In order for people to understand what is expected and behave properly in social situations, they must be able to:

- Process information quickly.
- Recall recent or past events (memory).
- Understand words and what they mean in a social setting.

People with a TBI may have impaired abilities in one or more of these areas. As a result, they may not understand what is socially appropriate and how to act in social situations. They may show:

- Poor impulse control.
- Lack of inhibition.
- Self-centered thinking and behavior (impolite or offensive).
- Acting out in sexual or other inappropriate ways.
- Disrespect for other people's boundaries.
- Inappropriate social responses (for example, laughing when someone is hurt).

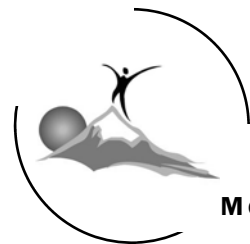
HOW TO HELP

- Let the person know when he or she uses appropriate social behavior.
- Model appropriate social behavior.
- Help the person find other ways to handle social situations.
- Help the person identify when limits need to be set.
- Develop a plan with the person on how to set limits.
- Focus on progress.
- Help the person find and participate in group or peer activities where he or she can learn and practice appropriate behavior.

♥ CAREGIVER TIP

A person with a TBI often has some awareness of his or her social problems and may isolate in order to avoid further embarrassment and failure.

Social isolation interferes with the person's overall well-being and recovery. If the person is choosing to isolate, encourage him or her to get help from a habilitation specialist who has experience working with people affected by TBI.



DIFFICULTY IN DEVELOPING AND MAINTAINING RELATIONSHIPS

Relationships take work, effort, and attention, and are not always easy. A TBI can make relationships even more difficult. Changes caused by TBI that affect relationships may include:

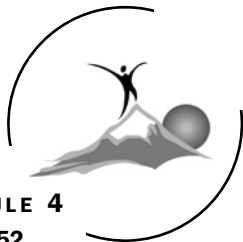
- Inability to feel or express empathy with others.
- Inability to maintain healthy personal boundaries.
- Focus on self, excluding, or interrupting others.
- Inability to verbalize opinions, needs and feelings, or expressing these inappropriately.
- Change in personality and sense of self.
- A new sense of dependence because of a person's change in physical or cognitive abilities.

HOW TO HELP

- Let the person know when a particular behavior is disrespectful.
- Demonstrate and encourage cooperative behavior.
- Remember that the person's behavioral changes are caused by changes in the brain. Most people do not choose to behave inappropriately. Do not make comparisons to how the person acted before the TBI.
- The person might benefit from practicing relationship skills in a safe environment of peers supervised by a professional. Help the person find and attend group therapy or a support group.

♥ CAREGIVER TIP

Following a traumatic brain injury, some relationships may end but others may become stronger. Relationships with others are very important in the recovery and overall well-being of the person with a TBI.



SUBSTANCE ABUSE

Use or abuse of alcohol or recreational drugs and abuse of medications can create a major additional problem for the adult with a TBI. Substance use or abuse causes:

- Slower recovery from brain injury.
- Further damage to an already injured brain.
- Increased frequency of aggressive or anti-social behaviors.
- Interference with motor and thinking processes that are already impaired due to brain injury.
- More failures in work, school, and relationships.

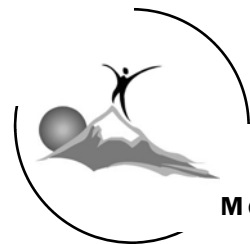
Following a TBI, many people have an increased risk for addiction. People with TBIs may drink or take drugs to self-medicate for depression, anxiety, or other kinds of physical or emotional pain. A person who could handle a minor amount of alcohol or drugs before the TBI may find his or her tolerance is much lower after a brain injury. For many people with a TBI, any amount of alcohol or drugs may make symptoms worse.

HOW TO HELP

- Encourage and assist the person to get an assessment and appropriate treatment for the underlying issues that are leading the person to drink or use drugs.
- If the person is drinking, using drugs, or misusing medications, especially if he or she has a history of alcohol or drug use before injury, try to encourage and help the person see a medical or rehabilitation professional for possible referral to a treatment program.
 - Ideally, the treatment provider would have experience working with TBI. The provider will need to assess and accommodate for symptoms that are caused by TBI—for example, memory problems, rather than resistance to treatment, might cause the person with a TBI to miss appointments.

♥ CAREGIVER TIP

Paid caregivers are not allowed to drink alcohol or to take drugs while providing care. However, if you are an unpaid caregiver, you can also model healthy behavior by not drinking alcohol, smoking, or taking drugs around the person with a TBI.



AGING AND TBI

As the population ages, the number of older adults with traumatic brain injuries will grow. While more research needs to be done, it appears that having a TBI may make the aging process harder, including:

- Increased risk of developing Alzheimer's disease, non-Alzheimer's-related dementia, and brain atrophy.
- Less ability to adapt to a TBI.

Older adults with TBIs are likely to have a greater need for in-home support and other types of specialized care.

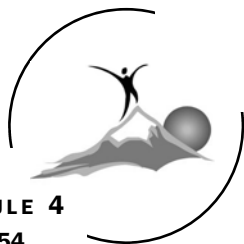
HOW TO HELP

- Follow care guidelines for both traumatic brain injury and age-related neurological conditions such as dementia. As always, adapt guidelines to fit the unique needs of the person.
- Encourage and assist the person with a TBI to be as mentally, physically, and socially active as possible.
- Be alert to other kinds of age-related problems and help the person get medical attention as needed.
- Give extra attention to safety-proofing the person's environment to prevent falls and other kinds of accidents.

Pre or co-existing physical, developmental, or mental health disabilities combined with TBI can create very complex challenges for caregivers.

- People with multiple disabilities may require specially trained caregivers and a variety of support services to enable them to survive and thrive.
- Care plans should be based on recent assessments of abilities, carefully followed by caregivers, and reviewed regularly by medical or rehabilitation professionals.
- If there are any sudden increases in problem behaviors or sudden changes in the person's need for care, consult with a medical professional as soon as possible.

OTHER PHYSICAL, DEVELOPMENTAL, OR MENTAL HEALTH DISABILITIES AND TBI



Dealing with behavior

www.biausa.org/word.files.to.pdf/good.pdfs/roadToRehab4.pdf

Post-traumatic stress disorder

www.headinjury.com/faqptsd.htm

Depression and TBI

From the Brain Injury Association of America:

“Coping with Depression After Traumatic Brain Injury,” Margaret Brown, Ph.D., 2004.

www.biausa.org/elements/BIAM/2004/depression.pdf

Caregiver’s manuals

For more training and ideas for working with people with disabilities, get a copy of the *Family Caregivers’ Handbook*. The *Handbook* includes information on:

- Dealing with problem behavior.
- Keeping yourself and the person you are caring for safe.
- Giving medications, and assisting people with limited mobility.
- Finding local community resources and services.

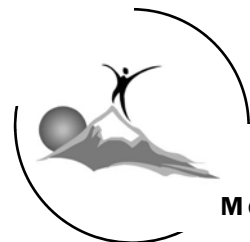
Read the *Handbook* on-line at:

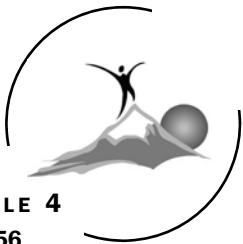
www1.dshs.wa.gov/pdf/Publications/22-277.pdf

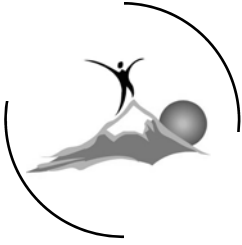
You can also get a free printed copy by calling 1-800-422-3263.

AACBIS training manual for certified brain injury specialists:

http://www.aacbিস.net/aacbismanual6_04.pdf







MODULE 5 – SUPPORTING RECOVERY

MODULE GOALS

- Understand the four general guidelines to support any adult who is recovering from TBI.
- Learn strategies that help to create a supportive, safe environment.
- Learn tips that apply to caregiving, managing stress, and making health a priority for both the adult with traumatic brain injury and the caregiver.

There are four general guidelines that will help you support any adult recovering from a TBI.

1. Encourage Independence.
2. Promote overall health.
3. Enjoy your time together.
4. Take care of yourself.

In the second module, it was pointed out that many different problems may result from injuring the brain and that no two adults with TBI are alike. Throughout Module 5, think about how you might adapt these guidelines to fit the unique needs of the person for whom you are caring.

Keep in mind:

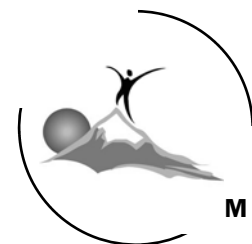
- An adult with a TBI may process information more slowly or in a different way than he or she used to. It is important to remember that **he or she still is a person** with thoughts, feelings, and intellect.
- A person who lives with a TBI should be treated like any other person of the same age. Never talk down to or “baby” a person with a brain injury.
- Treat a person who has a TBI with dignity and respect, just as you would want to be treated if you had the same kind of injury.

♥ CAREGIVER TIP

Caring for people with TBI is different in an important way from caring for people with brain diseases that get worse over time such as Alzheimer's Disease. Most people with TBIs can get better over time if the right kinds of support are provided and barriers to recovery are removed.

GENERAL GUIDELINES

A person with a TBI is still a person with thoughts, feelings, and intellect.



♥ CAREGIVER TIP

Focus on gains while acknowledging losses. The person with a TBI may not regain all the abilities he or she had before. However, some people have found that surviving brain injury brings new abilities, awareness, and relationships they otherwise would not have.

One individual who had been a very skilled computer technician before his TBI was unable to return to that work after his accident. Instead, he learned to garden and found that he had a talent for working with plants. Some years after his accident, he became a certified master gardener and now works part-time in a local nursery.

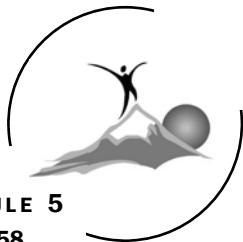
ENCOURAGE INDEPENDENCE

The first general guideline for helping adults with a TBI is to **encourage independence**. Allow and assist the person you are caring for to use the skills and strengths he or she has.

Here are ways to **be a helper instead of a doer**:

- Let the person do the task in his or her own way, even if you can do things faster or better.
- Ask the person his or her preferences regarding tasks and be flexible. Personal care—dressing, bathing, eating, and using the toilet—is **personal**. The person may not want or need a daily bath, or he or she might prefer several small, simple snacks to three large meals a day.
- Create a calendar together where you or the person with a TBI can record times for medications, baths, appointments, exercise, or any other tasks that the person would like to track. Make the calendar large and easy to read, and put it in a place where it can be seen every day by the person with a TBI .
- Divide tasks into smaller steps. If the person cannot do all of a task, he or she may still be able to do parts of it. If the person has trouble getting started, provide instructions or cues without taking over and doing the task.
- Before you step in to help in any situation, ask the person you are working with, “May I help with that or would you rather do it alone?”
- Remove barriers to independence by assisting the person to safety-proof the home. Help protect the person from further injuries while he or she is trying to do things for himself or herself.

*Be a helper
instead of a
doer.*



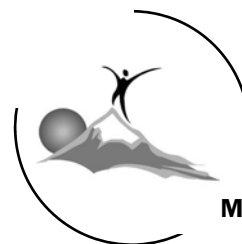
- Be aware of potential environmental dangers such as fire hazards, sharp objects, poisons, and inadequate lighting, loose rugs, furniture, or clutter in pathways.
- Look for assistive devices and gadgets that increase independence. Examples of these include: day planners, palm pilots, large calendars, talking watches that can be programmed with daily reminders, and other devices that can help a person with memory challenges.
- Praise the person for trying, and celebrate every success, no matter how small, especially when a person's abilities are limited. Encouraging words support the person to keep trying.
- At the end of each day, discuss successes of the day. Emphasize celebrating the small and large victories of surviving and recovery.
- Encourage the person to get professional help to learn easier ways to do things that support increased independence. Nurses, home health aides, physical and occupational therapists, and speech therapists teach people ways to do things at home.
- Encourage the person to develop a new hobby or to adapt a hobby he or she did before the brain injury. Help the person to find an activity that suits his or her current abilities.
- Do not criticize or scold a person who cannot do something today that he or she was able to do before. People with TBIs are usually trying to do their best, but have good days and bad days.
- If he or she becomes angry or frustrated when something doesn't go right, try not to take the anger personally. Distract the person with another topic, tell a silly joke, or invite the person to join you in a game or walk away from the area.

People with TBI are usually trying to do their best.

♥ CAREGIVER TIP

Skills that are not used are lost. It is good for a person with a TBI to be as active as possible and make his or her own decisions. Independence builds self-esteem and contributes to the person's overall well-being.

You may need to help the person learn to accept the changes that come with a TBI. The person may not be able to do some of the things he or she did before. You can best help the person if you acknowledge the changes that he or she is experiencing and encourage the person to try things in a new way.



PROMOTE OVERALL HEALTH

The second general guideline is to support the person's overall health.

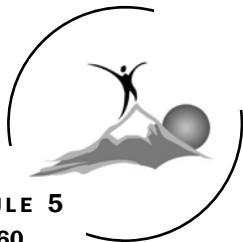
- Nutritious food and plenty of water are critical for healing.

Encourage the person to:

- Choose, prepare, and eat a variety of fresh, nutritious foods, including plenty of whole grains, vegetables, and fruit.
- Limit or avoid foods and drinks that are high in fat, sugar, caffeine or alcohol.
- Drink plenty of water—six to eight glasses a day.
- Regular exercise strengthens the body and mind. Exercise can improve coordination, regulate mood, reduce pain, and promote healthy sleep.

Recent research has found that people with a TBI who exercise regularly have fewer physical and emotional problems than those who don't exercise. They are more engaged in activities and have a more positive view of themselves.

- Find out what kinds of sports or exercise the person enjoyed before the injury and see if it is possible to resume that activity.
- You might also help the person get into a new activity he or she always wanted to try. Help the person adapt activities to his or her current abilities.
- Encourage and assist with a variety of exercises, including those that promote heart and lung capacity (aerobic exercise like brisk walking or swimming), those that strengthen and stretch muscles (for example, weight lifting), and those that create relaxation (for example, yoga, tai chi).
- Don't overlook the importance of healthy teeth and gums.
 - Encourage or help the person to brush and floss regularly.
 - Some impairments related to a TBI may make it difficult for a person to reach his or her own back teeth. Assist the person to purchase necessary dental equipment to help with brushing and flossing.

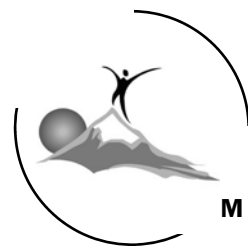


ENJOY YOUR TIME TOGETHER

The third general guideline is to add enjoyment to daily activities. People recovering from a TBI often find it difficult to maintain positive emotions on their own. They also need to interact in healthy ways with other people to retain or relearn social skills.

Enjoying the time you spend together promotes healing on many levels. Although many of the ideas below cannot be accomplished during paid caregiving time, here are some suggestions:

- Share a funny story or joke.
- Go outside. Take a walk or go for a ride in the countryside or visit a park or zoo.
- Rent a video or DVD, make some popcorn, and enjoy a movie.
- Bake bread or cookies together.
- Enter contests.
- Work in the yard or garden together.
- Play a video game, board game or card game. Change the rules if necessary.
- Look through magazines and find a new recipe to try.
- Make a tape, video recording, or book of the person's life.
- Visit the library—in person or through a website—and check out books and recordings to enjoy together or individually.
- Encourage activities to stimulate the brain such as board games, sudoku type puzzles, brain teasers, or crossword puzzles.
- Create a photo album together of family and friends.
- Ask the person every day, “What would you like to do today?” If the person doesn't want to suggest anything, give him or her a few options; too many options can be overwhelming and discouraging.
- If possible, engage family members on a regular basis, making sure the person you care for sees other people on a regular basis.
- Encourage the person to volunteer when he or she is ready. Helping others is empowering.
- Creative arts such as listening to or playing music, drawing, painting, writing in a journal, reading or writing poetry can help you and the person you are caring for express emotions and explore new meanings in your lives
 - Share works of art with others through community centers, support groups, or websites for people living with TBI.



♥ CAREGIVER TIP

Treat the person who lives with a TBI with dignity and compassion, and without pity. The attitude of caregivers toward the person with a TBI is extremely important as he or she tries to rebuild identity, regain as much independence and function as possible, and adapt to changes in all areas of life.

In many ways, the person is getting used to him or herself in a whole new way and may think of him or herself as a “whole new person.” The person may need to grieve the loss of the “old self” and get used to the new self. It may be important for you to acknowledge the changes that the person has experienced.

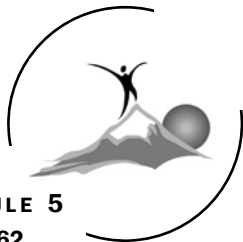
TAKE CARE OF YOURSELF

The fourth general guideline for caring for adults with a TBI is to practice self-care. Caregiver issues may affect both you as the caregiver and the person who has a TBI. It is important for you to monitor how you are doing as a caregiver, to identify stress, and to find support that will help you to stay healthy.

RECOGNIZING WHEN YOU NEED SUPPORT

Below you will find **symptoms** of caregiver stress. If you have one or more of the following symptoms, caregiving may be putting too much strain on you:

- Sleeping too much or too little.
- Change in eating habits, resulting in weight gain or loss.
- Feeling tired or without energy most of the time.
- Loss of interest in activities you used to enjoy.
- Easily irritated, angry, or sad.
- Frequent headaches, stomach aches, or other physical symptoms.



The following are **signs of caregiver stress**. Seek professional help if you have one or more of these signs:

- Using excessive amounts of alcohol, drugs, or medications like sleeping pills.
- Losing hope or feeling all alone with no one to help you.
- Having thoughts of death or suicide.
- Losing control physically or emotionally.
- Treating the person with a TBI roughly or neglecting his or her care.

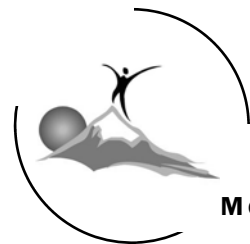
TIPS FOR MAKING YOUR HEALTH A PRIORITY

- Give yourself permission to take regular breaks to restore your energy and peace of mind. Arrange for back-up care providers to take your place while you take a break.
- Stay in touch with friends and family members whose company you enjoy. Seek out people and activities that raise your spirits.
- Avoid or say no to people or activities that drain your energy or waste your time. Social activities can help you feel connected, give you a different perspective, and help reduce stress.
- Join a support group for caregivers of people with TBI.
- Find time for exercise most days of the week. Even a little exercise, like a short walk, when done regularly will make a noticeable difference in your physical and mental health.
- Use organizational aids, like lists and daily routines, to help you use your time and energy efficiently.
- See your doctor for a checkup if you have any signs of depression or illness.
- Try to get plenty of sleep.
- Eat a healthy diet—low in saturated fat and including fruit, vegetables and whole grains. Drink plenty of water. Avoid excessive use of alcohol and drugs.
- Take things one day at a time.

As a caregiver of a person with a TBI, it is important to make your health a priority.

♥ CAREGIVER TIP

Recovery from TBI often takes a long time. Caregivers should plan early for scheduled back-up caregivers and take breaks before they become overwhelmed, exhausted, or ill.



TO LEARN MORE

Caregivers' Handbook: A Guide for Family and Other Unpaid Caregivers
from Aging and Disability Services Administration (ADSA)
Washington State Department of Social and Health Services
www1.dshs.wa.gov/pdf/Publications/22-277.pdf

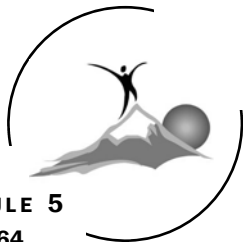
The Family Caregiver Support Program supports unpaid caregivers of older adults and grandparents or relative caregivers of children. Services are free or low cost and generally include:

- Information and help getting services.
- Caregiver support groups and counseling.
- Caregiver training and education.
- Respite care so caregivers can have a break.

To find the Family Caregiver Support Program in your area, go to:
www.adsa.dshs.wa.gov/resources/clickmap.htm

Encouraging independence
Assistive devices, from the Brain Injury Association of America:
www.biausa.org/at.htm

Health and wellness for both of you
USDA guidelines and tools for planning nutritious meals:
www.mypyramid.gov/



Ordering Additional Printed Copies of This Manual

Additional printed copies of this manual and the DVD are available through the Washington State Department of Printing (DOP) at a very reasonable fee (price includes shipping and handling).

Order additional copies on-line through the DOP's General Store:



www.prt.wa.gov

Click on “General Store”. After you sign in, click on “Shop by Agency” and then select:

- Department of Social and Health Services
- Aging and Disability Services Administration
- ADSA Caregiver Training Materials

Requests may also be placed by phone at (360) 586-6360.



Traumatic
Brain Injury

A Life
Altering
Impact

*Go online or call toll free
to find out more about TBI
resources and services:*

1-877-TBI-1766
www.TBIWashington.org



Washington State
Department of Social
& Health Services

ADSA Aging & Disability
Services Administration

For more information about Aging and Disability Administration Services call 800-422-3263 or visit:
www.adsa.dshs.wa.gov