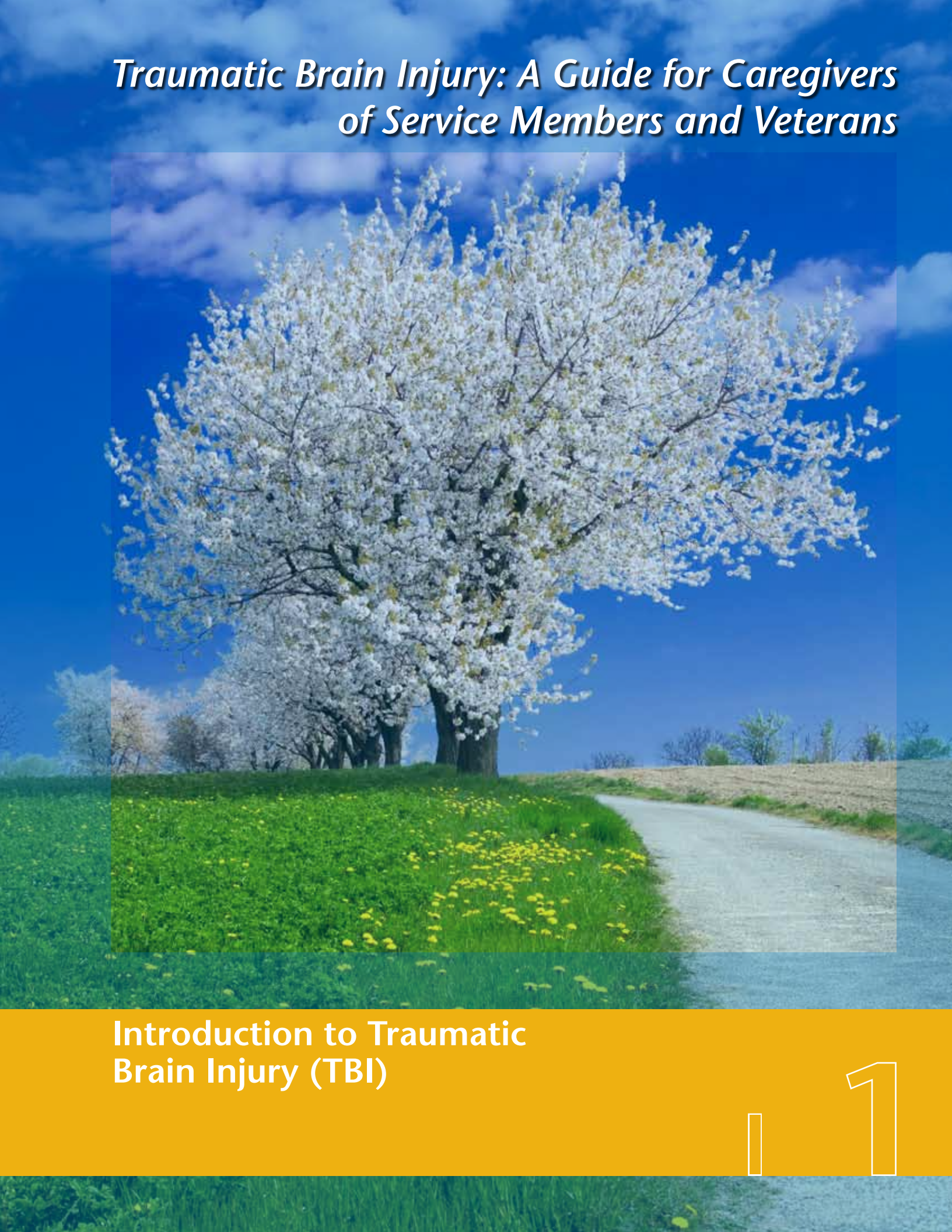
Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans



Introduction to Traumatic Brain Injury (TBI)

1

Table of Contents

An electronic version of this Guide can be found at the following Web address:
www.traumaticbraininjuryatoz.org

Module 1 Summary

In this section, you can find basic information about:

- the parts of the brain and what they do
- the causes of traumatic brain injury (TBI)
- how the brain changes after TBI
- how the brain begins to recover.

You can use this information to understand:

- how the brain works
- what you might see during recovery
- why you might see changes in how your service member/veteran thinks and acts due to a TBI.

TBIs are classified by how severe or serious they are at the time of injury. TBIs range from mild (concussion) to moderate to severe.

This module provides information on moderate to severe TBI. Doctors, nurses, and other health care providers who work with TBI guided the content.

As you read through this document, ask your health care providers to explain what you don't understand.

Some key points are:

- The brain is the body's control center.
- The parts of the brain work together to help us think, feel, move, and talk.
- A TBI is caused by a penetrating injury or by blunt force trauma to the head.
- TBI is very common in both civilian and military populations.
- Many different health care providers will help diagnose and treat your service member/veteran with TBI.
- It is the goal of health care providers to minimize complications, the things that can go wrong after the injury.
- Many service members/veterans with TBI go through common stages of recovery. Each person, however, progresses at his or her own pace.
- Recovery from a TBI may be measured in weeks, months, or years.
- Promising new research is showing the brain's capacity for healing.
- There are many ways you can support your service member/veteran with TBI throughout his or her recovery.

Be hopeful. The brain is very good at repairing itself.

What is a TBI?

A traumatic brain injury (TBI) is:

- A direct blow or jolt to the head
- A penetrating head injury, or
- Exposure to external forces such as blast waves that disrupt the function of the brain.

Not all blows to the head or exposure to external forces result in a TBI. The severity of TBI may range from "mild"— a brief change in mental status or consciousness—to "severe," an extended period of unconsciousness or confusion after the injury.

Source: DVBIC (2007). Fact Sheet.

Chapter 1

The Basics of TBI

What is a Traumatic Brain Injury?

A traumatic brain injury (TBI) happens when something outside the body hits the head with a lot of force. This could happen when a head hits a windshield during a car accident. It could happen when a piece of shrapnel enters the brain. Or it could happen during an explosion of an **IED** (improvised explosive device). There are many causes of traumatic brain injury (TBI).

An IED is an improvised explosive device. They are also called roadside bombs. They are placed on the side of the road and explode when someone drives by. IEDS are a leading cause of TBI in Iraq and Afghanistan.

How Long Does It Take to Recover from a TBI?

No two brain injuries are exactly alike. Some people who have a TBI recover quickly, others take much longer. Some will have very few long-term effects. Others will face lifelong challenges. The effects vary from person to person.

Recovery from a TBI may be measured in weeks, months, or years.

What Happens Right After the Injury?

In the days and weeks right after the injury, the tissue in the brain may swell or bleed. There may also be changes in the brain's neurochemistry system.

Sometimes there is so much blood that doctors have to remove it during surgery. This surgery reduces swelling and pressure within the brain. It helps the brain's blood flow and **neuro**chemistry system to recover. This usually helps the brain to work better.

"Neuro" means the body's nervous system.

"He actually ended up being in a coma for about three months after the brain injury."

- Pam E.

"He really won't tell me the whole story because I think he doesn't want to scare me. But, he brought me a piece of metal back home that was embedded in the wall right behind him. He said it missed his head by a few inches. He said that he thanks God every day that he's still alive, and that's why he brought the piece of metal home, to show me that that's how close he had come to dying."

- Lynn C-S.

How Does the Brain Recover Over Time?

No one completely knows what happens in the brain during long-term recovery from a TBI:

- Some researchers think that the healthy brain tissue learns over time how to do what the damaged brain cells used to do.
- Others think that connections between brain cells rearrange themselves or become more efficient.

The brain can repair itself more than people used to think was possible. Different things influence a person's ability to recover. They include:

- His or her age (younger brains often recover faster)
- How severe the TBI is
- Where the TBI is located.

Recovery, however, is a very individual process.

What Else Affects Recovery?

Often, a person with a severe brain injury also has serious injuries in other parts of the body. These injuries can cause bleeding, swelling, and damage to internal organs, blood vessels, bones, limbs, the sensory system, and nerves.

A fracture is a broken bone.

For example, think about a service member/veteran who was close to a blast from an IED. He or she may have a couple of **fractures**, lost an arm or leg, or lost some hearing. He or she may also have internal injuries. All of these injuries together can make recovery take longer. They may even cause more damage to the brain. Prompt treatment of these other injuries will help limit damage to the brain.

What Kind of Treatment Will My Service Member/ Veteran Receive?

Outpatient means living elsewhere and going to the doctor's office or hospital for care.

Depending on the nature of the brain injury and other injuries, some service members/veterans may need only regular follow-up appointments with their doctor.

Others may receive therapy, tests, and monitoring on an **outpatient** basis.

Others may begin treatment in an intensive care unit or general hospital. They may transfer later to a rehabilitation unit. They may also need outpatient therapy for a long time.

Rehabilitation means re-learning skills needed for everyday life.

How much and what **rehabilitation** therapy your service member/ veteran needs depends on many things.

No matter where your service member/veteran receives care, he or she is being treated with the most up-to-date methods based on what doctors know about the recovery process.

How Common is TBI?

TBI is the leading injury among U.S. forces serving in Afghanistan (Operation Enduring Freedom [OEF]) and Iraq (Operation Iraqi Freedom [OIF]).

The frequent use of IEDs in these wars increases the chance that service members will be exposed to blasts and other injuries that can cause a TBI.

Among service members evacuated from OEF/OIF to Walter Reed Army Medical Center in 2003-2007 because of injuries, 30 percent had a TBI.

In 2008, the Department of Defense (DoD) reported that:

- Seven out of 10 TBI injuries were due to a blast
- More than 1 in 10 were due to a fall
- More than 1 in 20 were due to a vehicular incident
- One in 20 were due to fragments
- The rest were due to other causes.

The Army reported that 88 percent of TBIs among soldiers were mild. Six percent were moderate and another six percent were severe.

How Are TBIs Rated?

Traumatic brain injuries (TBIs) range from mild to severe. Injuries are rated on the basis of their severity at the time of the injury.

How severe the TBI is when the injury first happens does not always predict how bad the later symptoms are. In other words, those who were severely hurt sometimes make very good recoveries. Others who seem to have mild injuries can experience symptoms for months to years.

It's impossible to accurately predict at the time of the injury who will recover rapidly and who will go on to experience symptoms. That's why the military tries to screen and diagnose anyone even remotely suspected of TBI. That way, they can receive the care and help they need.

Mild TBI (Concussion)

Most injuries to the brain sustained in Iraq and Afghanistan are mild. Another term for mild TBI (**mTBI**) is concussion.

mTBI stands for mild TBI, also called a concussion.

A TBI is rated as mild when the service member/veteran:

- Has brief or no loss of consciousness
- Is momentarily dazed or has confusion lasting an hour or less, and
- Has an initial **Glasgow Coma Scale** (GCS) score of 13-15.

Glasgow Coma Scale is used to rate someone's symptoms after a head injury. You can find the Glasgow Coma Scale in Appendix A.

In most cases of mTBI:

- The service member/veteran will complain of having "his or her bell rung"
- Thinking may be slow
- Memory and concentration may be affected
- Headaches, dizziness, and fatigue (tiredness) are common.

Most service member/veterans will feel much better and be back to normal within a couple of weeks to months.

Others with more complex mTBI may experience symptoms for several months or even longer.

Moderate to Severe TBI

A TBI is rated as moderate to severe when the service member/veteran:

- Has loss of consciousness for more than 30 minutes
- Confusion lasting for hours, days, or weeks
- A Glasgow Coma Scale (GCS) score ranging from 3-12.

In Computed Tomography (CT), a computer creates cross-sectional images of the inside of the body, based on x-ray pictures.

Computed Tomography (formerly known as Computerized Axial Tomography [CAT]) scans of the brain often reveal bruising or bleeding inside and/or outside of the brain.

The service member/veteran with this level of injury often spends weeks to months in hospital and rehabilitation settings.

Chapter 2

Learning about the Brain

The more you understand about the brain, the easier it is to understand how TBI affects your service member/veteran.

"Basically, they walked me through the process every day, because I had a lot of questions. I asked a lot of the same questions, and they were patient with me. I was very overwhelmed.

So I asked a lot of questions. They kept explaining to me that this is what happened, that they can fix it but that it's a long process. The doctors themselves were the best source of information."

- Emily S.

What Are the Parts of the Brain? How Do They Work?

The brain is the body's control center. The brain has billions of nerve cells. The cells are arranged in sections that work together to control all of our movements, breathing, thoughts, behaviors, and emotions.

The brain is constantly sending and receiving signals from all parts of the body. The body uses these signals to think, move, talk, and see. The brain controls our personalities, the way we behave, and the way we understand the world around us.

Each part of the brain has a specific job. Each part links with other parts of the brain to perform tasks.

"In the very beginning, I didn't want to know anything because I was so scared. But a little while later… the doctors would throw out tidbits to me, like he might never speak again and he might never walk again… but I couldn't understand why. So then I wanted to understand the part of the brain that was injured and why he was having these symptoms or why he was having this diagnosis."

- Patty H.

What is the Anatomy of the Brain?

The skull is the bony part of the head that protects the brain.

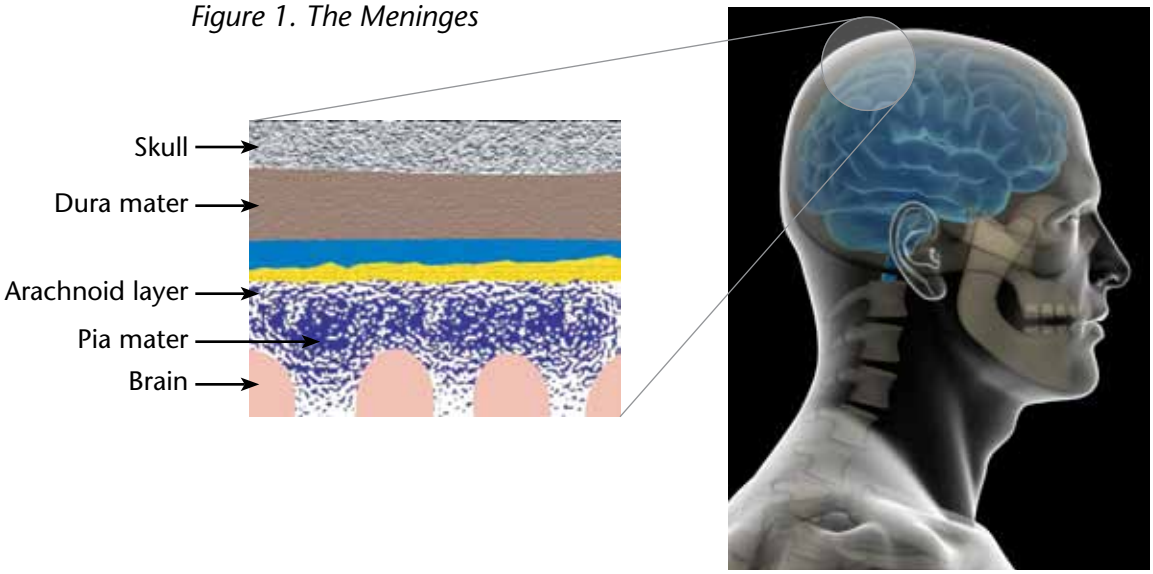
A healthy adult brain weighs about 2.5 to 3 pounds. It is located inside the **skull**.

The underside of the skull (referred to as the base of the skull) is rough, with many bony ridges. Forceful injuries to the head cause the brain to bounce rapidly around the inside of the skull. This bouncing results in brain damage in the area of these ridges.

A membrane is a thin sheet of tissue.

Just inside the skull, the brain is covered by three thin **membranes** called the **meninges**. They are the dura mater, arachnoid layer, and the pia mater.

Figure 1. The Meninges



*A **hematoma** is a collection of blood. It is also called a blood clot.*

You may hear doctors and nurses mention these membranes when they describe where a hematoma is located. For example, a subdural **hematoma** is blood that collects right below the dura mater. A **subarachnoid hemorrhage** is located just below the arachnoid layer.

Cerebrospinal fluid (CSF) is a clear liquid that surrounds the brain and spinal cord. It is produced within the **ventricles** of the brain. CSF allows the brain to float within the skull and cushions the brain.

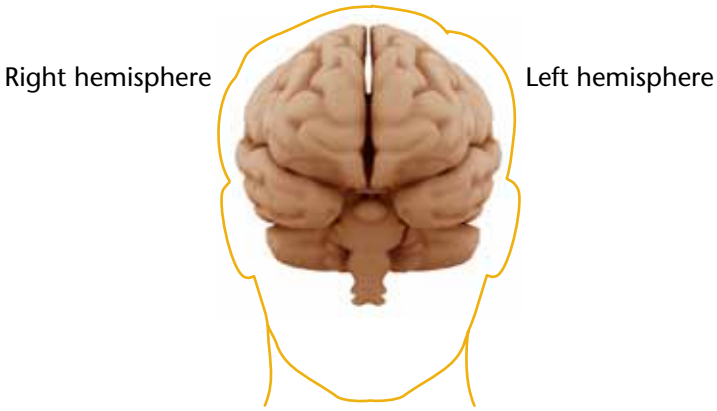
*The **ventricles** are butterfly-shaped spaces in the center of the brain.*

The outermost and largest part of the brain itself is called the cerebrum. The **cerebrum** controls thoughts and actions. It has a wrinkled surface and a deep crease that divides it into two halves, known as the left and right hemispheres.

Cerebral Hemispheres

The cerebral hemisphere means half the brain.

Figure 2. The Cerebral Hemispheres



These halves look nearly the same. But they differ in what they do. For most people, the **left half** of the brain controls:

- language (speaking, listening, reading, writing)
- thought and memory involving words.

The **right half** is involved in:

- nonverbal processes
- recognizing the differences in visual patterns and designs
- reading maps
- enjoying music and art
- expressing and understanding emotions.

The ***left side*** of the brain controls movement on the ***right side*** of the body. The ***right side*** of the brain controls movement on the ***left side*** of the body. This is just the opposite of what you might think.

Damage to the ***right half*** of the brain may cause movement problems or weakness on the ***left side*** of the body. Damage on the ***left half*** of the brain may cause movement problems or weakness on the ***right side***.

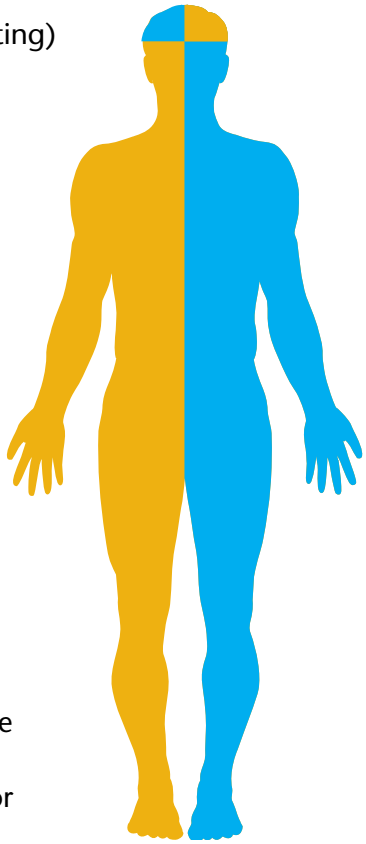


Figure 3. The brain controls movement on the opposite side of the body.

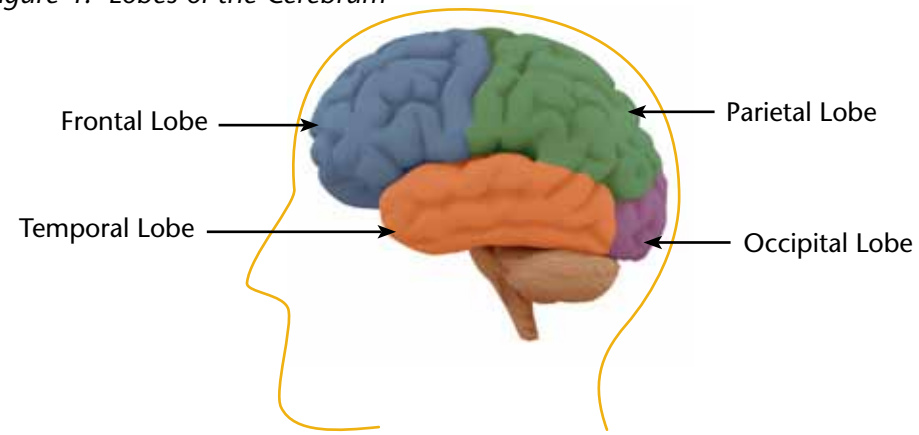
The Lobes of the Brain

The brain is divided into four sections called **lobes**. These lobes are known as the:

- frontal lobe
- temporal lobe
- parietal lobe
- occipital lobe.

Although it is easier to learn about each lobe separately, keep in mind that the lobes of the brain work together.

Figure 4. Lobes of the Cerebrum



The Frontal Lobe

- Problem solving
- Planning and anticipation
- Organizing and sequencing
- Understanding abstract concepts
- Attention and concentration
- Memory
- Judgment
- Impulse control
- Social and sexual behaviors
- Initiation
- Personality and behavior
- Awareness and self-monitoring

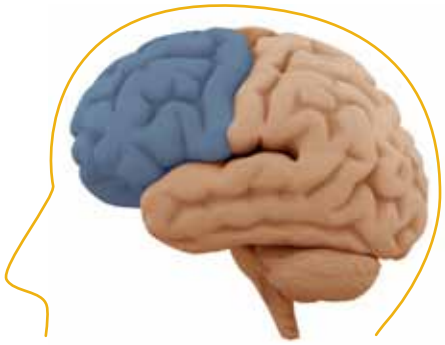


Figure 5. The Frontal Lobe

- Emotions
- Language/speaking
- Movement.

The **frontal lobe** is the largest of the four lobes. It is responsible for many important cognitive (thinking) processes.

You may hear doctors using the term **executive functions**. This refers to the higher-level, more complex thinking activities performed by the brain. The ability to form concepts, socialize, and think abstractly are executive functions.

Executive functions allow us to be creative, solve problems, and function independently. The frontal lobe is easily injured 1) because it is located towards the front of the head; and 2) because of where it sits inside the skull near several bony ridges.

The Temporal Lobe

- Memory
- Organization, categorization
- Learning
- Concept of time
- Understanding verbal language
- Emotion
- Hearing
- Some visual perception.

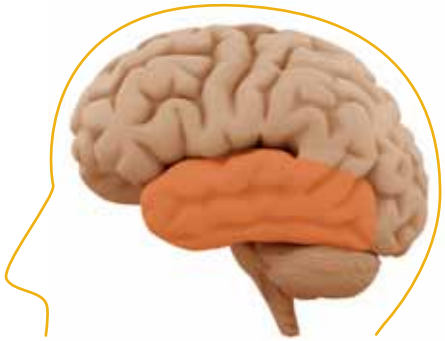


Figure 6. The Temporal Lobe

The temporal lobe is also easily injured because of its location. It is near several bony ridges on the underside of the skull.

The Parietal Lobe

- Sense of touch
- Identification of sizes, shapes, colors
- Spatial perception
- Visual attention
- Integration of senses
- Manipulation of objects.

The parietal lobe is more protected from traumatic injury. But it can also be injured.

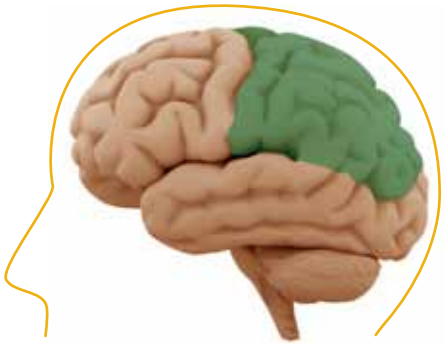


Figure 7. The Parietal Lobe

The Occipital Lobe

- Vision
- Visual recognition.

The occipital lobe is more protected from traumatic injury because of its location at the back of the brain.

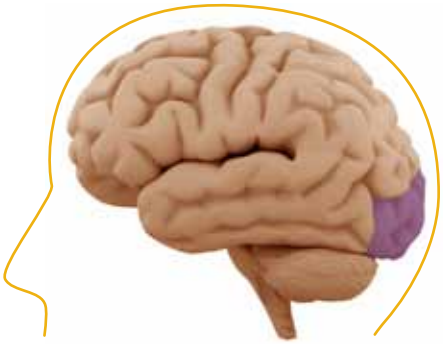


Figure 8. The Occipital Lobe

Deeper Parts of the Brain

The most basic functions of the brain are controlled at the deepest level, called the **brainstem** (see Figure 9). This primitive part of the brain controls automatic functions such as:

- breathing
- heart rate
- blood pressure
- consciousness and alertness
- sleep/wake cycles
- sweating
- temperature regulation
- swallowing
- sense of balance.

The deeper structures of the brain include the brainstem, thalamus, and hypothalamus.

The **thalamus** is near the top of the brainstem and nearly all information from our senses (taste, touch, etc.) passes through it to the outer levels of the brain.

The **hypothalamus** sits under the thalamus. It produces some hormones. It helps control many critical functions, including:

- body temperature
- hunger
- thirst
- emotional and behavior responses.

Directly beneath the cerebrum is the **limbic system**. This part of the brain is involved with human emotions and memories.

Located at the back of the brain, beneath the occipital lobes, is the cerebellum. The main job of the **cerebellum** is to control, regulate, and coordinate movement, posture, and balance.

These deeper structures also help to regulate alertness and attention and share information among the parts of the brain.

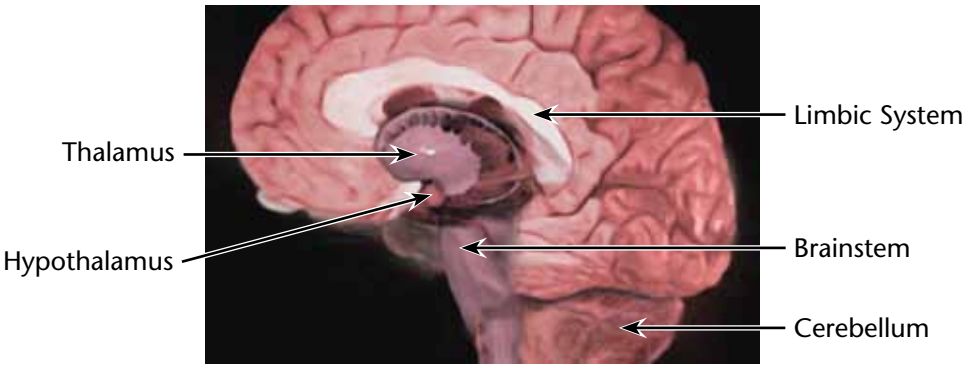


Figure 9. Deeper Brain Structures

Understanding the various parts of the brain and what each part controls allows you to understand why your service member/veteran is having certain kinds of effects. Where the injury happened influences the effects you are seeing.

"We agreed that the resident doctor could present Jason's case to a conference of doctors at the University of Maryland. Of course, she wouldn't use his name. She asked if we would come too, and we said yes.

So we're in front of this whole room of doctors and she finishes her presentation, and the doctors start asking questions. And this one doctor raised his hand, and he said, 'I was the surgeon who treated him when he was first injured in Balad. I remember him.' And he said that seeing how far Jason has come and how responsive Jason is from when he saw him, from when they brought him off the field... he said that the brain is a lot more repairable than they even anticipated was possible."

- Pam E.

Chapter 3

Causes and Types of TBI

What Types of TBI are There?

There are two types of traumatic brain injury:

Penetrating Head Injury

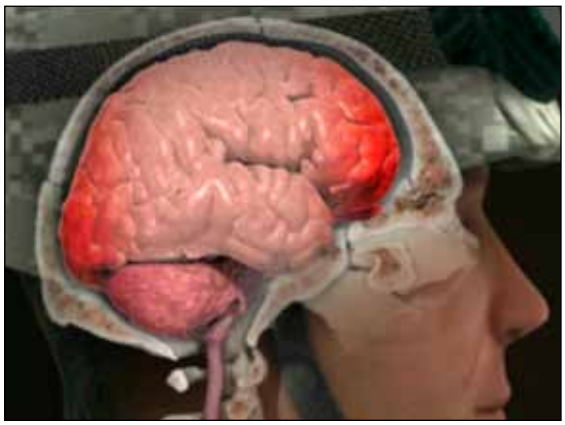
Penetrating head injury happens when an object goes through the skull and enters the brain. These injuries are easy to identify. They are cared for right away. Items that may enter the brain are:

- bullets
- knives
- debris from an explosion
- bone or metal fragments.

Closed Head Injury

Closed head injury occurs from any force that causes violent shaking of the brain inside of the skull. A closed head injury can happen in many ways:

- exposure to blast waves during an explosion
- motor vehicle crash where the head hits the windshield
- a fall
- when a blunt object, such as a fist or weapon, strikes the head.



Sometimes, when the front of the head is struck by something, the whiplash motion set into place causes the brain to rock back and forth inside the skull. This leads to damage to both the front and back of the brain. This rocking motion with damage to opposite sides of the brain can also happen in a side-to-side manner or in a diagonal manner. This is called a **coup-contrecoup injury**.

For service members in Iraq and Afghanistan, attacks involving explosions or blast by rocket-propelled grenades, improvised explosive devices (IEDs), and land mines are common causes of TBIs. Gunshot wounds, falls, and motor vehicle crashes also cause TBI in combat. Over 90 percent of combat-related TBIs are closed head injuries.

Sometimes, in the case of mild TBI (concussion), there may be no visible sign of injury.

The brain is quite fragile. It has the consistency of firm gelatin. Imagine that the brain is like gelatin in a bowl. When you tilt the bowl, you can move the gelatin around. If you shake the bowl more forcefully or drop the bowl, you can cause tiny or even large cracks in the gelatin. This is similar to what happens to the brain when it is exposed to external forces. When the head is severely jarred, the brain moves rapidly around the rough bony interior of the skull. The brain can be ripped, twisted, torn, and bruised. The brain is somewhat protected by the skull, but can still be injured if enough force is applied.

When the head is injured, many things can happen:

- skull fractures
- bleeding on the outside or inside of the brain (hemorrhage, hematoma)
- bruising of the brain tissue itself (contusion)
- widespread stretching and straining of the brain cells (diffuse brain injury).

"I had no idea really what kind of injury he suffered. They said there was brain shearing. What's brain shearing? Because I think if I understood what the medical terms meant, it would have educated me to ask more questions."

- Pam E.

What Injuries Co-Occur With TBI?

What is a Skull Fracture?

There are several types of **skull fracture**:

- **Simple fracture**: A break in a skull resembling a thin line or crack that does not splinter, cave in, or change the shape of the skull. No surgery is usually required for simple fractures. They tend to heal on their own.
- **Compound fracture**: A break in or crushing of a part of the skull. Bone fragments may remain on the outside of the dura or may splinter off and penetrate the **dura**. This is known as a **depressed skull fracture**. Depressed skull fractures may require surgery. During surgery, small screws are used to hold the bones in place. If there is a tear in the dura, doctors will work to prevent an infection in the brain.
- **Basal skull fracture**: Fractures at the base (underside) of the skull can injure nerves, blood vessels, or other parts of the brain. Some fractures may cause cerebrospinal fluid **(CSF)** to leak. A sign of a CSF leak is clear fluid dripping from the nose or ears. Doctors and nurses will closely monitor any leaks. Most leaks stop on their own, but sometimes surgery is necessary.

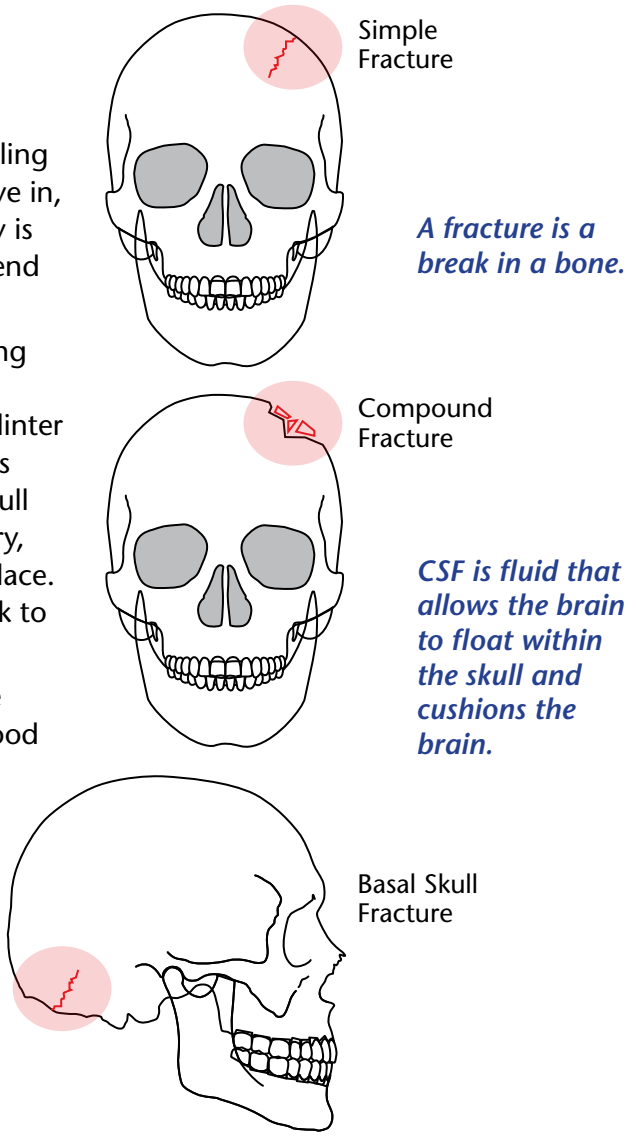


Figure 10. Skull Fractures

A fracture is a break in a bone.

CSF is fluid that allows the brain to float within the skull and cushions the brain.

What about Bleeding?

Bleeding can occur on either the outside or inside of the brain. Another term for bleeding is hemorrhage. You may also hear the term hematoma.

Sometimes the bleeding is very small and simply requires close monitoring. Sometimes blood builds up and pushes against the surrounding brain tissue. If this happens, the blood needs to be removed by surgery. The **neurosurgeon** is the specialist on the team who will make this decision.

The dura is the tough covering of the brain.

A hematoma is an accumulation of blood. It's also called a blood clot.

Hemorrhage means bleeding.

There are several types of bleeding. Types of bleeding are described in terms of where the blood lies in relation to the skull, **dura**, and brain:

- **Epidural hematoma**: A blood clot outside the brain and the dura but under the skull. This blood clot can cause fast changes in the pressure inside the brain and may need to be removed surgically. When the brain tissue is compressed, it can quickly change the brain's normal functions.
- **Subdural hematoma**: A blood clot between the brain and the dura. The clot may cause increased pressure and may need to be removed surgically.
- **Subarachnoid hemorrhage**: Bleeding within the layers of the dura, specifically under the arachnoid layer.
- **Intracerebral hematoma**: Bleeding within the brain tissue itself caused by the rupture of a blood vessel within the brain.
- **Intraventricular hemorrhage**: Bleeding into the ventricles (butterfly-shaped spaces) of the brain.

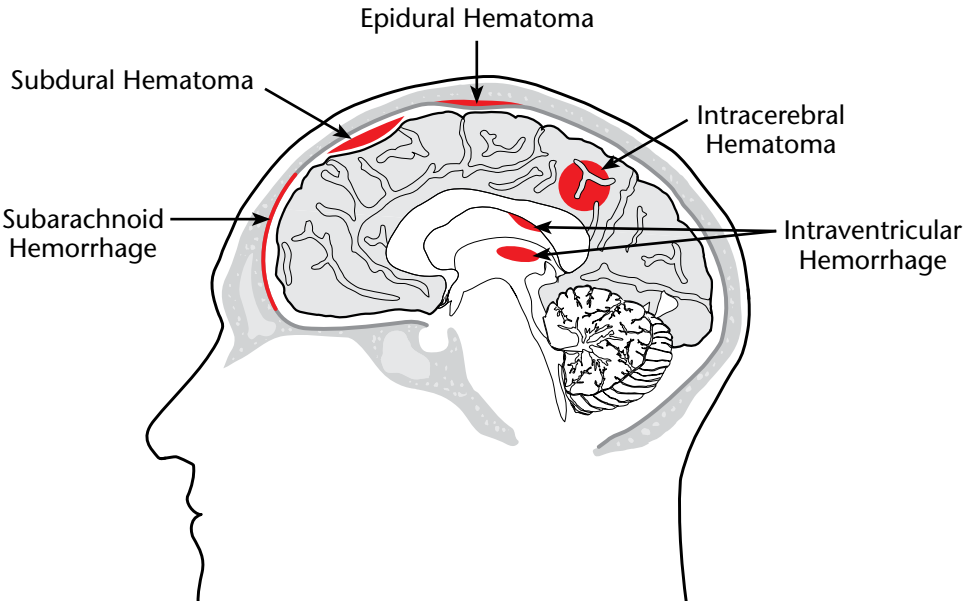


Figure 11. Types of Brain Bleeding

What about Bruising?

Along with bleeding on the inside or outside of the brain, the brain tissue itself may be bruised. This is a **contusion** and can occur throughout the brain. Sometimes severely bruised brain tissue needs to be surgically removed. You may be surprised to know that many people who have small portions of the brain removed in order to save their lives still have the potential to make a meaningful recovery.

A contusion is another word for a bruise.

What is a Diffuse Brain Injury?

A diffuse (widespread) brain injury is one of the most common and potentially severe types of TBI. In this injury, damage to the brain occurs over a large area. It is one of the major causes of unconsciousness and long-term **coma** after a TBI occurs.

A coma is when someone is unable to be awakened.

Brain cells are made up of neurons (the body of the cell) and axons (the long tail of the cell). Axons are important as they are the information highway on which signals travel in the brain. Axons allow cells to communicate with each other in order to carry out the many processes of the brain.

Diffuse axonal injury (DAI) is the result of stretching, twisting, and shearing (tearing) of axons. DAI is often caused when the head violently starts or stops, which commonly happens when it is exposed to external forces.

Diffuse axonal injury is widespread injury to the axons, the long tails of brain cells.

The diagrams below illustrate the differences between a healthy axon and injured ones.

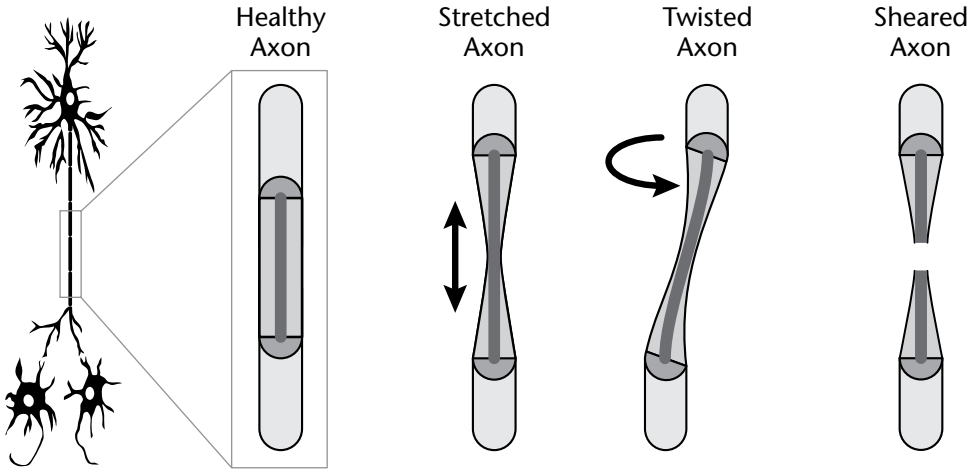


Figure 12. Healthy and Injured Axons

Changes in Neurochemistry

Along with straining and stretching of brain cells, the chemistry system in the brain is often affected with TBI. The brain has a delicate neurochemistry system. Chemicals called neurotransmitters help brain cells communicate with each other. This allows the brain to carry out its many jobs. TBI disrupts this communication system. It can take weeks to months for the neurochemistry system to return to a normal state.

Chapter 4

Diagnosis and Treatment of TBI

There are many **health care providers** involved in the diagnosis and treatment of service members/veterans with TBI. These providers are experts in disorders of the brain and how these disorders affect a person's ability to function.

Health care providers are all the people on the medical treatment team. They include doctors and nurses, along with many other medical specialists. You can find out more about the members of the health care team in Module 2.

Some of these specialists work in the acute care hospital setting where diagnosis and early medical treatment are priorities. Others work in the rehabilitation setting where treatment focuses on restoring function and adapting to residual effects of the TBI.

Treatment for severe TBI can last weeks to months, and sometimes longer.

How is a Traumatic Brain Injury Diagnosed?

With a severe TBI--especially in cases of penetrating injury--doctors can usually make a diagnosis immediately. A closed head injury could be overlooked when the service member has other life-threatening or serious physical injuries. However, a closed head TBI will be detected later when more detailed evaluation is possible.

A detailed **neurological exam** is helpful in detecting TBI. This exam usually includes a series of questions and simple commands to see if the service member/veteran can open his or her eyes, move, speak, and understand what is going on around him or her.

What is the Glasgow Coma Scale and How is it Used?

You may have heard about the **Glasgow Coma Scale** (GCS). The GCS is used to evaluate brain function and the severity of the TBI.

You can find a copy of the Glasgow Coma Scale in Appendix A.

The GCS rates three things:

- the ability to open eyes
- the ability to respond to a command to move
- the ability to speak.

A score of 3 is the lowest score possible and means the person is in a **coma**. A score of 15 is the highest score and means the person is fully awake and understands what is going on around him or her.

A coma is when someone is unable to be awakened.

GCS scores can be affected by other things. For example, being sedated or having a breathing tube inserted affects GCS scores.

What is Post-Traumatic Amnesia (PTA)?

Another measure of how serious a TBI may be is severity and depth of confusion, also known as **post-traumatic amnesia** (PTA). The longer someone is confused, the more serious the damage to the brain.

"Something that was really helpful for me was the list of the Glasgow Coma Scale because they used that a lot and I didn't understand what it meant. People would throw out these numbers—'Oh, he's at number 4 or 5'—well, what does that mean?

When I read the list, it's up to 15. I could watch Pat's recovery, too, because at the beginning he was 3, and then I could say, okay, now he's a 4 or 5, he's making progress."

- Patty H.

What is a CT Scan? Why is it Used?

*A **CT scan** is a computerized x-ray that doctors use to view areas of the brain and to look for areas of bleeding and bruising.*

If your service member/veteran was knocked unconscious or was very confused following his or her injury, doctors probably used a **Computed Tomography (CT)** (formerly known as Computerized Axial Tomography [CAT]) scan of the brain to look for signs of TBI.

Why Did the Doctor Order an MRI? What is it?

An MRI scan provides detailed images of the brain using magnetic energy rather than x-ray technology.

Sometimes, when a CT scan is negative for obvious injury but the service member/veteran is still showing signs and symptoms of TBI, a **Magnetic Resonance Image (MRI)** may be ordered.

What Other Tests are Used to Diagnose TBI?

An **electroencephalograph (EEG)** may also be ordered. An EEG measures electrical activity in the brain. Special patches are applied to the head to measure activity. EEG is one way to detect seizure activity and to look for an increased risk for seizures in the future.

Intracranial means within the skull.

Elevated intracranial pressure (ICP), the pressure inside of the brain, can indicate the presence of TBI. An **ICP monitor** may be placed through a small hole in the skull to measure the pressure inside the brain.

How are Traumatic Brain Injuries Medically Treated?

Early medical treatment for TBI seeks to:

- stop any bleeding
- prevent and control increased pressure in the brain

"My son had a closed head injury. Initially, he was in a coma. If you're not in the medical field, it's pretty horrendous to see your son on a vent and a ventriculostomy coming out of the brain to measure the intracranial pressure. They had to control the intracranial pressure. If it kept going up, they would have to do a cranioplasty. It is horrendous to walk in and see all the tubes and not be able to communicate with him."

- Cindy P.

- maintain adequate blood flow to the brain
- remove large blood clots as necessary.

Treatments vary with the type of injury. The doctors and nurses will decide which ones will be used. Some common treatments are:

Positioning

The head of the bed will be elevated and the neck kept straight. This position may decrease pressure inside the brain.

Fluid Restriction

Your service member/veteran's intake of fluids may be limited. The brain may be swollen and limiting extra fluids can help control the swelling.

Medications

There are many possible medications that doctors may use to treat TBI. Medications can:

- decrease the amount of fluid in the body and brain
- prevent seizures
- prevent and treat infections
- maintain blood pressure
- control pain.

Sometimes medications are given to purposefully keep your service member/veteran asleep while his or her injuries are being identified and treated.

Ventricular Drain (Ventriculostomy)

A small tube may need to be placed in one of the ventricles of the brain. (See page 6 for a description of ventricles.) This tube drains **cerebrospinal fluid (CSF)** if there is more than there should be. Too much CSF causes unwanted pressure on the brain.

CSF is fluid that allows the brain to float within the skull and cushions the brain.

Ventilator

A ventilator is a machine used to support someone's breathing or to provide breaths. This is also sometimes called a respirator. Strong regular breathing provides good oxygen flow to the brain.

When is Surgery Needed?

There are different kinds of surgery that your service member/veteran may need:

- A **craniotomy** involves opening the skull to relieve the causes of increased pressure inside the skull. The causes may be fractured bones, blood clots, or bruised brain tissue.
- **Burr hole** surgery involves a small opening into the skull to remove a pool of blood.
- **Craniectomy** involves removing a piece of bone from the skull to relieve pressure caused by swollen brain tissue.

It can be quite a shock to see your service member/veteran for the first time after a craniectomy because his or her head will not be its normal shape. Craniectomy allows the brain to swell upward instead of downward. This is very important as downward swelling in a closed vault like the skull can be fatal. Without a complete skull to protect the brain, the service member/veteran may be required to wear a protective helmet until the bone can be replaced.

- A **cranioplasty** will follow a craniectomy. In this surgery, the bone piece (also called **bone flap**) that was removed during the craniectomy is replaced, after the risk of brain swelling is gone. Cranioplasty may involve placement of screws or small plates to keep the bone flap in place. If the original bone was too damaged to be replaced, artificial materials may be used during cranioplasty.

Cranioplasty is also performed in cases of penetrating injury or complex skull fractures.

What are All These Tubes?

Various tubes may be used in the early treatment phase following TBI. These tubes have different purposes:

- Some are in place to provide nutrition. A nasogastric tube (**NG tube**) passes through the nose into the stomach. It is a short-term source for nutrition. If the service member/veteran is unable to swallow for many days to weeks, a per cutaneous gastronomy tube (**PEG tube**) will be placed directly into his or her stomach.
- Other tubes help with breathing. If a ventilator is needed to assist with breathing, the short-term option is an **endotracheal tube**. It is inserted through the nose or mouth. If a longer option is needed, a **tracheostomy** tube may be placed directly into the **trachea**.
- **Intravenous tubes (IVs)** may also be used for several days or weeks to provide medications and nutrition.
- A tube may be placed in the bladder to drain urine (**urinary catheter**).

Seeing your service member/veteran with many tubes can be scary. The good news is that tubes are almost always temporary measures used in early treatment. Rarely are any of these tubes permanent.

The trachea is the main airway that runs from the base of the throat down to the lungs.

"Intravenous" refers to veins.

Chapter 5

Potential Complications Following TBI

Doctors and nurses work very hard to prevent **complications** after a TBI. During the first several days to weeks after the injury, the risk of further damage from complications is high. So the health care team takes all the steps it can to control complications.

A complication is a secondary injury that can hamper the recovery process.

Are There Common Complications Following Severe TBI?

Some complications are a direct result of injury to the brain. Others come from being bedridden for many days or weeks. Some result from the overall shock the body is experiencing.

Here are some common complications that happen in the days or weeks after the injury:

- **Increased intracranial pressure (ICP)**: The pressure inside the brain can increase to dangerous levels. Sometimes, the pressure is life-threatening. An ICP monitor alerts doctors to the pressure. Medications can prevent or treat high pressure.

Intracranial means within the skull.

- **Edema**: Swelling that occurs when the brain contains more fluid than normal. When swelling happens within the brain, there is no place for the tissue to expand. This is because the brain is encased in the skull. Swelling can cause pressure to build up. This results in damage to brain cells. It also interrupts blood flow. Medications and fluid restrictions often help. Sometimes, surgery is needed.

Edema is another word for swelling.

- **Hydrocephalus**: Also known as "water on the brain," hydrocephalus happens when cerebrospinal fluid (CSF) collects in the ventricles. This condition may occur during the initial period after TBI or develop later (usually within the first year). If hydrocephalus is severe, doctors may place a shunt in the brain. The **shunt** drains the extra fluid from the brain to other places in the body.

A shunt is a tube.

- **Low blood pressure**: Blood carries oxygen to the brain. The brain needs oxygen. Doctors and nurses work hard to keep blood pressure from getting too low. This helps increase blood flow to the brain.
- **Fever**: Some parts of the brain regulate temperature. Injury to these parts may cause high fevers. This is especially true during the first hours or days after an injury. Fever is also a sign of infection. Medications and/or cooling blankets can bring the fever down.
- **Pneumonia**: Being in bed and not able to move around increases the risk of pneumonia. The health care team will carefully monitor your family member's breathing and lung status. They may take frequent chest x-rays

Pneumonia is an infection in the lungs.

to look for pneumonia. Fever is also a sign of pneumonia, a common complication. Fortunately, antibiotics usually work to treat pneumonia.

The dura is the tough outer membrane around the brain.

An abscess is an inflammation that contains pus.

- **Brain infection**: Infections may occur on the outside of the **dura**, below the dura, in the membranes surrounding the brain (meningitis), or within the brain itself (**abscess**). Depressed skull fractures or penetrating brain injuries can cause brain infections. Antibiotics treat brain infection. Sometimes, surgery is needed.
- **Other infections**: To treat TBI, your service member/veteran may have one or more tubes (see page 23). These tubes are needed. But they may cause infection. Body temperature readings and blood tests are ways to monitor for infection. Antibiotics control infections.

The veins carry blood to the heart.

Pulmonary refers to the lungs.

An embolism is a mass that blocks the flow of blood in the vein.

- **Blood clots**: Not being able to move around leads to slower blood flow throughout the body. Slower blood flow can lead to blood clots in the legs or arms. These are known as **deep vein thromboses (DVT)**. Signs of a clot include a leg or arm that is warm, red, and swollen.

  If a DVT travels to the lungs, it is known as a **pulmonary embolus (PE)**. A PE can be very dangerous. It requires immediate treatment. A tiny filter may be placed in a large vein called the vena cava. This keeps DVTs from reaching the lungs. This filter is usually removed later. Medication to thin the blood is often used to prevent and treat blood clots.

Bedsores are ulcers on the skin.

- **Skin breakdown**: Being in bed all the time and having other injuries may cause the skin to break down (**bedsores**). Nurses work hard to prevent bedsores by changing the person's position often and inspecting all areas of the skin. Various treatments or topical applications may be used.

You are an important part of the team. You know your service member/veteran better than anyone. If you notice any of these signs or symptoms, tell the health care team what you are seeing or thinking. Do this even if you simply feel as if "something is wrong," even though you can't quite put your finger on what it is. Family members may notice small changes before anyone else. The earlier a complication is detected, the sooner it can be treated.

Chapter 6

Recovery Process

It is hard to predict a person's long-term recovery from a TBI. You want to know if your service member/veteran will fully recover. But doctors may not be able to give you a definite answer.

"When my son was hurt, I said, 'What can I expect? What's going to happen to my son?' The doctor looked at me, and said, 'Even we don't know. The injuries that these guys are coming home with now are new to us. Five years ago, an injury like this would have killed him. He would never survive it. These are young people. They now get better and they survive it. We are re-writing the medical books.'"

- Nellie B.

After a TBI, the body begins to repair itself. In most cases, brain swelling begins to go down within a few weeks. The pressure inside the skull lessens. The brain's chemical balance returns to normal within several months.

For most people with moderate to severe TBI, the most rapid recovery will happen in the first six months following injury. But there is reason to stay hopeful. Most will also continue to improve for years after injury. Recovery is individual. Everyone progresses at his or her own pace.

It takes time for people to "wake up" after a severe TBI. It is a process. It does not happen overnight. Most people with severe TBI will "wake up" and "clear up" over the course of several days or weeks. Sometimes, this takes months. The extent to which someone fully wakes up and clears up is not fully known by anyone. However, it becomes clearer as time passes.

Here are some ways that the brain repairs itself over time:

- New connections may develop between damaged cells.
- Existing connections may also be used in new ways to make up for damaged ones.
- Other parts of the brain may slowly learn to assume functions of damaged brain tissue.
- The body may even be able to replace damaged brain tissue.

Sometimes, the term "brain plasticity" is used to describe the brain's ability to bounce back and recover after TBI.

People with milder injuries tend to recover sooner. But this is not always true. People with more severe injuries usually take longer to recover. Some recover fairly well over time. Some will need help for the rest of their lives.

A coma is when someone is unable to be awakened.

Moderate to severe TBI may involve a **coma** that lasts days, weeks, or months. Very rarely, a coma lasts even longer. In general, the longer a person remains in a coma, the more challenging recovery may be.

Recovery from a moderate to severe brain injury is also affected by:

- How severe the damage is
- The areas of the brain affected
- The areas of the brain not affected
- Age at the time of injury
- The early pattern of recovery
- The length of time the person is very confused
- Other injuries to the body
- The overall health of the person before this injury.

Rehabilitation means re-learning how to do things. A rehabilitation specialist might be a physical therapist, an occupational therapist, or a speech-language pathologist.

There is no way to speed the process of recovery. Good medical care gives your service member/veteran the best chance of recovery. **Rehabilitation** by specialists in TBI helps your family member re-learn how to do things. Most people return to their homes, families, and communities. This is true even for people with severe TBI.

"It had been 15 months and he had slowly improved. But he couldn't talk. He'd kind of start trying to mouth words, but he just couldn't talk. And so, on October 21st, 2005, I'll never forget that morning. I came in to the bedroom and I said, 'Fred, how are you doing?' And he said, 'Fine.' Okay. I think he just talked to me. So I just turned around and went back into the kitchen, got his breakfast, came back in and thought, okay, let me try this again. I said, 'Fred, how are you doing?' And he said, 'Fine.' It wasn't a lot at first, but he could talk."

- Denise G.

As a caregiver, keep hope alive as you support the recovery process of your family member with TBI. Waiting for your service member/veteran to become more awake and aware can make you feel sad and frustrated. (See Module 3 to read about caring for yourself during this time.)

On the positive side, you are likely to see progress. Remember, progress is progress, even if it's slower than you would like to see.

Keeping a journal and writing down what is happening during your service member/veteran's recovery may help you track recovery milestones. Months from now, you may look back on earlier journal pages and be amazed at how far he or she has come.

Using a journal to record your own feelings may also help you cope with stress and anxiety. Most people have these feelings when a family member has been injured.

What are the Stages of Recovery?

As your service member/veteran recovers from TBI, he or she often moves through stages known as the Rancho Los Amigos Levels. The **Rancho Los Amigos Levels of Cognitive Functioning** describe the stages of recovery from TBI. The levels are based on the person's behaviors.

You can find a copy of the Rancho Los Amigos Levels in Appendix B.

Key Points to Keep in Mind:

- There is no accurate way to predict exactly how recovery will progress or what the final outcome will be.
- Many service members/veterans with severe TBI go through similar stages and patterns of recovery but at their own pace.
- Most service members/veterans will make progress.
- Progress is still progress!

The Rancho Los Amigos Levels help you understand what point your service member/veteran has reached in his or her recovery. On the folllowing pages are the four broad stages of recovery and how you can help during each stage.

Emergence from Coma (Rancho Levels II and III)

Unlike the dramatic reawakening you may have seen on television, waking up from a coma is usually very gradual after a severe TBI. Although the term "coma" suggests closed eyes, your service member/veteran's eyes may open before other signs of consciousness appear.

Consciousness is judged by a person's ability to pay attention to or interact with the world around him. It is usually tested by how well the person can follow commands and respond to stimulation.

It may be helpful to understand the medical terms commonly used to describe a service member/veteran with TBI who is very sleepy:

- **Coma** – unconscious, no sleep/wake cycles, does not respond at all to the world around him or her, does not show emotion
- **Vegetative State** – sleep/wake cycles are apparent, may startle, may occasionally "track" with his or her eyes
- **Minimally Conscious State** – partly awake and conscious, may reach for objects, more often "tracks" with the eyes, might be able to occasionally talk or make noises, can show emotion.

Some individuals with TBI may remain in a minimally conscious state. Most, however, will progress to greater awareness. As people come out of a coma, they typically move from inconsistent responses with only certain people to responses that are more consistent. Your service member/veteran's sleep/wake cycle improves and he or she begins to follow objects with his or her eyes (tracking). Other signs of awakening

"My brother was in a minimally conscious state. You hear all these miracle stories and you start getting your hopes up. But then day after day goes by, week after week, month after month, and no sign of major improvements. Meanwhile, you watch as others on the same ward or whom you've met continue to improve. You want to be happy for them--and you are, but why is your loved one not improving at the same rate? During these times, take comfort and support from those around you. At my most cynical of times, I would continue to be inspired by the generosity and strength of others."

- Liza B.

may appear before your service member/veteran begins consistently responding to commands. These signs could be assisting in therapy or showing facial expressions or emotions.

During this time, the health care team looks for purposeful responses and encourages these responses by **stimulating** the person. Stimulation techniques include:

- range-of-motion exercises
- stimulating taste and smell
- using sounds to reach the person
- providing visual stimulation
- using touch
- encouraging frequent position changes.

Families and friends are often uncomfortable about interacting with a person with a brain injury. This is particularly true when the individual is in a coma or minimally conscious, in an **ICU**, and full of tubes.

The odds are that your family member will recognize you when he or she begins to awaken. The incidence of true "**amnesia**" is almost unheard of after a TBI. As early confusion clears, most people with TBI keep their long-term memories and recognize their family and friends.

What Can I Do To Help?

- No one knows for certain if people in a coma can hear. But that doesn't really matter. What matters is they "might" hear. Hearing your voice and knowing you are there can be very comforting.
- Watch doctors and nurses as they try to stimulate the person. Try doing what they do.
- Do simple activities for short periods of time. Describe what you are doing ("I am holding your hand now.").
- Ask your service member/veteran to look at you and others in the room when his or her eyes are open.
- Present one simple direction at a time. Allow ample time for a response.
- Touch is very important and stimulating. If you are uncomfortable touching your service member/veteran, ask about ways to effectively touch, pat, or massage the person in reassuring ways.
- Bring in tape recordings of familiar music, the family dog barking, messages from friends, and other sounds that might be stimulating.

Stimulation means prodding the person to get him or her more active, aware, or involved with the world.

An ICU is an Intensive Care Unit where people with the most serious illness or injury are treated.

Post-traumatic amnesia (PTA) is the inability to acquire new memories. For example, a person with TBI may not be able to remember what he or she had for breakfast. Long-term memories, such as those from childhood, are not affected. PTA may range from a period of just a few minutes to a more permanent condition.

- Move back and forth between stimulating activities and periods of rest, quiet music, or soothing touch.
- Each time you are in the room, tell your service member/veteran the date and where he or she is. The more your family member hears accurate information about where he or she is and what has happened, the more that information will begin to stick.
- Calendars, pictures of the family, friends, home, and favorite things are helpful.
- Encourage visitors and the health care team to not talk about the person as if he or she is not there. Everyone should introduce themselves when they enter the room, explain why they are there, and say when they plan to leave.
- You don't need to always talk to your service member/veteran. It is also fine to just be with your family member and spend quiet time together.
- Setbacks, such as pneumonia, are not unusual in the early days. These can be scary. The health care team knows how to manage complications.
- As his or her responses to commands become more consistent, keep asking your service member/veteran to follow simple commands.
- Ask questions in a "yes" or "no" format. These are easier to respond to.
- If you are concerned about how much stimulation is appropriate for your family member, please ask for guidance from the doctor or other team members.

Inconsistency throughout recovery from TBI is expected. Don't be alarmed if your service member/veteran does something (follows a command, opens his or her eyes, speaks) one day, but not the next. The capacity is still there. He or she will again show the behavior. It is usually just a matter of "when."

People recovering from TBI have good days and bad days. Fatigue and impaired memory contribute to inconsistency. Many families learn to embrace the good days and tolerate the bad days.

Agitated State (Rancho Level IV)

A phase of restless, **agitated**, or aggressive behavior can occur in your service member/veteran as he or she progresses. He or she will also show confusion during this period.

Agitated refers to a lot of movement, sometimes violent movement.

In any case of severe TBI, the injured person will probably not remember much, if anything, about:

- what happened
- how he or she was transported
- the early days in the ICU
- his or her early interactions with doctors and nurses.

"In the beginning, he thought he was captured. On that kind of heavy medication, he was super-disoriented. Plus, he was injured and he didn't know about losing his eye. He didn't know where he was. He couldn't see. He was strapped down to the bed, and it took eight doctors at different points in time to restrain him because he kept trying to leave.

I had to seriously get down next to him and just explain to him that he was at Walter Reed, because he kept fighting these doctors. He punched out a nurse. It was really bad because they had to restrain him and that's really sad to see, when you're all bandaged up like that, to have to be restrained on top of it."

- Emily S.

Your service member/veteran may perform routine activities such as sitting up and reaching out without much sense of purpose. He or she may be very focused on basic needs: going to the bathroom, eating, and going back to bed.

Behavior may seem bizarre and out of character. The person's responses may seem out of proportion to what he or she is seeing and hearing or being asked to do. Yelling is not uncommon, nor is pulling at tubes.

Try not to let this overwhelm you as a caregiver. Doctors and nurses who work with TBI are very familiar with this stage of recovery. They will help you and your family member through it.

Safety and "riding out the storm" are the primary goals. The vast majority of people with TBI pass through this stage in a number of days to weeks. The odds of remaining in this state forever are very low.

Post-traumatic refers to after a trauma or injury. Amnesia means forgetting.

The inability to store new information and memories is called **post-traumatic amnesia (PTA)**. PTA often goes hand-in-hand with extreme confusion. Signs that someone is in PTA are:

- inability to recall if he or she just spoke to you
- the use of repetitive statements and questions
- confusion about where he or she is.

These behaviors are part of the recovery process. Your service member/veteran will probably not exhibit them over the long term.

During this time of restlessness and confusion, the health care team will take steps like these:

- reduce distracting stimuli (i.e., television, radio, noise level)
- try to establish normal sleep/wake patterns
- create a safe environment.

Protection may include the use of mats or a specially-designed bed to allow your service member/veteran to move freely without harm. Behavior management strategies and medications are also helpful for some individuals.

What Can I Do To Help?

Fatigue is weariness and exhaustion.

- Be aware of and reduce anything that promotes agitation.
- Being overstimulated and overtired contribute greatly to **fatigue**. Work with the health care team to set up a schedule that promotes rest.
- Most people with TBI respond best to a regular schedule. Try to maintain the schedule set up by the health care team.
- Continue to seek responses to commands and questions. But speak in gentle, low tones. Move about quietly and slowly.
- Explain in simple language what happened to cause the injury.
- Speak slowly. Use simple language when speaking.
- Talk about familiar things: family members, pets, places, and events the individual has experienced.
- Unusual behaviors, including swearing, are common. Be patient. These behaviors tend to go away over time.
- Complex tasks are difficult to complete. Break tasks down into simple steps. Offer step-by-step instructions.

- Don't get into long explanations or arguments. Simple instructions or conversations are best.
- Distraction is a powerful tool. Change the topic often if you find the person is becoming upset over a certain topic.
- Reassure the person that everything is being done to provide the care and treatment needed to restore health and well-being.
- Move the person to another type of activity if he or she becomes "stuck" on a certain topic or behavior.
- Give accurate information. But don't argue. It is best for your service member/veteran to hear correct information and not believe things that are not true.
- You can set limits on very inappropriate behavior. But do not expect to control your service member/veteran into "normal" behavior.
- It is often wise to limit visitors during this stage of recovery. Get directions from the health care team about how to do this.
- If visitors are allowed, have only 1-2 in the room at a time. Have only one person speak at a time.

It is important to remember that the agitated stage is a step forward in the recovery process. Agitated behaviors may be difficult to watch and respond to. But they are often signs of improvement. This is a stage that requires a great deal of open-mindedness and understanding by everyone. The health care team is very familiar with this stage of recovery. They are not embarrassed or taken aback by any behaviors. Safety for everyone is the primary goal.

Confused State (Rancho Levels V and VI)

Most individuals with severe TBI pass through a period of confusion and lingering restlessness. They have a hard time keeping a coherent line of thought. They often mix up past and present events.

In this stage, your service member/veteran with TBI may not recall new information and may not know where he or she is, what has

happened, the time of day, or time of year. People in this stage often have a hard time remembering the names and roles of their health care providers. They often do not understand why they are in the hospital or rehabilitation unit.

The ability to pay attention is often very short at first. Sometimes, it is only a few minutes. There is usually a gradual improvement in the ability to pay attention. Learning begins to take place during this stage.

As your service member/veteran becomes less confused, the ability to focus on and complete simple tasks improves. So does the ability to recall the events of the day (for example, what he or she had to eat, who visited, what he or she worked on in therapy). The health care team often begins to use calendar or memory notebook systems at this time. These tools remind the person with TBI of important facts and the daily schedule.

Many individuals know when they need to use the bathroom and are beginning to eat by now. Awareness of physical problems usually comes before awareness of thinking or behavioral problems.

As recovery continues, you will find more meaningful ways to interact with your service member/veteran. Your service member/veteran is probably becoming less passive and able to do much more.

Once equipment such as feeding tubes is no longer needed, there is more opportunity to be out of bed. Then, your family member can go to therapy and other activities. This promotes recovery and brings pleasure to all.

What Can I Do To Help?

- Ask simple questions that encourage memory.
- Offer generous words of encouragement and praise for attempts to respond.
- Create steady routines to develop greater organization.
- Learn the calendar and memory notebook systems put into place by health care providers. Reinforce their use by your service member/veteran.
- Learn how to best cue the person (see Module 2). A consistent **cueing** approach between the health care team and family members is very useful.
- Do not treat your service member/veteran as a child because his or her thinking is muddy. Do continue to be as honest and direct as possible.
- As he or she progresses through this stage, help with organization to perform simple daily tasks.

Cueing means to give a signal to begin a specific action.

- Build greater independence by offering only occasional support to complete tasks.
- Ask health care providers how you can be involved:
  - Ask the physical therapist (PT) how to safely transfer your service member/veteran in and out of the wheelchair or bed.
  - Ask the nurse to show you how to assist with toileting.
  - Ask the occupational therapist (OT) how to correctly perform range-of-motion exercises and how to help with meals or dressing.
  - Ask the speech and language pathologist (SLP) how to communicate best with the person.
- Do not bring in food or offer snacks without checking with the health care team. Eating the wrong kinds of foods can cause problems for your service member/veteran.
- Tape record all family conferences with the health care team. This can benefit family members who cannot attend. It can also give you a valuable review of information and progress.
- Your service member/veteran is likely processing information very slowly. It takes time for messages to be processed and motor responses to be carried out. Allow extra time for responding. Repeat your request after allowing time.
- Memory is often weak during early recovery from TBI. Check with health care providers to learn what restrictions your service member/veteran has (for example, not getting out of bed alone, not leaving the premises, smoking restrictions, diet restrictions).
- **Confabulation** is not uncommon. Talk with health care providers about how to manage confabulation.
- Keep in mind that repetition is important in order for the person to learn and remember.
- Your service member/veteran's tolerance levels for activities will still be low. Try to be patient and maintain realistic expectations.
- Limit visitors during this stage of recovery so as not to overstimulate the person.
- Encourage your family member to participate in all therapy sessions.

Confabulation means that the person tries to fill in memory gaps by making things up.

High Functional Level (Rancho Levels VII and VIII)

Although most people with TBI are medically stable when they reach this stage, they may continue to have physical, thinking, and behavior problems.

They are probably able to follow a schedule with little assistance. Memory for day-to-day events has improved. But activities that need higher-level thinking (solving complex problems, making hard decisions, doing more than one thing at a time) are probably still challenging.

The ability to participate in therapy full-time has improved. So has awareness of the need for therapy. Your service member/veteran may know what he or she needs to do, but has some trouble carrying it out. He or she will likely still feel overwhelmed when under stress or in emergency situations.

Physical recovery has often continued to the point that others think the person looks "back to normal."

Treatment seeks to help your service member/veteran recognize these difficulties and learn how to compensate for them. Ongoing goals are to develop independence and begin to make plans to move from the hospital or rehabilitation setting to home.

Your service member/veteran may be anxious about returning to family, community, school, and/or active duty. This may come across as ambivalence or disinterest in the future. Psychological counseling can help you and your service member/veteran to develop coping skills and better understand how his or her levels of functioning have changed.

In this stage, you may need to encourage full participation in daily activities. Your service member/veteran should begin taking responsibility for his or her personal care. He or she should begin to use ways that will help compensate for thinking and/or physical problems.

What Can I Do To Help?

- Do not promise your service member/veteran that life will return to normal. Time will settle those issues for you. Then you won't have to feel guilty about making false promises.
- No two brain injuries are the same, just as no two people are the same. Comparisons with others may be disappointing and misleading.
- All discussions should take place with the person with TBI present. These discussions may seem harsh when there is talk of long-term effects and the future impact they will have on the life of your service member/veteran. Still, it is best to have full disclosure. This helps

develop plans that everyone agrees with. Open honest discussion also develops trust and coping.

- While your service member/veteran is still in the hospital or rehabilitation setting, learn as much as you can about how to help your family member apply the skills he or she is learning back in the home setting.
- Hospitals and rehabilitation units are very structured, just like the military. Routines have been set up that you can continue at home. Practice as soon as you get home. Without structure and routine, skills may seem to be lost and confusion may increase. But with a good family support system and practice, these skills often quickly reappear.
- Discourage your service member/veteran from using alcohol or drugs (see Module 3).
- After your service member/veteran is settled into a comfortable and workable home routine, begin to practice activities outside the home (grocery shopping, going to a movie, seeing friends). See Module 3.
- Be sure you fully understand restrictions on your service member/veteran. These might limit driving, working, being left alone, using power equipment, and climbing.
- Be sure you fully understand the plan for outpatient therapy and follow up with all members of the health care team.
- Treat your service member/veteran as an adult. Provide guidance, cues, and assist with decision making. But always respect his or her opinions.

"The doctor said to both of us, do you believe in miracles? And I said yes. And he said, then you need to pray for a big one. You need to pray for a real big miracle because your son—we don't know if he's going to make it. And he said if I were you, I would let him go. I'll give him my assistance, but he's not going to make it.

And I said to him, you don't make those decisions, you don't tell me he's not going to make it. That's not up to you. You go back in there and you do what you said you can do, now, to keep my son alive.

And two weeks later, my son opened his eyes for the first time. Three weeks later, he was taken off the ventilator and has never been on another one.

We were looking at my son three years ago to now. You don't even think it's the same person."

- Nellie B.

Journal

The questions below can help you reflect on your experience as a caregiver. You can write your thoughts here, copy this page and add it to your journal if you keep one, or reflect on these questions in your journal.

What have the doctors told me about my service member/veteran's injury? Describe the injury as best you can, in your own words.

What are my strongest fears or concerns at this moment in time?

What do I feel joyful or optimistic about?

Appendix A

Glasgow Coma Scale

The Glasgow Coma Scale is used to assess the consciousness and neurological functioning of a person who has just received a TBI. The total score is the sum of the scores in three categories: eye-opening response, verbal response, and motor response. The Scale provides a score in the range 3-15. A score of 3-8 indicates a severe TBI; a score of 9-12, a moderate TBI; and a score of 13-15, a mild TBI. For adults, the scores are as follows:

Eye Opening Response	Spontaneous--open with blinking at baseline	4 points
	Opens to verbal command, speech, or shout	3 points
	Opens to pain, not applied to face	2 points
	None	1 point
Verbal Response	Oriented	5 points
	Confused conversation, but able to answer questions	4 points
	Inappropriate responses, words discernible	3 points
	Incomprehensible speech	2 points
	None	1 point
Motor Response	Obeys commands for movement	6 points
	Purposeful movement to painful stimulus	5 points
	Withdraws from pain	4 points
	Abnormal (spastic) flexion, decorticate posture	3 points
	Extensor (rigid) response, decerebrate posture	2 points
	None	1 point

Appendix B

Rancho Los Amigos Levels

Family Guide to the Rancho Los Amigos Levels of Cognitive Functioning

Rancho Los Amigos
National Rehabilitation Center

Cognition refers to a person's thinking and memory skills. Cognitive skills include paying attention, being aware of one's surroundings, organizing, planning, following through on decisions, solving problems, judgment, reasoning, and awareness of problems. Memory skills include the ability to remember things before and after the brain injury. Because of the damage caused by a brain injury, some or all of these skills will be changed.

The Levels of Cognitive Functioning is an evaluation tool used by the rehabilitation team. The eight levels describe the pattern or stages of recovery typically seen after a brain injury. This helps the team understand and focus on the person's abilities and design an appropriate treatment program. Each person will progress at his or her own rate, depending on a variety of factors, including the severity of the brain damage, the location of the injury in the brain, and length of time since the brain injury. Some individuals will pass through each of the eight levels, while others may progress only to a certain level and no farther.

It is important to remember that each person is an individual and there are many factors that need to be considered when assigning a level of cognition. There is a range of abilities within each of the levels and your family member may exhibit some or all of the behaviors listed below.

Cognitive Level I: No Response

A person at this level:

- does not respond to sounds, sights, touch, or movement.

Cognitive Level II: Generalized Response

A person at this level will:

- begin to respond to sounds, sights, touch, or movement;
- respond slowly, inconsistently, or after a delay;
- respond in the same way to what he or she hears, sees, or feels. Responses may include chewing, sweating, breathing faster, moaning, moving, and/or increasing blood pressure.

Cognitive Level III: Localized Response

A person at this level will:

- be awake on and off during the day:
- make more movements than before;
- react more specifically to what he or she sees, hears, or feels. For example, he or she may turn towards a sound, withdraw from pain, and attempt to watch a person move around the room;
- react slowly and inconsistently;
- begin to recognize family and friends;
- follow some simple directions such as "Look at me" or "Squeeze my hand";
- begin to respond inconsistently to simple questions with "yes" and "no" head nods.

What family/friends can do at Cognitive Levels I, II, and III

- Explain to the individual what you are about to do. For example, "I'm going to move your leg."
- Talk in a normal tone of voice.
- Keep comments and questions short and simple. For example, instead of "Can you turn your head towards me?", say, "Look at me."
- Tell the person who you are, where he or she is, why he or she is in the hospital, and what day it is.
- Limit the number of visitors to 2-3 people at a time.
- Keep the room calm and quiet.
- Bring in favorite belongings and pictures of family members and close friends.
- Allow the person extra time to respond, but don't expect responses to be correct. Sometimes the person may not respond at all.
- Give him or her rest periods. He or she will tire easily.
- Engage him or her in familiar activities, such as listening to his or her favorite music, talking about family and friends, reading out loud to him or her, watching TV, combing his or her hair, putting on lotion, etc.
- He or she may understand parts of what you are saying. Therefore, be careful what you say in front of the individual.

Cognitive Level IV: Confused And Agitated

A person at this level may:

- be very confused and frightened;
- not understand what he or she feels or what is happening around him or her;
- overreact to what he or she sees, hears, or feels by hitting, screaming, using abusive language, or thrashing about. This is because of the confusion;
- be highly focused on his or her basic needs, i.e., eating, relieving pain, going back to bed, going to the bathroom, or going home;
- not understand that people are trying to help him or her;
- not pay attention or be able to concentrate for a few seconds;
- have difficulty following directions;
- recognize family/friends some of the time;
- with help, be able to do simple routine activities such as feeding him/herself, dressing, or talking.

What family/friends can do at Cognitive Level IV:

- Tell the person where he or she is and reassure him or her that he or she is safe.
- Bring in family pictures and personal items from home, to make him or her feel more comfortable.
- Allow him or her as much movement as is safe.
- Take him or her for rides in a wheelchair, when this has been approved by the treating team.
- Experiment to find familiar activities that are calming to him or her such as listening to music, eating, etc.
- Do not force him or her to do things. Instead, listen to what he or she wants to do and follow his or her lead, within safety limits.
- Since he or she often becomes distracted, restless, or agitated, you may need to give him or her breaks and change activities frequently.
- Keep the room quiet and calm. For example, turn off the TV and radio, don't talk too much, and use a calm voice.
- Limit the number of visitors to 2-3 people at a time.

Cognitive Level V: Confused and Inappropriate

A person at this level may:

- be able to pay attention for only a few minutes;
- be confused and have difficulty making sense of things outside him/herself;
- not know the date, where he or she is, or why he or she is in the hospital;
- not be able to start or complete everyday activities, such as brushing his or her teeth, even when physically able. He or she may need step-by-step instructions;
- become overloaded and restless when tired or when there are too many people around;
- have a very poor memory. (He or she will remember past events from before the accident better than new information he or she has been told since the injury.);
- appear to "make things up" to try to fill in gaps in memory;
- may get stuck on an idea or activity (perseveration) and need help switching to the next part of the activity;
- focus on basic needs such as eating, relieving pain, going back to bed, going to the bathroom, or going home.

What family/friends can do at Cognitive Level V:

- Repeat things as needed. Don't assume that he or she will remember what you tell him or her.
- Tell him or her the day, date, name and location of the hospital, and why he or she is in the hospital when you first arrive and before you leave.
- Keep comments and questions short and simple.
- Help him or her organize and get started on an activity.
- Bring in family pictures and personal items from home.
- Limit the number of visitors to 2-3 at a time.
- Give him or her frequent rest periods when he or she has problems paying attention.

Cognitive Level VI: Confused And Appropriate

A person at this level may:

- be somewhat confused because of memory and thinking problems. He or she will remember the main points from a conversation, but forget and confuse the details. For example, he or she may remember he or she had visitors in the morning, but forget what they talked about;
- follow a schedule with some assistance, but becomes confused by changes in the routine;
- know the month and year, unless there is a severe memory problem;
- pay attention for about 30 minutes, but has trouble concentrating when it is noisy or when the activity involves many steps. For example, at an intersection, he or she may be unable to step off the curb, watch for cars, watch the traffic light, walk, and talk at the same time;
- brush his or her teeth, get dressed, feed him/herself etc., with help;
- know when he or she needs to use the bathroom;
- do or say things too fast, without thinking first;
- know that he or she is hospitalized because of an injury, but will not understand all of the problems he or she is having;
- be more aware of physical problems than thinking problems;
- associate his or her problems with being in the hospital and think that he or she will be fine as soon as he or she goes home.

What family/friends can do at Cognitive Level VI:

- You will need to repeat things. Discuss things that have happened during the day to help the individual remember recent events and activities.
- He or she may need help starting and continuing activities.
- Encourage the individual to participate in all therapies. He or she will not fully understand the extent of his or her problems and the benefits of therapy.

Cognitive Level VII: Automatic and Appropriate

A person at this level may:

- follow a set schedule;
- be able to do routine self care without help, if physically able. For example, he or she can dress or feed him/herself independently, have problems in new situations, and may become frustrated or act without thinking first;

- have problems planning, starting, and following through with activities;
- have trouble paying attention in distracting or stressful situations. For example, family gatherings, work, school, church, or sports events;
- not realize how his or her thinking and memory problems may affect future plans and goals. Therefore, he or she may expect to return to his or her previous lifestyle or work;
- continue to need supervision because of decreased safety awareness and judgment. He or she still does not fully understand the impact of his or her physical or thinking problems;
- think more slowly in stressful situations;
- be inflexible or rigid, and he or she may seem stubborn. However, his or her behaviors are related to the brain injury;
- be able to talk about doing something, but will have problems actually doing it.

Cognitive Level VIII: Purposeful and Appropriate

A person at this level may:

- realize that he or she has problems with his or her thinking and memory;
- begin to compensate for his or her problems;
- be more flexible and less rigid in his or her thinking. For example, he or she may be able to come up with several solutions to a problem;
- be ready for driving or job training evaluation;
- be able to learn new things at a slower rate;
- still become overloaded with difficult, stressful, or emergency situations;
- show poor judgment in new situations and may require assistance;
- need some guidance to make decisions;
- have thinking problems that may not be noticeable to people who did not know the person before the injury.

What family/friends can do at Cognitive Levels VII/VIII:

- Treat the person as an adult; show respect for his or her opinion when attempting to provide guidance and assistance in decision making.
- Talk with the individual as an adult. There is no need to try to use simple words or sentences.

- Because the individual may misunderstand joking, teasing, or slang language, be careful to check for understanding when using humor or other abstract language.
- Encourage the individual to be as independent as is safe. Help him or her with activities when he or she shows problems with thinking, problem solving, and memory. Talk to him or her about these problems without criticizing. Reassure him or her that the problems are because of the brain injury.
- Strongly encourage the individual to continue with therapy to increase his or her thinking, memory, and physical abilities. He or she may feel he or she is completely normal. However, he or she is still making progress and may possibly benefit from continued treatment.
- Be sure to check with the physician on the individual's restrictions concerning driving, working, and other activities. Do not rely on the brain injured individual for information, since he or she may feel ready to go back to his or her previous lifestyle.
- Discourage him or her from drinking or using drugs, due to medical complications.
- Encourage him or her to use note taking as a way to help with memory problems.
- Encourage him or her to carry out his/her self care as independently as possible.
- Discuss what kinds of situations make him or her angry and what he or she can do in these situations.
- Talk with him or her about his or her feelings.
- Learning to live with a brain injury is difficult and it may take a long time for the individual and family to adjust. The social worker and/or psychologist will provide family members and friends with information regarding counseling, resources, and support organizations.

– Los Amigos Research and Educational Institute (LAREI), 1990

Disclaimer: Information presented on this page is for specific health education purposes only. Persons should consult qualified health professionals regarding specific medical concerns or treatment. Each clinician caring for the patient is responsible for determining the most appropriate care.

References/Credits

Chapter 1: The Basics of TBI

Definition of TBI: Defense and Veterans Brain Injury Center, "OIF/OEF Fact Sheet" (Washington, D.C., June 2007).

New research on factors affecting recovery: Novak, T. and Bushnik, T. (2008). Understanding TBI. Part 3: The Recovery Process. Seattle, WA: TBI Model Systems Knowledge Translation Center. (DRAFT)

Statistics on TBI in OEF/OIF: CRS (Congressional Research Service) Report for Congress. "United States Military Casualty Statistics: Operation Iraqi Freedom and Operation Enduring Freedom." The Library of Congress. Order Code RS22452. September 9, 2008.

This guide was produced in collaboration with
The Defense Health Board
The Defense and Veterans Brain Injury Center
and
The Henry M. Jackson Foundation for the Advancement of Military Medicine

www.traumaticbraininjuryatoz.org Version: 1-2010