



# Traumatic Brain Injury

A Guide for Caregivers  
of Service Members  
and Veterans





# WELCOME

**Welcome to *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans* – 2<sup>nd</sup> edition.** Traumatic brain injury (TBI) experts, survivors, and experienced caregivers, along with representatives from the Department of Defense, the Department of Veterans Affairs, and organizations that support the military comprised the TBI Caregiver Revision Working Group that oversaw the review and revision of this guide.

This guide was developed in 2010 for caregivers of service members and veterans with moderate, severe, or penetrating traumatic brain injury. This revision includes the addition of content relevant to caregivers of those who sustained mild TBIs. A caregiver is defined as, “Any family or support person(s) relied upon by the service member or veteran with TBI who assumes primary responsibility for ensuring the needed level of care and overall well-being of that service member or veteran” (NDAA of 2007, Sec. 744, December 2006). For the purposes of this guide, “family” or “family caregiver” includes spouses, parents, children, other extended family members, as well as significant others and friends. Additionally, the terms “family member” and “loved one” refer to the service member or veteran who has sustained a TBI.

You have started one of the most important jobs in your life—becoming a family caregiver to a service member or veteran who has a TBI. The guide’s purpose

is to provide you, the caregiver, with the information you need to care and advocate for your injured loved one, and to care for yourself in the process. Just as no two individuals are alike, no two brain injuries are identical. It is impossible to determine the speed and extent of recovery in the immediate aftermath of a TBI. Throughout the recovery process, there are likely to be many steps forward and perhaps a few steps back. Time and treatment will lead to an optimal level of recovery. We hope this guide will sustain you along the way and allow you to identify and access the information and support you need and deserve.

Being a caregiver can be both challenging and rewarding. During the development of this guide, caregivers repeatedly shared that what helped them the most was taking each day one-at-a-time, learning to ask for and accept help, taking steps to reduce stress, and maintaining hope.

Revising this resource designed specifically for you, the caregiver, was an honor. We hope that it will provide you with information when you need it, and will be a voice of support and encouragement for the journey ahead. We would like to express our sincere appreciation and gratitude for the military service of your distinguished veteran or service member and for your own unique contribution to our country.

- *The TBI Guide for Caregivers Revision Workgroup*

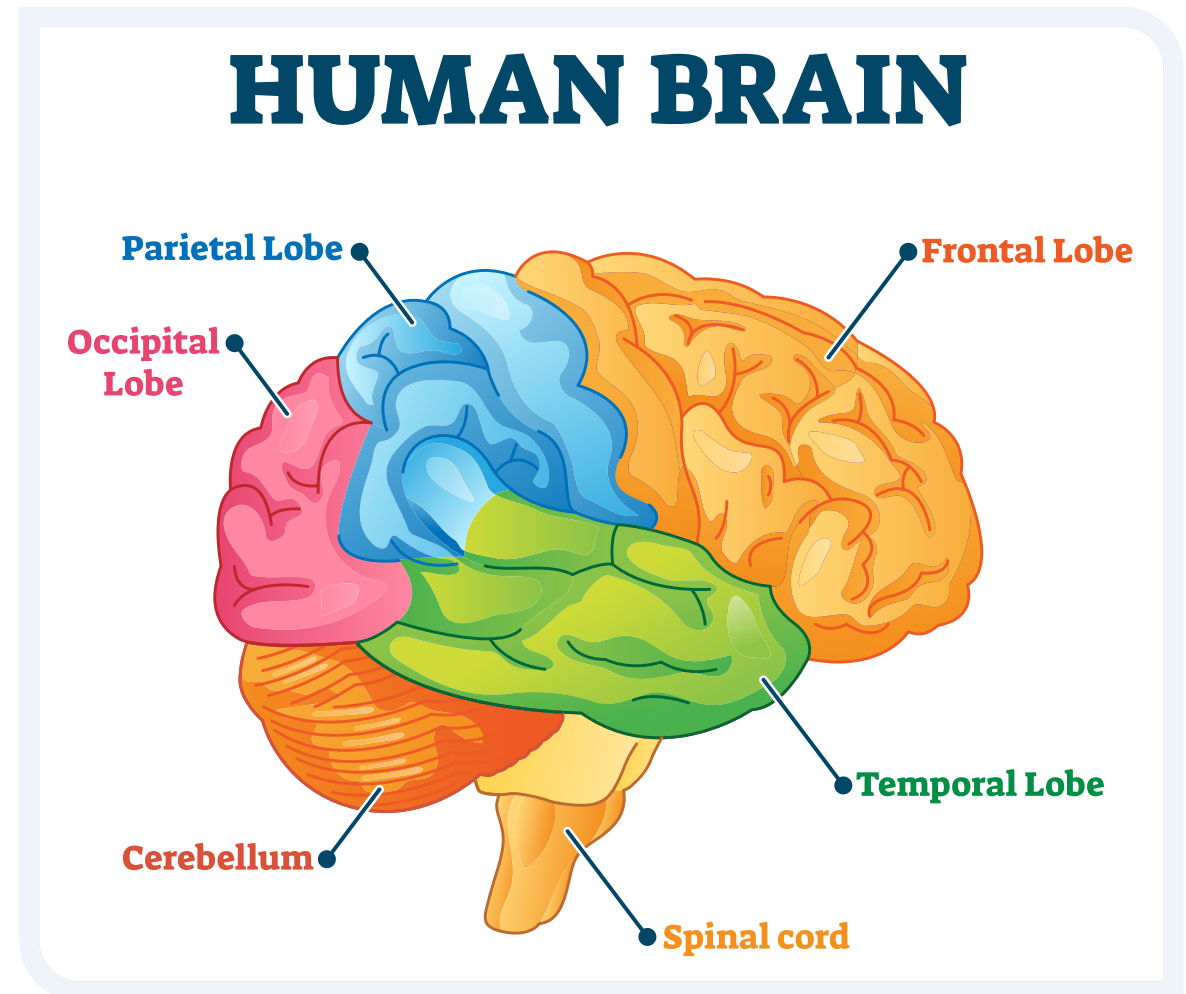
# UNDERSTANDING TBI

## Learning About the Brain

The brain is the body's control center and is constantly sending and receiving signals to and 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 and links with other parts of the brain to perform tasks. The more you understand about the brain, the easier it will be to understand how traumatic brain injury affects your service member or veteran.

The Air Force Center of Excellence for Medical Multimedia has developed an interactive brain that you can use to learn about the normal functions of the brain as well as what happens when a part is injured.

[Click here to learn all about the brain.](#)



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## What Is a TBI?

A traumatic brain injury (TBI) is a blow or jolt to the head, or exposure to an external force (such as a blast wave), that disrupts the normal function of the brain. It can also result from a sudden increase or decrease in speed, even if the head doesn't strike anything. Examples include when a head hits the windshield during a car accident or when a piece of shrapnel enters the brain. There are many causes of TBI, but not all blows to the head, or exposure to external forces, will result in a TBI. At least one of the following needs to occur to be considered a TBI:

- **Alteration of Consciousness (AOC):** This means feeling dazed, confused, or “seeing stars.”
- **Loss of Consciousness (LOC):** This means loss of awareness of oneself and one's surroundings. It can be for a brief or an extended period of time.
- **Post-traumatic Amnesia (PTA):** This means not being able to remember what happened.





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## How Common Is TBI?

TBI is a significant health issue that affects service members and veterans during times of peace and war. TBI affects the health and safety of individual service members, the level of unit readiness, and troop retention. The effects of TBI are felt within each branch of the military and throughout both the Department of Defense (DOD) and the Department of Veterans Affairs (VA) health care systems.

Active duty, reserve and National Guard service members are at an increased risk for sustaining a TBI compared to civilians. This is because of unique factors specific to the military. Many operational and training activities, which are routine in the military, are physically demanding and even potentially dangerous. Service members can also be deployed to areas where they are at risk of experiencing blast exposures from improvised explosive devices (IEDs), suicide bombers, land mines, mortar rounds, and rocket-propelled grenades. These and other combat-related activities put service members at increased risk for sustaining a TBI.

While TBIs can occur during deployment, they are actually more common in garrison. They can occur during military physical training and during recreational activities, such as when riding motorcycles, playing competitive sports, climbing mountains and parachuting from planes.

The [Traumatic Brain Injury Center of Excellence \(TBICoE\)](#) tracks TBI data in the U.S military. Between 2000 and 2019, more than 400,000 service members were diagnosed with a TBI. Click on the link above to find the annual and quarterly reports of active-duty service members—anywhere U.S forces are located—with a first-time TBI diagnosis since 2000.

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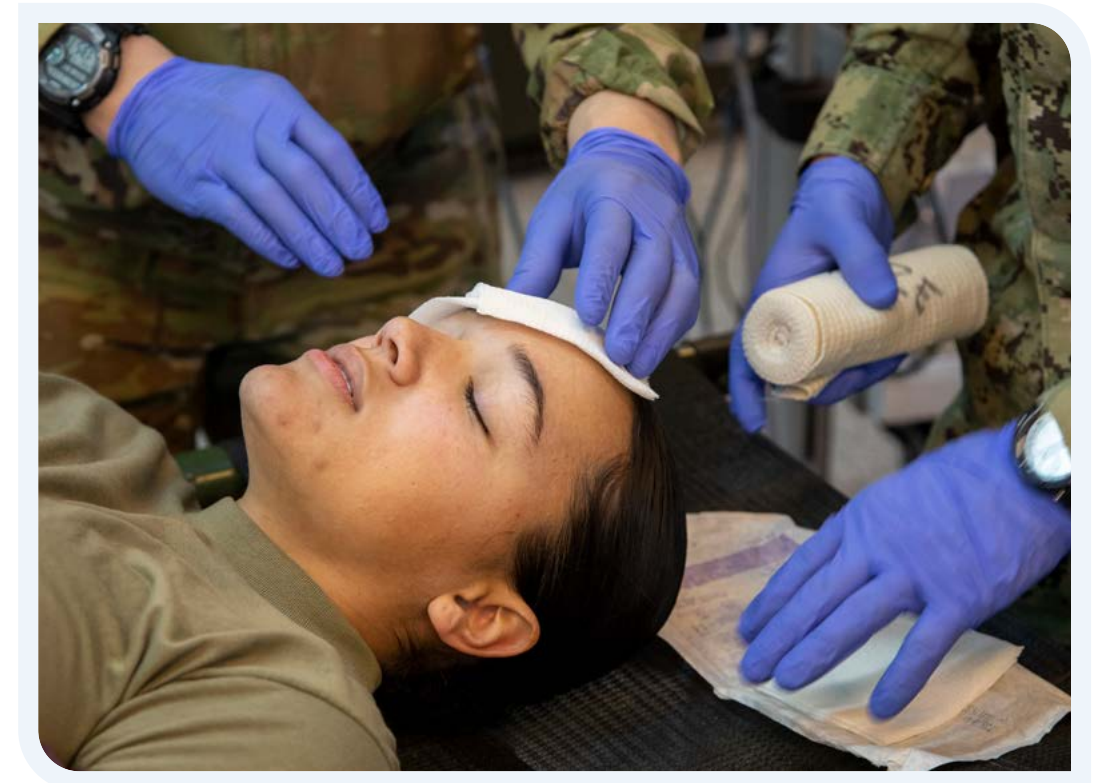
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## What Types of TBI Are There?

There are two types of traumatic brain injury:

- **Open or Penetrating Head Injury:** Occurs when an object goes through the skull and enters the brain, such as when a foreign body pierces the brain.
- **Closed Head Injury:** Occurs when a blow or jolt to a person's head causes the brain to shake violently inside the skull. When the soft brain hits the hard bones of the skull the brain's tissue and blood vessels bruise and tear. 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



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## How Are TBIs Categorized?

TBIs range from mild to severe. Injuries are rated based on their severity at the time of the injury and not by the severity of symptoms the service member or veteran experiences. How severe the TBI is when the injury first happens does not always predict how bad the symptoms will be later. 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 having a TBI as close to the time of injury as possible. That way, they can receive the care and help they need.

The DOD and VA categorize the severity of a TBI by the service member or veteran experiencing any of the symptoms in Table A.

Your service member or veteran may have a CT scan or MRI to help diagnose their TBI. A CT scan is a computerized x-ray that doctors use to view the brain and look for areas of bleeding and bruising. An MRI shows detailed images of the brain using magnetic energy rather than x-ray technology. Keep in mind that many of the brain changes that occur with a TBI cannot be seen on a CT or MRI. Because of this, it is possible to see significant changes in your loved one's behavior or ability, even when the imaging results do not show any changes.

**Table A - Traumatic Brain Injury Classification**

Mild (also called a concussion)	Moderate	Severe
Loss of consciousness lasting for up to 30 minutes. Loss of consciousness with a mild TBI is not common.	Loss of consciousness that lasts more than 30 minutes, but less than 24 hours.	Loss of consciousness that lasts more than 24 hours.
Alteration of consciousness or post-traumatic amnesia that lasts up to 24 hours.	Alteration of consciousness that lasts more than 24 hours, or post-traumatic amnesia that lasts one to seven days.	Alteration of consciousness that lasts more than 24 hours, or post-traumatic amnesia that lasts longer than seven days.
Although CT scans or MRIs are not usually performed for mild TBI, if an imaging test is done, the results are normal.	CT scans or MRIs are done, and their results may be normal or abnormal.	As with moderate TBI, a CT scan or MRI will be done, and the results may be normal or abnormal.

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**What Types of TBI Damage are There?**

The brain is quite fragile; it has the consistency of firm gelatin. Imagine 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. Like the gelatin, many different types of damage can happen when the brain is injured:

- **Functional Brain Injury:** Along with straining and stretching of brain cells, the chemistry inside the brain is often affected by a 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 brain's neurochemistry system to return to a normal state.
- **Intracranial Hematomas:** *Intracranial hematoma* (ICH) is bleeding in or around the brain. There are several types of hematomas that can happen after a TBI, and they are categorized by their location in

the brain. An ICH can range from a mild head injury to serious and a potentially life-threatening injury. See diagram 1 on the next page for a visual of these injuries. The different types of ICH include:

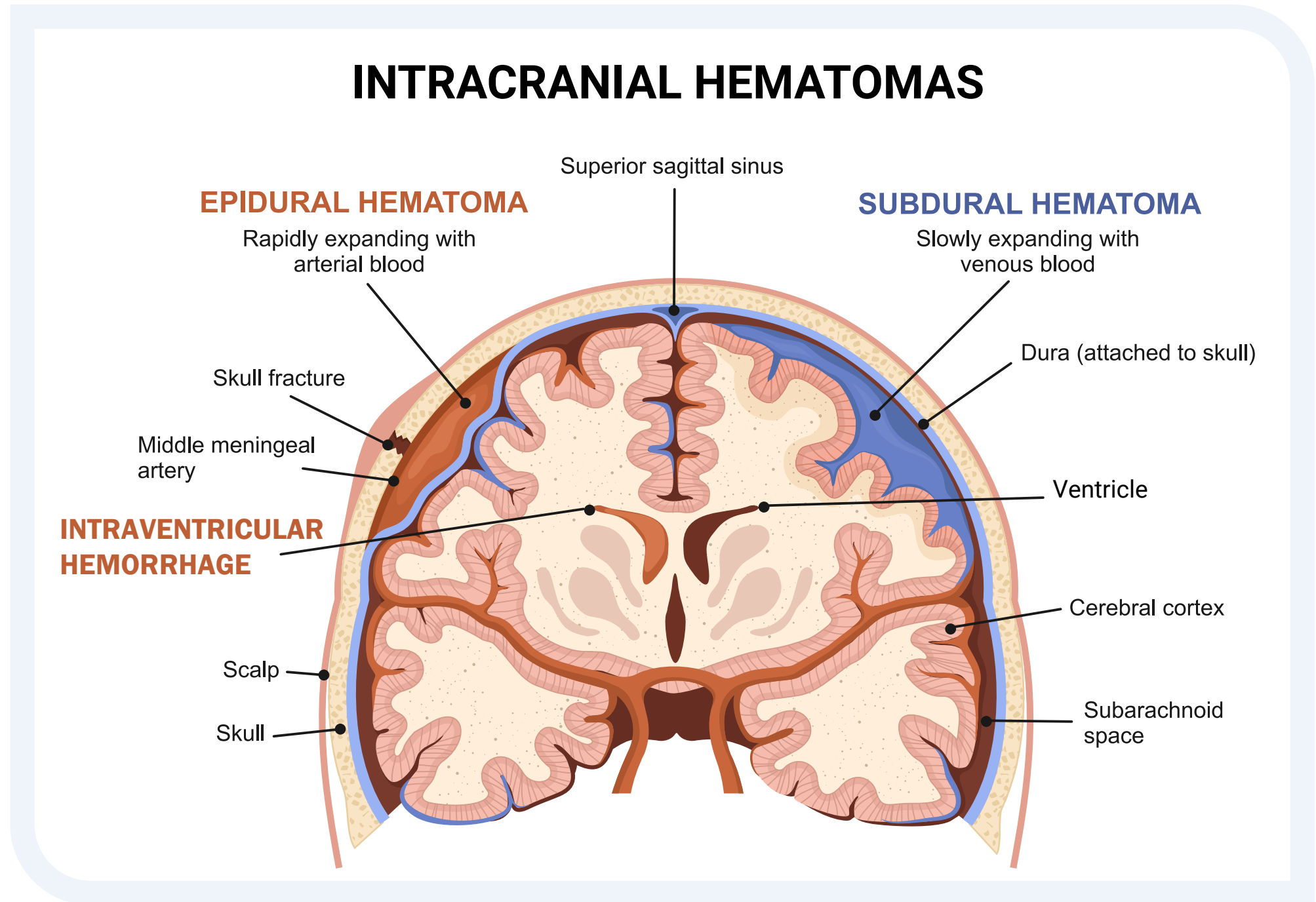
- **Epidural Hematoma:** This is when a pocket of blood forms between the skull and the tough outer layer of the brain's protective cover, called the *dura mater*. This pocket of blood increases the pressure inside of the skull. As the *epidural hematoma* grows, the pressure pushes on the brain. This pressure can damage the brain.
- **Subdural Hematoma:** If the bleeding occurs one layer down, between the *dura mater* and the next protective layer called the *arachnoid mater*, it is known as a *subdural hematoma* (SDH). Subdural hematoma symptoms can range from very mild to life-threatening.
- **Subarachnoid Hemorrhage:** Bleeding in the next level, between the *arachnoid mater* and the *pia mater*, is called *subarachnoid hemorrhage* (SAH). Some people with SAH fully recover, but the condition can be life-threatening even with treatment. Outcomes can vary widely depending on the location and amount of bleeding.
- **Intracerebral Hematoma:** Bleeding within the brain tissue itself is called an *intracerebral hematoma*.



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Diagram 1



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- **Intraventricular Hemorrhage:** *Intraventricular hemorrhage* is bleeding into the ventricles (butterfly-shaped spaces) of the brain.
- **Skull Fractures:** A skull fracture is a break in the skull bone. There are three major types of skull fractures:
  - **Linear skull fracture:** This is the most common type of skull fracture. In a linear fracture, there is a break in the bone resembling a thin line or crack that does not splinter, cave in or change the shape of the skull. Your service member or veteran may be hospitalized for observation for a brief amount of time, and usually can resume normal activities in a few days.
  - **Depressed skull fracture:** This type of fracture may be seen with or without a cut in the scalp. In this fracture type, part of the skull is sunken-in from the trauma, and may require surgery depending on its severity.
  - **Basilar skull fracture:** This is the most serious type of skull fracture and involves a break in the bone at the base of the skull. The service members or veterans may have bruises around their eyes and behind their ears. They may also have clear fluid draining from their nose due to a tear in part of the covering of the brain. They usually require close observation in the hospital.
- **Contusion:** A *contusion* is a bruise on the surface of the brain. It can either cause small or large amounts of bleeding (hematomas) around the area where the head was struck.
- **Laceration:** These are tears in brain tissue caused by a foreign object or by a sunken bone fragment from a skull fracture.
- **Coup-contrecoup injury:** When the front of the head is struck by something, the whiplash 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 can damage the opposite side of the brain, and can happen in a side-to-side manner or in a diagonal manner.
- **Diffuse axonal injury:** One of the most severe types of brain injury is known as a *diffuse axonal injury* (DAI). With DAI, the damage to the brain occurs over a large area. DAI is a “stretching injury” to the neurons (the cell bodies of the brain) and axons (fibers that allow communication from one neuron to another neuron). When the brain is injured, the axons can be pulled, stretched, and torn. If there is too much injury to the axons, the neurons will not survive. In a DAI, this happens to neurons all over the brain.



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## How Is a Traumatic Brain Injury Diagnosed?

There are many health care providers involved in the diagnosis of service members or veterans with TBI. These providers are experts in disorders of the brain and how these disorders affect a person’s ability to function. A mild TBI may not be readily identified, unlike a more serious closed or penetrating head injury. With severe TBI—especially in cases of penetrating injury—doctors can usually make a diagnosis immediately. A closed head injury can be overlooked when the service member has other life-threatening or serious physical injuries. However, a closed head TBI will be detected later when a more detailed evaluation is possible.

Recognizing the importance of early detection, the DOD and VA have established system-wide screening and evaluation procedures to identify concussion in service members and veterans at the earliest opportunity. Screening for a concussion involves a quick evaluation when there is a possible exposure to a traumatic event. The evaluation usually consists of a neurological exam, which includes a series of questions and simple commands to see if the injured person can open his or her eyes, move, speak, and understand what is going on around them.



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## How Is Mild Traumatic Brain Injury Medically Treated?

Mild TBI, or concussion, has become known as one of the “signature wounds” of the conflicts in Operation Enduring Freedom (OEF), Operation Iraqi Freedom (OIF), and Operation New Dawn (OND). Medical personnel at field hospitals are now more aware of the symptoms of mild TBI, including the more subtle ones, and the value of early battlefield evaluation and treatment. The earlier that a mild TBI is diagnosed, the sooner proper medical treatment can begin. Treatment of mild TBI is symptom-based—meaning the provider will recommend treatment solutions, provide information about symptoms, and about the expected recovery for each TBI symptom. For example, if a service member or veteran is experiencing headaches after a mild TBI, the provider may recommend specific medications to decrease the pain.

The health care team will provide education on preventing future injuries as well as guidance on healthy sleep practices, relaxation techniques, progressively resuming pre-injury activity, and returning to duty safely. It is important that your service member or veteran follows the guidance from their provider. This is because a second TBI before the brain has completely recovered can cause a snowball effect, making the symptoms worse and recovery more difficult. Also, the common symptoms following a mild TBI, such as dizziness, balance problems and fatigue, make it more difficult to return to normal activities safely.

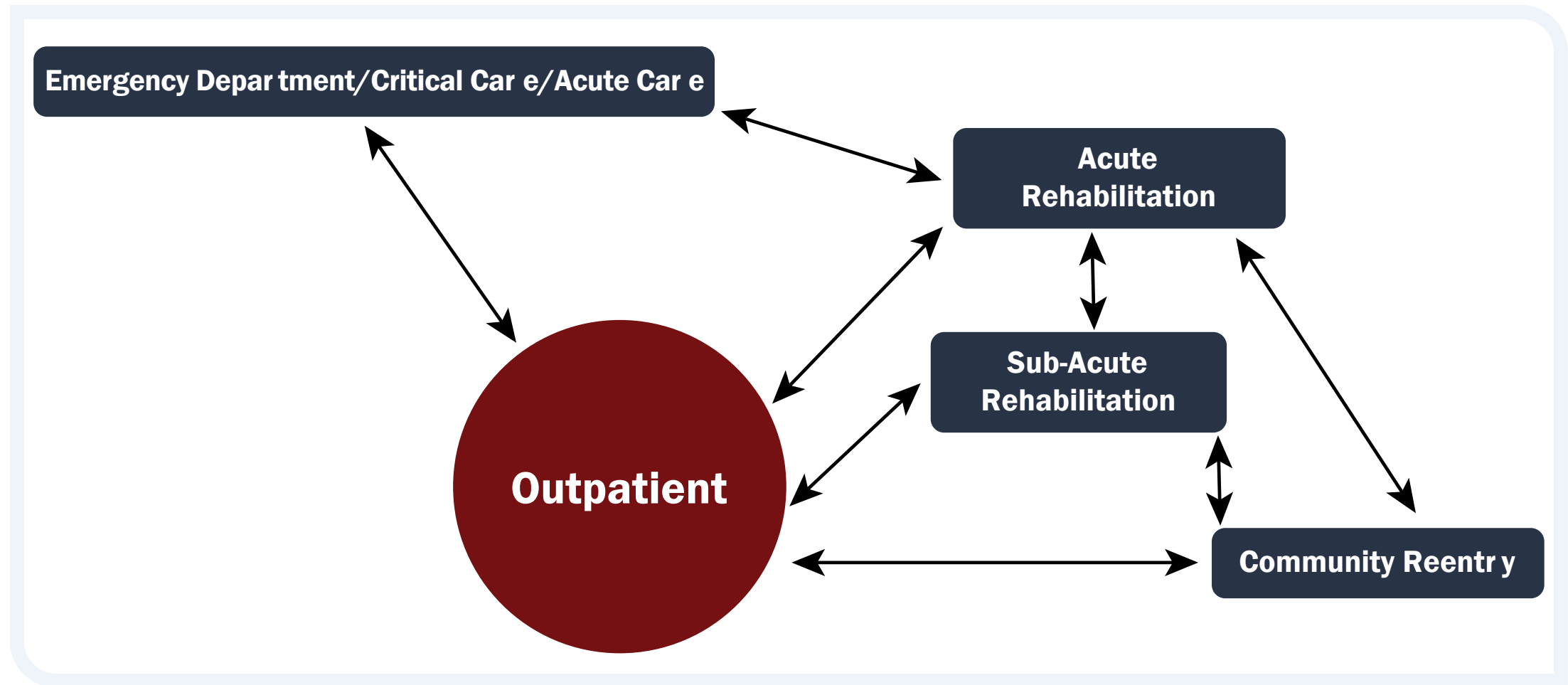
Although most service members or veterans recover from a mild TBI within the first few weeks to months after the injury, some may need extended care and follow the stages of treatment typically seen in those with moderate-to-severe TBI.



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How are Moderate and Severe TBI Medically Treated?



Typically there are several stages of treatment for moderate-to-severe TBI. It is important to remember that no two patients, and no two brain injuries, are exactly the same. That means each treatment plan will follow a unique path and pace that's best suited to the individual and their circumstances.

Depending on how your service member or veteran's condition progresses and the precise nature of their injury, they may enter, exit, and reenter the different treatment stages. Treatment may be needed continuously or intermittently throughout your loved one's life. The general stages of treatment include:

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- **Acute Care:** This stage refers to emergency medical treatment and time in the intensive care unit (ICU). Generally, early treatment for a moderate or severe TBI seeks to stop any bleeding, prevent and control increased pressure in the brain, and maintain adequate blood flow to the brain. After that, treatments vary with the type of injury. The doctors and nurses may use positioning, fluid restriction, ventricular drains, ventilators, and medications to treat your service member. Occasionally, surgery may be needed.
- **Acute Rehabilitation:** This is an intensive inpatient stage where rehabilitation is conducted for two-to-six hours daily. Rehabilitation means relearning skills needed for everyday life to improve function and quality of life.

- **Post-acute Care:** Sometimes called transitional rehabilitation, this stage usually takes place in a rehabilitation facility. Post-acute care focuses on helping your service member or veteran regain as much independence as possible, and involves learning new ways to compensate for potentially long-term or permanent disabilities.
- **Outpatient Care:** In this stage, your loved one is able to live at home while they continue rehabilitation during the day. Daytime rehabilitation can take place at an outpatient center or at home.
- **Community Reentry:** These are programs that can help your service member or veteran prepare to return to independent living and, if possible, work or school.
- **Long-term Care:** This is a facility that provides ongoing skilled nursing care for those who sustained a severe brain injury requiring lifelong care.





## Who Is on the Health Care Team?



Your service member or veteran will have many people invested in their health. The health care team may include members with different skills and training, but they all have the same goal of helping your loved one recover. Remember that you are not alone. There are many people you can reach out to with any questions or concerns. The health care team may include:

- **Your service member or veteran with TBI— the most important member of the team:** Participating in the rehabilitation process and setting goals helps your family member feel in control.
- **You, the caregiver:** You are an important member of the team. You know your family member best and can help report issues to the health care team. Your participation also ensures that the needs and preferences of the family are considered in all aspects of care.

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- **Audiologist:** A specialist who evaluates and treats hearing loss and related disorders, including balance disorders and *tinnitus* (ringing in the ears). They also fit and dispense hearing aids and other assistive devices for hearing.
- **Blind and Low Vision Specialist:** A licensed doctor of optometry who is trained in the examination and management of patients with visual impairments.
- **Case Manager:** A case manager's title can vary based on location. Other titles can include care coordinator, nurse case manager, transition manager, patient navigator, or patient care facilitator. They are usually a social worker or registered nurse (RN) at a military hospital or VA center. They primarily act as the liaison between you and the health care team by learning about the needs (medical, financial, and emotional) of your service member or veteran. They also provide coordination of services, such as during the transition from a military hospital to a VA medical center, and facilitate communication between service member or veteran, their family, and the VA rehabilitation team.
- **Chaplain:** A member of the clergy who can offer spiritual comfort. They can also counsel you and your family member about how to accept and cope with the changes a TBI may bring.
- **Department of Defense Military Liaison:** A person who helps with questions about benefits and other military-related issues.
- **Dietitian:** A licensed/certified nutrition care specialist who reviews your family member's diet and develops meal plans based on his or her medical needs.
- **Neurologist:** A doctor who treats disorders of the brain, spinal cord, nerves, and muscles. They are often called upon to manage seizures, headaches, and sleep problems.
- **Neuro-ophthalmologist or Neuro-optometrist:** A doctor who treats visual problems related to the nervous system (that is, vision problems that do not come from the eyes themselves). They may track changes in vision, perception, or the need for corrective lenses.
- **Neuropsychologist:** A licensed clinical psychologist with special training in how the brain affects a person's behavior. They give and evaluate certain types of cognitive and emotional tests. They can help service members, veterans, and their family members cope with life after TBI.
- **Neurosurgeon:** A doctor who performs surgery on the nerves, brain, or spine.
- **Occupational Therapist (OT):** A medical professional who specializes in "activities of daily living," like eating, grooming, dressing and bathing. They can also help injured people to relearn or adapt skills they will need to return to work or school, such as shopping, cooking, and money management. They provide adaptive equipment, make suggestions for changes in the home, and can provide cognitive or vestibular rehabilitation.



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- **Palliative Care Team:** Specialized medical care that focuses on providing relief from the symptoms and stress of serious illness. It is provided by a trained team of doctors, nurses, and other specialists who work together with your other doctors to provide extra support.
- **Physiatrist (Physical Medicine and Rehabilitation Specialist):** A doctor who treats problems of all the major systems in the body and medical conditions affecting the brain, spinal cord, joints, bones, nerves, tendons, ligaments, and muscles. A physiatrist also directs and coordinates rehabilitation care. They are often the leader of the health care team.
- **Physical Therapist (PT):** The team member who provides services that help restore body function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities from an injury. They also determine the patient's level of independence and ability to reenter the community or workplace after an injury. PTs treat vestibular disorders and can teach service members or veterans to use assistive and adaptive devices, such as crutches, prosthetics, wheelchairs, and specialized equipment.
- **Primary Care Provider or Primary Care Manager:** This person coordinates the ongoing care of all your family member's general medical needs. They may include family practice physicians, internal medicine physicians, clinical nurse practitioners, and physician assistants.
- **Psychiatrist:** A medical doctor who assesses both the mental and physical aspects of psychological problems.
- **Recreational Therapist (RT):** The team member who helps service members or veterans with social reintegration and to become independent in leisure activities by applying practical skills to real-life situations.
- **Rehabilitation Nurse:** A nurse who specializes in rehabilitation. They educate service members or veterans and their families about TBI and safety, skin care, toileting, medication, and other issues. They also reinforce the skills being learned in therapy and help carry out the treatment plan.
- **Rehabilitation Psychologist:** A licensed clinical psychologist who has been specially trained to assess and treat the many issues facing service members or veterans and their families (e.g., coping and adjustment problems related to chronic or traumatic injury). They work to help achieve the highest possible level of functioning after injury.

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- **Social Worker:** This professional helps patients and families find resources they need during treatment. A Licensed Clinical Social Worker (LCSW) is trained in psychotherapy and helps individuals deal with mental health and daily living problems.
- **Speech Language Pathologist (SLP):** Also called a speech therapist, they specialize in the evaluation, treatment, and rehabilitation of communication, cognition, and swallowing disorders. They may work to reestablish communication, provide training on memory strategies and technologies for returning to work or school, or offer community reintegration techniques. SLPs may also assist with safe swallow functions for persons with disorders of consciousness.

- **VA, DOD Liaison for Healthcare, or VA, DOD Polytrauma Rehabilitation Nurse:** Clinical staff with the Veterans Health Administration who work to connect your loved one to the VA for various care requirements. They provide administrative and clinical expertise to assist active-duty service members and veterans with the coordination of VA rehabilitation programs—both inpatient and outpatient care.
- **Veterans Benefits Associate (VBA):** The team member who assists with the transition process by identifying VA, DOD and community resources and by helping find and apply for VA benefits.
- **Vocational Rehabilitation Counselor:** The professional who helps your service member or veteran prepare for or retrain for employment.



## What Is the TBI Continuum of Care?

Each injured service member or veteran will have their own pattern of care, rehabilitation, and recovery. Some will have injuries that require care in a military hospital—others will not. Some will need months of inpatient care in the VA system—others will not. Your health care team will tell you the type of care your family member needs. They will also explain when it is time to move along the *Continuum of Care* and why.

Know that throughout treatment, as a caregiver, you are an important member of your service member or veteran’s team. The more you know about TBI and the specific symptoms of your service member or veteran, the easier it will be to work with the health care team and help your family member recover from TBI.

Your service member or veteran will receive the medical and surgical care they need throughout treatment and recovery. The DOD and VA worked together to create a Continuum of Care for service members or veterans with TBI. A continuum means a series of steps that keep moving forward. In this case, the steps show movement from initial injury through surgical or medical stability, to rehabilitation, and lastly to optimal recovery. The DOD and VA care systems have many levels of care and service. That is because your family member’s medical, psychological, rehabilitation, and other needs may appear or change over time.



Traumatic Brain Injury  
Polytrauma System of Care  
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If your injured family member was deployed overseas, or if their injury occurred during training in or outside a military base, treatment began immediately. The on-site military health care team (or stateside hospital staff) stabilized your service member so they could be moved to the next level of care. After stabilization, your family member transitioned to acute care in a hospital within or outside the United States. This often occurs at a military hospital, commonly referred to as a *military treatment facility* (MTF). Once definitive treatment (both medical and surgical) and stability has occurred, considerations for the next level of care are discussed. This may be to transfer the service member back to their unit or military base or to a local MTF for additional care. This care may be continued inpatient care or outpatient appointments for care and rehabilitation services.

If intensive rehabilitation is required, transfer to acute inpatient rehabilitation may be recommended. VA's *Polytrauma TBI System of Care* (PSC) is dedicated to the rehabilitation of veterans and service members with both combat and civilian-related TBI or polytrauma. The PSC program provides an integrated and coordinated continuum of services at regional centers, network sites and local VA medical centers. TBI care at a

VA facility is provided with the expertise necessary to manage your loved one's rehabilitation, medical, surgical, and mental health needs. When travel is required for highly specialized rehabilitation, [Fisher Houses](#) may provide you and your family the opportunity to remain closely involved in all aspects of your veteran or service member's care.

Doctors consider many issues when recommending where to transfer your family member for inpatient rehabilitation. These can include:

- Medical condition and type of specialty care or therapy required
- Type of facility that can provide services for your family member's needs to recover
- How close the acute rehabilitation treatment center is to their home, their caregiver's home, or their assigned military base
- Military service command involvement
- Their interests, spouse's desires, or parents' desires
- How easy it is for the caregiver to get to and from the rehabilitation treatment center

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Once your service member or veteran’s injuries are stable, they may be transferred from a military hospital to a VA Polytrauma Rehabilitation Center (PRC) for continued inpatient rehabilitation care and specialized TBI therapy services. Rehabilitation means relearning old skills to regain as much independence as possible. At the PRC, your family member will receive specialized medical and rehabilitation attention and treatment for the effects of TBI and other serious injuries they may have. The PRC offers a variety of programs where service members or veterans can rehabilitate and gain as much independence as possible. Their day in rehabilitation will be scheduled with many therapies that may include OT, PT, SLP, assistive technology, blind or low vision, psychology, music, art, recreation, and others.

Often, the final phase of treatment (and the first phase for those who sustained a mild TBI) is outpatient care at a MTF, VA, community facility, or clinic that is closer to your family member’s home. Outpatient care is when the patient lives in the community and comes to the hospital or clinic for care. In this phase, you may be the primary caregiver for your service member or veteran with TBI. For some with a severe brain injury, the

next step may include at home, skilled nursing care, respite care, care in a long-term care facility, or other similar options. The case manager can provide further information about the various options and guide you to the best one for your service member or veteran.

Many service members with a mild TBI are treated and return to active duty. Others, depending on how much healing has occurred, and to what level of independence is gained, may return to duty or medically retire.

Wounded, ill, and injured service members may be able to use TRICARE for their health care services. The TRICARE Network is divided into geographic regions. Each TRICARE Managed Care Contractor has programs to assist the wounded, ill, or injured service member. In some cases, some portions of your family member’s care may be provided at the VA or in the community under their TRICARE benefit.

It is important to always be in contact with your various health care team members throughout this process. They can help ensure your family member receives the right care and that all their service-related needs (e.g., orders) are addressed.



# What Complications Can Happen Following a Mild TBI?

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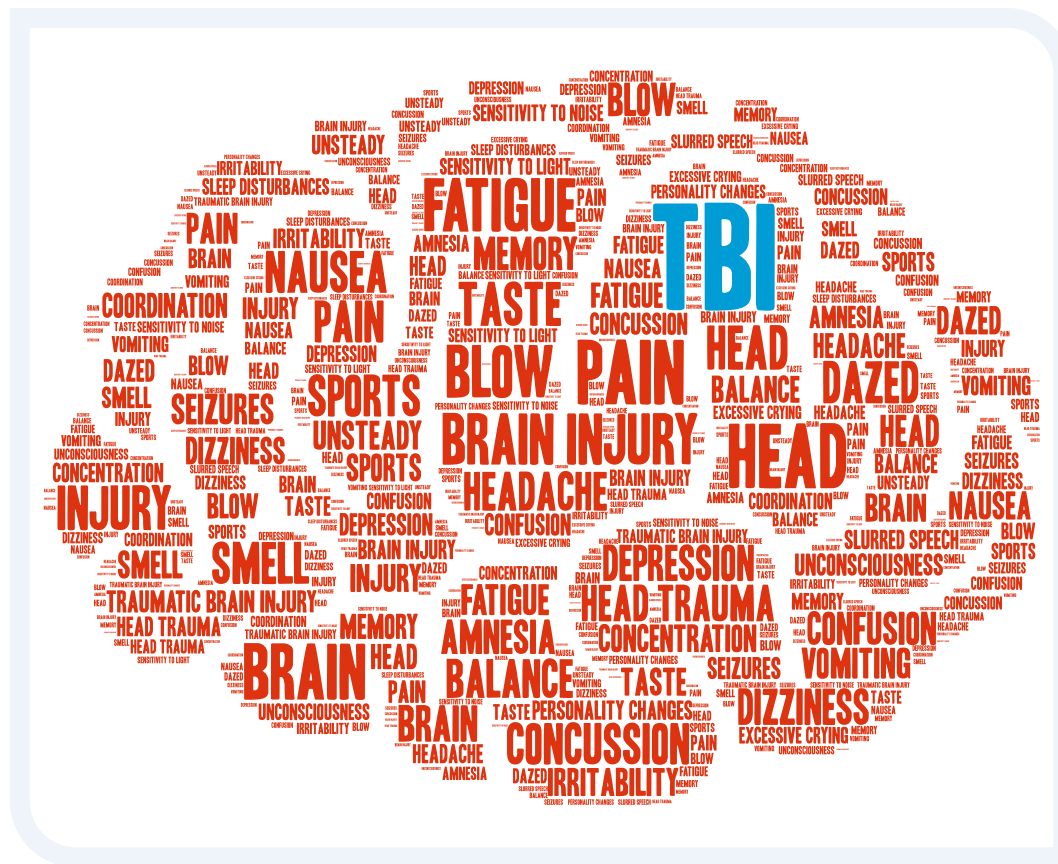
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Most service members or veterans do not experience any complications and fully recover from a mild TBI within the first few weeks to months after the injury. But a small number of people can have short- or long-term complications. Some of these complications may include:

- **Post-concussion Syndrome:** A set of symptoms that persist beyond the expected recovery period of one-to-three months. It includes headaches, dizziness, fatigue, irritability, anxiety, insomnia, concentration difficulties, loss of memory, and noise sensitivity.

Studies show that educating a service member or veteran about the common symptoms seen after a mild TBI, as well as providing reassurance, can actually decrease the severity and longevity of post-concussion symptoms.

The symptoms that service members and veterans often find difficult to manage are the emotional ones. Research shows that very often these emotional symptoms started before the TBI or are co-occurring with the TBI. This means they are not directly related to the TBI. Service members or veterans often incorrectly credit the cause of emotional symptoms to the mild TBI when often they are from prior or co-occurring conditions—like post-traumatic stress disorder (PTSD), anxiety, or depression. The symptoms of these conditions often overlap or mimic post-concussion symptoms.

- **Post-traumatic Epilepsy:** Seizures within the first week after injury are usually from the direct effects of the TBI and do not indicate any long term damage. However, seizures that happen after the first week of head injury can indicate more permanent changes within the brain and the start of post-traumatic epilepsy. *Epilepsy* is when there are recurrent seizures or abnormal electrical discharges in the brain. Symptoms can include staring and unresponsiveness; stiffening or shaking of the body, legs, arms, or head; strange sounds, tastes, visual images, feelings, or smells; and the inability to speak or understand.



## What Complications Can Happen Following a Moderate or Severe TBI?

Doctors and nurses work very hard to prevent complications after a 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.

Remember you know your loved one better than anyone. If you notice any of the signs or symptoms below, tell your 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.

In addition to the complications mentioned in the mild TBI section, here are some common complications that can happen in the days or weeks after a moderate to severe injury:

- **Increased Intracranial Pressure (ICP):** *Intracranial* means within the skull. The pressure inside the brain can increase to dangerous levels after a TBI, which can then cause decreased blood flow to the brain. Sometimes, the pressure is life-threatening and causes a *midline shift* or *brain herniation*. A midline shift is a shift of the brain past its center line. A brain herniation occurs when brain tissue shifts from its normal position inside the skull.

An ICP monitor alerts doctors to any increase in pressure. Medications can be used to prevent or treat a high pressure; however, sometimes surgery is needed.

- **Edema:** Is swelling that occurs when the brain contains more fluid than normal. When swelling happens within the brain, it can cause the pressure to build up. This is because there is no place for the tissue to expand because the brain is encased in the skull. This results in damage to brain cells and interrupts blood flow. Medications and fluid restrictions often help. Sometimes, surgery is needed.
- **Hydrocephalus:** Also known as “water on the brain,” *hydrocephalus* happens when there is increased build-up of *cerebrospinal fluid* (CSF) within the brain cavities. This condition can lead to increased pressure in the skull and 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. A shunt is a tube that drains the extra fluid from the brain to other places in the body.
- **Low Blood Pressure:** Blood carries oxygen to the brain. If the blood pressure becomes too low, the brain may not get enough of the oxygen it needs. Doctors will use medications to keep the blood pressure stable after a TBI.

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- **Paroxysmal Sympathetic Hyperactivity or Sympathetic Storm:** When the body is unable to regulate blood pressure, sweating, body temperature, and posture. This occurs in episodes that can last a few minutes to a few hours. Medications are used to end an episode and prevent a reoccurrence.
- **Fever:** Some parts of the brain regulate body temperature. Injury to these parts may cause high fevers. This is especially true during the first hours or days after an injury. Fever can also be a sign of infection. Medications or cooling blankets can bring a fever down.
- **Pneumonia:** *Pneumonia* is an infection in the lungs, which unfortunately is a common complication after a severe TBI. This is because 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 to look for pneumonia. Fortunately, antibiotics usually work to treat pneumonia.
- **Infections:** To treat TBI, your service member or veteran may have one or more tubes. These tubes are needed, but they may cause infection. Infections may also occur in the brain—either on the outside of the *dura* (the tough outer membrane around the brain,) 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. Body temperature readings and blood tests are ways to monitor for infection. Antibiotics can control infections; however, sometimes surgery is needed.

- **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 and 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. Medications to thin the blood are often used to prevent and treat blood clots.
- **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 are used for treatment.





## What Is the Recovery Process?



You may want to know if your service member or veteran will fully recover, but doctors may not be able to give you a definite answer. For a mild TBI, most service members or veterans will completely recover within weeks or months. However, this is not true for all cases. There are some with mild TBI who will have a very long recovery process. For a moderate to severe TBI, it can be even harder to predict a person's

long-term recovery. No two brain injuries are exactly alike. Some people will recover quickly; others may take much longer. Some will have very few long-term effects. Others will face lifelong challenges. The effects vary from person to person. There is no way to speed the process of recovery. The recommended care and rehabilitation give your service member or veteran the best chance of recovery.

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Recovery from TBI can be affected by

- How severe the damage is
- The areas of the brain affected
- The areas of the brain not affected
- Age and other factors 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

For most people with moderate to severe TBI, the most rapid recovery will happen in the first six months following injury. Right after the TBI, the body begins to repair itself. In most cases, brain swelling begins to go down and the pressure inside the skull lessens within a few weeks. The brain's chemical balance usually returns to normal within several months. The brain will continue to recover from there for months to years. Remember that recovery is individual. Everyone progresses at his or her own pace.

The brain can repair itself more than people used to think was possible. Sometimes, the term "brain plasticity" is used to describe the brain's ability to bounce back and recover after TBI. Here are some ways that the brain may repair 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.

- Healthy brain tissue may learn over time how to do what the damaged brain cells used to do.
- The body may even be able to replace damaged brain tissue.

Often, a person with a severe brain injury also has serious injuries in other parts of their body. Injury to multiple organs or body parts is known as polytrauma. These injuries can cause bleeding, swelling, and damage to internal organs, blood vessels, bones, limbs, nerves, and the sensory system. For example, think about a service member or 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.

A moderate or severe TBI may involve a disorder of consciousness. This may range from a coma to a minimally-conscious or semi-comatose state. A coma is when someone is unconscious and will not respond to sounds or any activity going on nearby. A coma can last days, weeks, or months. Very rarely, a coma lasts even longer. The length of time a person is in coma is used by doctors to help estimate the extent and severity of injury to the brain.

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The process of waking up from coma after TBI is usually gradual. Unlike TV scenarios where a person suddenly wakes up and appears normal, coming out of a state of coma after TBI happens in stages. Each person moves through the stages of opening their eyes and regaining consciousness at a different pace. Some will come out of coma early on, while others may be medically stable enough to start rehabilitation still in a minimally-conscious state. A minimally-conscious state is when a person is semi-comatose, gaining awareness of things happening around them and having periods of wakefulness.

As your loved one starts to wake up and regain function after a coma, they will show signs of confusion and disorientation. This period of recovery is known as post-traumatic amnesia and is another temporary step on the road to recovery after TBI. A health care team will be available during a hospitalization to care for your loved one and help the family understand the recovery process. These are likely to be worrisome and difficult times for you and other members of the family. Hospital support staff and other members of the family will be key to getting through tough times. Accept help and keep in mind that every step forward is a step in the right direction.



## What Is Your Role in the Recovery Process?

As a caregiver, keep hope alive as you support the recovery process of your family member with TBI. Waiting for your service member or veteran to return to “normal” can make you feel sad and frustrated. On the positive side, you are likely to see progress. Remember, progress is progress, even if it’s slower than you would like it to be.

Keeping a journal and writing down what is happening during your service member or 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 they have 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.

Each person will progress through recovery at his or her own rate, depending on many factors. The **Rancho Los Amigos Revised Scale (RLAS-R)** is an evaluation tool used by the health care team to track recovery after a moderate or severe TBI. It is a ten level scale with each level describing the cognitive and behavioral patterns found in brain injury patients as they recover. Cognition means a person’s thinking and memory skills. The ten levels include:

- **Level 1:** No response
- **Level 2:** Generalized response

- **Level 3:** Localized response
- **Level 4:** Confused and agitated
- **Level 5:** Confused and inappropriate, non-agitated
- **Level 6:** Confused and appropriate
- **Level 7:** Automatic and appropriate
- **Level 8:** Purposeful and appropriate: stand by assistance
- **Level 9:** Purposeful and appropriate: stand by assistance on request
- **Level 10:** Purposeful and appropriate: modified independent

There are certain things that you as the caregiver can do to help your loved one in each of these levels of the recovery process. Here are some tips you can try:

- **Levels 1–3:**
  - Talk to your loved one. 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.
  - Talk in a normal tone of voice.
  - Watch doctors and nurses as they try to stimulate the person. Try doing what they do.

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- Do simple activities for short periods of time. Describe what you are doing (“I am holding your hand now”).
  - Ask your service member or veteran to look at you and others in the room when his or her eyes are open.
  - Keep comments and questions short and simple. For example, instead of “Can you turn your head towards me?” say, “Look at me.”
  - Tell your loved one who you are, where they are, why they are in the hospital, and what day it is. Reassure them that they are safe. The more your family member hears accurate information about where they are and what has happened, the more that information will begin to stick.
  - Know that setbacks, such as pneumonia, are not unusual in the early days. These can be scary, but the health care team knows how to manage any complications.
  - Limit the number of visitors to two or three people at a time.
  - Keep the room calm and quiet.
  - Bring in favorite belongings and pictures of family members and close friends.
  - Allow extra time for your service member or veteran to respond, but don’t expect responses to be correct. Sometimes they may not respond at all.
- Give them rest periods. They will tire easily.
  - Engage them in familiar activities, such as listening to their favorite music, talking about family and friends, reading out loud, watching TV, combing their hair, putting on lotion, etc.
  - Know that inconsistency throughout recovery from TBI is expected. Don’t be alarmed if your service member or veteran does something (follows a command, opens their eyes, speaks) one day, but not the next. The capacity is still there—they will again show the behavior. It is usually just a matter of “when.”
- **Level 4:**
    - Allow them as much movement as is safe. Do not force them to do things. Instead, listen to what they want to do and follow their lead, within safe limits.
    - Complex tasks are difficult to complete. Break tasks down into simple steps. Offer step-by-step instructions.
    - Take them for rides in a wheelchair, when this has been approved by the health care team.
    - Since they will often become distracted, restless or agitated, you may need to give them breaks and change activities frequently.
    - Unusual behaviors, including swearing, are common. Be patient. These behaviors tend to go away over time.

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- Provide reassurance that everything is being done to provide the care and treatment needed to restore their health and well-being.
- 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.
- **Levels 5 and 6:**
  - Repeat things as needed. Don't assume that they will remember what you tell them. Discuss things that have happened during the day to help your family member remember recent events and activities.
  - Ask simple questions that encourage memory. Offer generous words of encouragement and praise for attempts to respond.
  - Keep comments and questions short and simple.
  - Help them organize and get started on an activity. They may also need help continuing activities.
  - Give them frequent rest periods when they have problems paying attention.
  - Encourage them to participate in all therapies. They will not fully understand the extent of their problems and the benefits of therapy.
- 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 or veteran.
- **Levels 7-10:**
  - Treat your service member or veteran as an adult; show respect for their opinion when attempting to provide guidance and assistance in decision making. There is also no need to try to use simple words or sentences.
  - Because they may misunderstand joking, teasing, or slang language, be careful to check for understanding when using humor or other abstract language.
  - Encourage your family member to be as independent as is safe, especially with self-care. Help them with activities when they show difficulties with thinking, problem-solving, and memory. Talk to them about these problems without criticizing. Reassure them that the problems are because of the brain injury.
  - Be sure to check with your health care team for any restrictions concerning driving, working, and other activities. Do not rely on the brain injured individual for information, since they may feel ready to go back to their previous lifestyle.

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- Discourage them from drinking or using drugs, due to medical complications.
  - Encourage them to use note taking as a way to help with memory problems.
  - Do not promise your service member or 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.
  - Do not make comparisons. 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 with the health care team should take place with your family member 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 or 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 or 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 they are 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.
  - After your service member or veteran is settled into a comfortable and workable home routine, begin to practice activities outside the home (grocery shopping, going to a movie, or seeing friends).
  - Be sure you fully understand the plan for outpatient therapy and follow up with all members of the health care team.





## Caregiver Reflections

*“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.

*“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.

*“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 rewriting the medical books.’”*

Nellie B.

*“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.

*“We are 10 years post injury and are still learning new ways to cope with life with TBI. Learning about TBI was an important step to caring for my husband. Understanding the injury, symptoms as well as the therapies and treatment options helped us both.”*

Melissa C.

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### Journal Questions

The questions below can help you reflect on your experience as a caregiver. You can write your thoughts down or reflect on these questions in your mind.

1. What have the doctors told me about my service member/veteran's injury? Describe the injury as best you can, in your own words.
2. What are my strongest fears or concerns at this moment in time?
3. What do I feel joyful or optimistic about?

# EFFECTS OF TBI AND CAREGIVER STRATEGIES FOR MANAGEMENT

There may be cognitive, physical, behavioral, and emotional changes you see in your family member after a TBI. These are the effects or symptoms of the TBI. After reading this module, you may feel relieved that your service member or veteran is experiencing only a few effects from their TBI. On the other hand, you may feel overwhelmed by the number and complexity of changes that you are learning to address. **It is important to remember that no two cases of TBI are exactly the same. Each person with TBI can experience a different set of symptoms, and their variations can impact each person's unique pace of recovery. Your service member or veteran is likely to experience some, but not all, of these symptoms.** Many of the effects of TBI are common right after the injury. Many are likely to improve over time. Some of this module's information may apply to your service member or veteran, but some may not. Some information may apply now, but not in the future.

Though we know more now about TBI than ever before, no one can say with certainty just what effects each injured person will have. The pace of recovery also varies from person to person. Having "plateaus" is a normal part of the recovery process. We do know that most people with TBI can and will make improvements. Proper diagnosis, treatment, and follow-up care, as well as the support of family and friends, will help. The number of symptoms, and the presence of other health conditions, will also play a role in how well and how quickly your family member will recover.

While you are going through your journey, keep in mind that it is perfectly okay and normal to experience periods of trial and error while adjusting to helping your loved one. It is also normal for strategies that worked well for you in the past to no longer be effective. Acknowledge your frustration, but keep on trying and embracing new ideas.

**Know that you are not alone.** There are thousands of other military families struggling to understand and cope with changes similar to what you and your service member or veteran are encountering. Health care providers are learning more every day about how to effectively treat TBI. Your service member or veteran is the beneficiary of new medical knowledge gathered from the experiences of other service members. In return, his or her experience will add to the wealth of knowledge about how to treat TBI. Keep hope in your heart and mind as you move forward into the future.

What Are the Physical Effects of TBI?

What are the Cognitive Effects of TBI?

What are the Communication Effects of TBI?

What Are the Behavioral and Emotional Effects of TBI?

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What Are the Physical Effects of TBI?

What are the Cognitive Effects of TBI?

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Symptoms by TBI Severity

All TBI Severities

- Acute and Chronic Pain
- Attention Problems
- Changes in Self-esteem
- Changes in Sexual Behaviors
- Depression
- Difficulty with Decision Making and Problem Solving
- Difficulty Taking Turns in Conversation
- Fatigue or Loss of Stamina
- Frustration, Increased Anger or Aggressiveness
- Headaches
- Impulsivity or Difficulties in Self-Control
- Increased Anxiety
- Lack of Self-awareness
- Less Effective Social Skills
- Mood Swings
- Nonverbal Communication Issues

Moderate and Severe TBI

- Planning and Organization Problems
- Poor Judgment
- Problems Following a Conversation
- Problems Starting a Conversation
- Psychological Trauma
- Reading Comprehension Problems
- Reduced or Lack of Initiation
- Seizures
- Sensory Changes
- Sleep Changes
- Substance Misuse
- Suicide
- Topic Selection Problems
- Vestibular Effects
- Word Finding Problems
- Writing Problems
- Apraxia
- Bladder or bowel Changes
- Changes in Swallowing and Appetite; Weight Loss or Gain
- Confusion
- Difficulties with Memory
- Hemiparesis, Hemiplegia
- Repetitive Behaviors
- Slurred Speech
- Spasticity

## What Are the Physical Effects of TBI?

After a TBI, the nerve cells in the brain may no longer send information to each other the way they do normally. This is why people with a TBI may have changes to their physical abilities, such as balance, mobility and coordination, as well as their muscle strength, tone, and control. It may also affect the body's senses, including hearing, vision, smell, touch, and taste.

With the help of your health care team, many physical effects can be treated or managed with positive results. You can help your loved one by following the treatment plan and using the suggestions in this section. Talk to the team members about what to do if your service member or veteran begins to have new symptoms or problems or reacts differently to treatments.

The following strategies can be useful for any of the physical effects described in this section. Try using these strategies in addition to the ones mentioned here.

Encourage your service member or veteran to

- Keep track of the frequency and severity of symptoms. Keeping a symptom journal can be helpful. Always report back to the health care team if you notice any changes.
- Pay attention not only to what your loved one is saying, but also to their non-verbal communication, and how they are saying it. They may be reluctant to talk about how they feel, but may give indications in their behavior.
- Get enough rest and sleep.
- Avoid or limit alcohol, tobacco, and caffeinated drinks (coffee, tea, and soda).
- Tell their health care team if they are taking any over-the-counter medications.
- Manage stress.
- If advised by the health care team, get some exercise.

What Are the Physical Effects of TBI?

What are the Cognitive Effects of TBI?

What are the Communication Effects of TBI?

What Are the Behavioral and Emotional Effects of TBI?

Caregiver Reflections

## What Are the Physical Effects of TBI?

### All TBI Severities

#### Acute and Chronic Pain

Fatigue or Loss of Stamina

Headaches

Seizures

Sensory Changes

Sleep Changes

Vestibular Effects

Visual-spatial Problems

### Moderate/Severe TBI

Apraxia

Bladder or Bowel Changes

Changes in Swallowing and Appetite; Weight Loss or Gain

Hemiparesis, Hemiplegia

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## Acute and Chronic Pain

Many service members or veterans experience some aches and pains after a TBI, which usually go away with time. This is referred to as acute pain. But some may experience prolonged and persistent pain, known as chronic pain. Your service member or veteran may find that chronic pain and the restrictions it places on his or her daily activities can lead to feelings of sadness or irritability. This can compound the pain. Don't delay in talking to the health care team if your service member or veteran is in pain. When speaking with them about the pain, share as much detail as possible about the nature of the pain and the impact it has on your family member's daily life. Note activities that are important to your service member or veteran, but are hard to do now because of the pain. These details can help the health care team determine which treatment options to recommend.

After a severe TBI, your family member may have *heterotrophic ossification*. Heterotrophic ossification happens when bone forms in an unnatural location, such as in soft tissue or muscle. It most commonly occurs in the hips and knees and causes aching pain.

Each person experiences and responds to pain differently. No single treatment will work for everyone, and people respond differently to various treatment options. It is important to work with the health care team to create a personalized plan to help your service member or veteran manage their pain and reduce any suffering. The plan may include complementary or alternative modalities, such as yoga, deep breathing, relaxation techniques, massage, art or music therapy, meditation, chiropractic or acupuncture care, or medications. If the treatment options do not seem to help the pain, don't give up. Let the doctor know because they can try something new.

### What you might see:

- Trouble sleeping
- Irritability
- Lack of energy, decreased activity level
- Depression, hopelessness
- Increased anxiety
- Swelling, warmth, limited range of motion, pain in soft tissue areas or a muscle (heterotrophic ossification)



## What Are the Physical Effects of TBI?

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Bladder or Bowel Changes

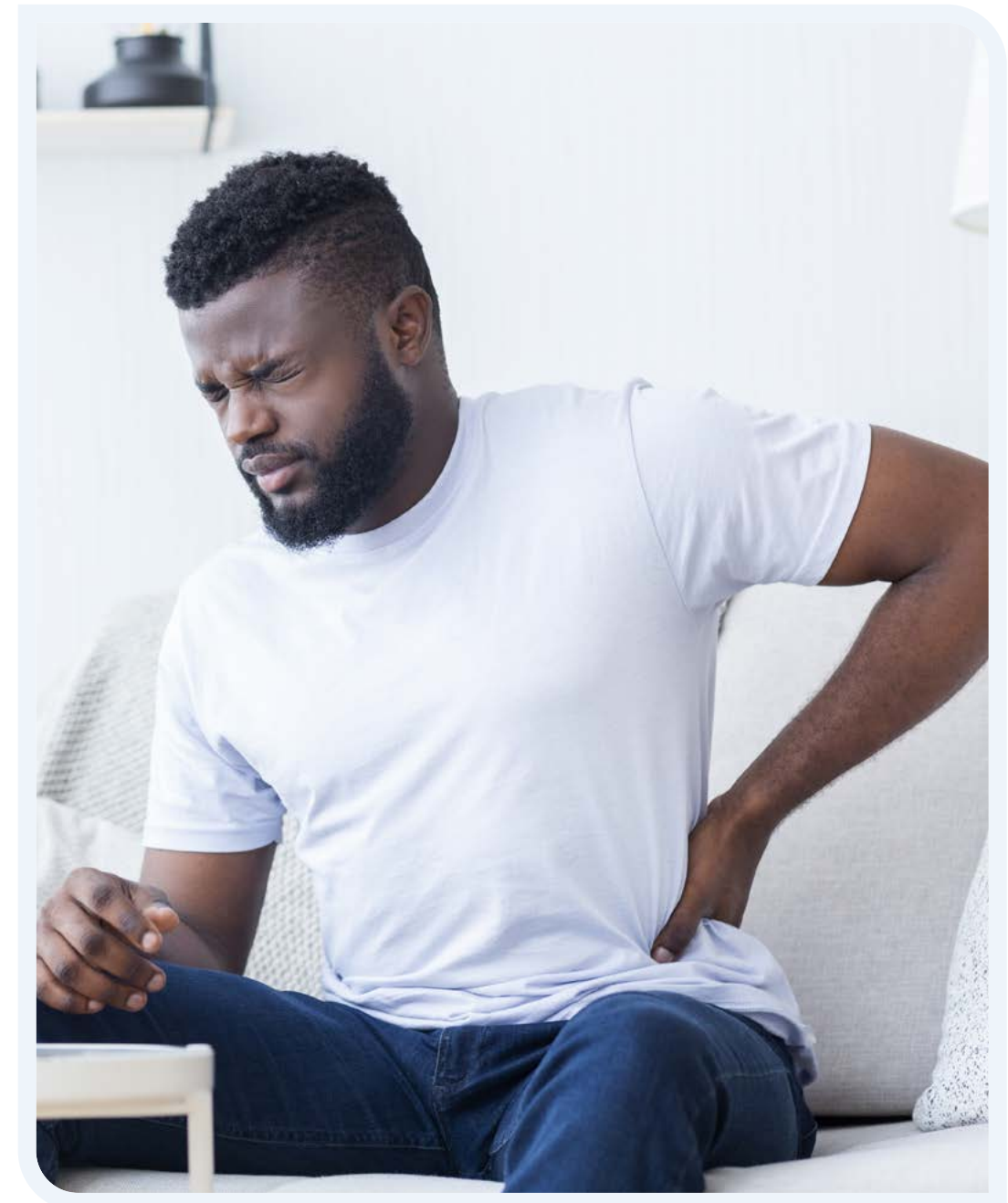
Changes in Swallowing and Appetite; Weight Loss or Gain

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### How you can help:

- Encourage your service member to communicate clearly and openly about the location, severity, and quality of their pain. Helpful words to describe the quality of the pain include sharp, dull, stabbing, burning, crushing, throbbing, nauseating, shooting, twisting, or stretching.
- Don't let pain take over your loved one's life. Encourage them to do things that they like to do. Although they might not be able to do these things the same way or for the same amount of time, encourage them to adapt instead of giving up.
- Keep your loved one connected and engaged socially. Your service member or veteran may feel a desire to withdraw from relationships and activities. Help facilitate social interaction for your loved one, and encourage them to connect with friends and family.
- Practice exercises that can reduce your loved one's pain, such as relaxation exercises and mindfulness.
- Help your service member or veteran keep track of their pain in a journal. Keep notes on the time of day that they experience pain and the degree of pain they feel doing certain activities. Share this information with the health care team.
- If your service member is dealing with heterotrophic ossification, try to help them rest the painful arm or leg. Ask for physical therapy so that your service member can maintain their range of motion. With the health care team's help, many physical effects can be treated or managed with positive results.



## What Are the Physical Effects of TBI?

### All TBI Severities

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**Fatigue or Loss of Stamina**

Headaches

Seizures

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## Fatigue or Loss of Stamina

Fatigue is common among people with TBI. The body needs a vast amount of energy for healing after traumatic injuries. Usual patterns of rest and activity are often very different for many weeks to months after TBI. Fatigue reduces the speed and quality of rehabilitation and can slow down the return to normal life activities, such as school or work. For most people, fatigue gradually lessens over time. Stamina and endurance improve. However, some people with TBI say that, for the rest of their lives, their endurance is not what it used to be. They have to pace themselves more than they did before.

### What you might see:

- Frequent comments about being tired
- Need for sleep after a short activity, lack of energy
- Poor stamina
- Extreme fatigue after a busy stretch of hours
- Slurred speech
- Irritability
- Slower thinking speed

### How you can help:

- Set up a daily schedule for your family member in a calendar. Make sure it includes enough rest and sleep.
- Reduce family and social demands.
- Help your family member pace themselves. Ask them to conserve energy for important tasks in the day.
- Allow time for undisturbed rest during the day.
- Schedule important appointments for times of the day when your family member is most awake.
- Learn the signs of fatigue in your service member or veteran. Ask them to do the same. Make a list of these signs, and keep it in their calendar or memory notebook.
- Inform the health care team about changes in sleep patterns or stamina.
- Ask the health care team to rule out any common causes of fatigue, such as sleep problems or diabetes.

## What Are the Physical Effects of TBI?

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### Moderate/Severe TBI

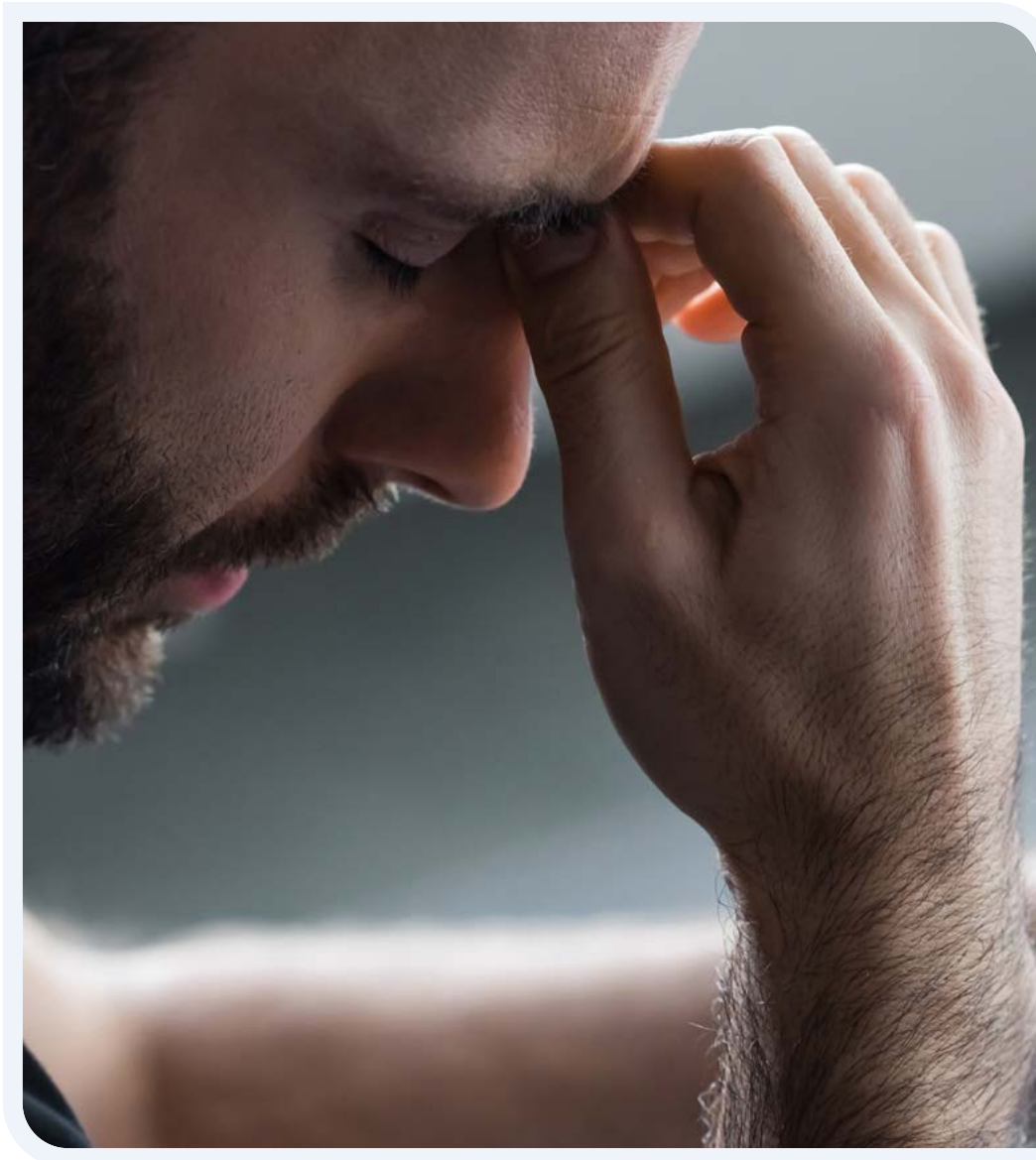
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## Headaches

Headaches are common following a TBI and may occur as a result of an injury to the head, neck, or face. Some people have long-lasting headaches while others have headaches that come and go. Fatigue, stress and a history of migraines can make these headaches worse. Fortunately, post-traumatic headaches usually improve over time. The health care provider may prescribe your service member or veteran medicine to help relieve or prevent headaches, but they may also suggest non-drug treatments, such as stress management, acupuncture, relaxation therapy, or physical therapy. There are several types of post-traumatic headaches, and each type may require different treatment. Talk to the health care team about the best options for your family member. Keep in mind that it can take some time to find the right treatment. The four most common types of headaches following TBI are:

**1. Migraine Headaches:** This is the most common type of post-traumatic headache. Migraines occur when chemicals in the brain cause swelling and pain.



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### What you might see:

- A dull, throbbing sensation, usually on just one side of the head
- Nausea or vomiting
- Moderate to severe pain
- An aura (a warning signal that a migraine is coming, such as seeing flashes of light, feeling tingling or numbness, or slurring or mumbling words)

**2. Tension Type Headaches:** These headaches are often associated with muscle tension or muscle spasms and stress.

### What you might see:

- A pressing, tightening sensation around the entire head
- Mild to moderate pain that does not increase with daily activities

**3. Cervicogenic Headaches:** These headaches occur when there is an injury to the muscles and soft tissues in the neck and the back of the head. Many nerves located in the neck travel to the skull and can cause these headaches.

### What you might see:

- Pain that starts in the neck, shoulders, or back of the head that travels upwards towards the skull
- Pain that worsens with neck movement or repositioning

**4. Neuropathic Headaches:** This type of headache is caused by injury to the soft tissue in the scalp or face that can damage nerves located in these areas.

### What you might see:

- Burning, aching, tingling, or numbness in the affected area
- Pain that can be constant or start and stop
- Long lasting headaches; the pain may not resolve even after the injuries to the scalp and face have healed.

### How you can help (for all headache types):

- Encourage your family member to do the following:
  - Avoid bright sunlight, especially going from a dark building into bright sunlight (may need to wear very dark sunglasses).
  - Avoid things that trigger headaches. These can include cold foods, alcohol, tobacco, caffeine, or chocolate.
  - Keep track of headaches in a journal. Note the time of day, the activity and intensity of the pain. Share this information with the doctor.
  - Take all medications exactly as the doctor directs.
  - Call the doctor if headaches do not improve or worsen.

Your service member or veteran does not need to suffer. New treatment options can be tried. Your family member may be referred to a headache specialist (such as a neurologist) if headaches do not improve with standard treatment.

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## Seizures

One of the problems that may occur after a TBI is a seizure. Although most people who have a brain injury will never have a seizure, it is important to understand what a seizure is and what to do if your service member or veteran has one. Seizures happen when the electrical system in the brain misfires and can be frightening to watch.

Most seizures happen in the first several days or weeks after a brain injury. Some may occur months or years after the injury. They can be temporary or chronic. A neurologist is the member of the health care team who usually diagnoses seizures. He or she will treat seizures with medications. Ask your doctor early on about how to recognize a seizure and what to do if one occurs.

### What you might see:

- Generalized shaking or jerking of the arms and legs
- Loss of consciousness
- Altered attention, emotion, sensation, or movement
- Complaining of strange odors or sensations
- Urinary incontinence

### How you can help:

- For a first seizure, call your doctor as soon as possible.
- If not a first seizure, alert the doctor. Make an appointment to have anti-seizure medication and blood levels checked.
- Talk to the doctor before adding or stopping medications or herbal treatments. These can change the blood level of the anti-seizure medication and make it ineffective.

- Some things are triggers for seizures, including stress, overuse of alcohol, drugs, being overworked, or tired. Help your service member or veteran to avoid these triggers.
- Driving laws for people with seizures vary from state to state. Check with your Department of Motor Vehicles to find out what the rules are for your family member if they have a seizure disorder.
- During a seizure, do the following:
  - Keep calm
  - Don't hold your family member down or try to stop his or her movements
  - Loosen ties or anything around the neck that makes breathing hard to do
  - Clear anything hard or sharp from the surrounding area
  - Put something flat and soft under their head
  - Turn the person gently onto one side—this helps keep the airway clear
  - Do not try to force the mouth open
  - Stay with the person until the seizure ends
- **CALL 911** if your service member or veteran experiences:
  - Difficulty breathing during or after a seizure
  - Seizure lasting more than five minutes
  - Second seizure that happens immediately after the first seizure
  - Difficulty waking up from the seizure or a second seizure without waking up in between

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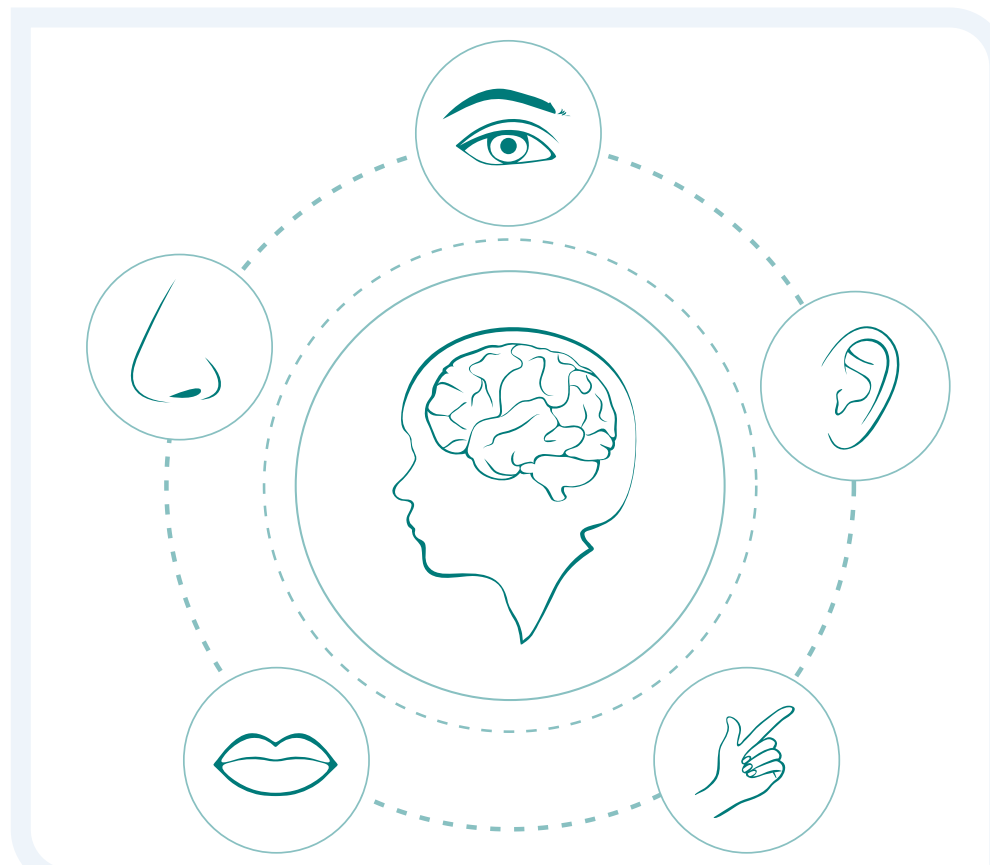
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## Sensory Changes

The brain is the center for all five of our senses: sight, hearing, taste, smell, and touch. When the brain is injured, each of the senses is at risk for change, with vision being the most commonly affected. Vision problems can cause headaches, fatigue, dizziness, and issues with reading and writing that may appear as cognitive problems. If your service member or veteran has any sensory changes, it is important that you seek early evaluation and treatment from the health care team. Your family member may be referred to specialists, such as a neuro-ophthalmologist or neuro-



optometrist for a visual evaluation or a neurologist for other sensory changes. They may recommend strategies and appliances to temporarily compensate for these sensory problems. For some sensory changes that don't go away over time, surgery may be recommended.

### What you might see:

- Vision changes, such as blurry vision, double vision, or sensitivity to light
- Hearing changes, including muffled hearing or ringing in the ears (tinnitus) in one or both ears
- Changes in taste and smell. This could be a complete lack of taste and smell or an altered taste, such as a metallic flavor in the mouth

### How you can help:

- Reinforce wearing of an eye patch or special glasses if ordered for double vision.
- If he or she is having vision changes, seek professional advice about whether or not it is safe for your family member to drive.
- Have their hearing checked. Use hearing aids, if needed.
- Ask a dietitian about tips for eating, if taste and smell are lost or altered.
- Make sure you have a working smoke alarm in the house, especially if their sense of smell has been lost.



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## Sleep Changes

Changes in sleep patterns are very common after TBI. Sleep problems after TBI, such as *obstructive sleep apnea* (OSA) and insomnia, are also common. OSA is when someone periodically stops breathing during sleep, causing their sleep to be fragmented. It is important that any sleep issues your family member may have are brought to the attention of the health care team. This is because treating any sleep problems early helps recovery and decreases the chances of long-term TBI complications. Stay hopeful. Most people with TBI usually resume a more normal sleep routine, similar to the one they had before the injury.

### What you might see:

- Difficulty falling or staying asleep (insomnia)
- Snoring, gasping, or choking for air during sleep (symptoms of OSA)
- Awake at night, sleeping during the day
- Frequent naps
- Sleeping too much or too little

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### How you can help:

- Work with the health care team to establish a consistent sleep routine and helpful sleep environment.
- Encourage your service member or veteran to
  - Limit daytime naps (talk to the health care team first)
  - Avoid caffeine after noon (coffee, tea, energy drinks, soda)
  - Exercise during the day and avoid exercise too close to bed time
  - Avoid fluids for two hours before bedtime
  - Try to eat the last meal of the day four hours before bedtime
  - Go to bed at the same time every night, and get up at the same time every morning
  - Avoid using the bed for activities other than sleep and sexual activity (e.g., watching TV)
- If worrying or nightmares are contributing to poor sleep, consult the health care team.
- Turn the bedroom into a sleep-friendly place; turn the clock away from the bed, use room darkening shades and make sure the room's temperature is comfortable.
- If your service member or veteran simply cannot fall or stay asleep, have them get out of bed and watch TV or read (if they can easily do this without assistance) until they feel tired and are ready to try again. Also, try relaxation techniques, such as deep breathing, progressive muscle relaxation, or mindfulness.
- Talk with your service member or veteran's doctor about temporarily using sleep medication or complementary or alternative therapies to help establish a sleep schedule.

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## Vestibular Effects

With a TBI, the *vestibular* system in the brain may be damaged. This system is responsible for providing our brain with information about motion, head position, and spatial direction. It is also involved in helping us keep our balance by stabilizing our head and body during movement. When the vestibular system is damaged, common effects that may be seen are dizziness and balance problems. Dizziness is a term used to describe everything from feeling faint or lightheaded to feeling weak or unsteady. Under normal circumstances, your sense of balance is controlled by a number of signals that your brain receives from several locations. A TBI can disrupt this. The greatest concern about dizziness is the tendency to fall when dizzy or lightheaded. Dizziness is often an early effect. It frequently goes away in the first weeks following injury. If dizziness does not go away on its own, there are therapies and medications that may be used under the supervision of the health care team.

### What you might see:

- Complaining of their surroundings spinning or moving (vertigo)
- Loss of balance, unsteadiness
- Nausea
- Wooziness, lightheadedness
- Blurred vision during quick or sudden head movements
- Unsteadiness when walking
- Inability to walk or sit without assistance
- Falls
- Holding onto furniture, walls, or other objects when walking

### How you can help:

- Be aware of the possible loss of balance; this can lead to falling and serious injury.
- Make your home fall-proof: remove area rugs and electrical cords that someone could slip on; use non-slip mats in your bathtub and on shower floors.
- If prescribed, encourage the proper use of aids such as walkers or canes in all settings (community or home).
- Falls are the leading cause of non-combat TBI: once you are home, provide or arrange for supervision to prevent falls and another TBI.
- Work with your physical therapist to learn how to assist your service member or veteran while he or she is sitting or walking. Here are some tips you can try:
  - Sit for a few minutes before walking—this gives the brain time to adjust
  - Sit or lie down as soon as dizziness feeling appears
  - Avoid driving a car if frequent dizziness or lightheadedness is present
  - Use good lighting when getting out of bed at night
  - Avoid sudden movements or bending over



## What Are the Physical Effects of TBI?

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## Visual-spatial Problems

Visual-spatial problems mean changes in the brain's ability to understand what the eyes see. Spatial awareness can also be affected by TBI. This means the ability to perceive where you are in space and in relation to other items in the environment.

### What you might see:

- Tendency to ignore things on one side of the body
- Bumping into things on the affected side
- Difficulty finding his or her way around, especially in new places
- Difficulty recognizing shapes and telling the difference between shapes
- When reading, cutting words in half or beginning to read in the middle of the sentence or page
- Mistaking the location of a chair when sitting down
- Misjudging distance—for example, missing the cup when pouring
- Standing too close or too far from others in social situations
- Confusion between right and left
- Reports of impaired vision

### How you can help:

- Stand on, and place objects on, the affected side. Encourage your service member or veteran to look to that side (this is called *visual cueing*).
- Remind your service member or veteran to frequently look around the environment, especially toward the affected side (this is called *visual scanning*).
- Use visual cues (e.g., a dark line) on one side of a page to encourage visual scanning of the entire page.
- Arrange your house to make tasks easier. For example, have items to accomplish a task organized in one place.
- Show your service member or veteran around new places several times. Avoid sending them to new places alone.
- Limit clutter in the house. Try not to move items around.
- Remind your service member or veteran to use handrails when available.
- Provide gentle reminders to your service member or veteran when he or she is standing too close or far away during social encounters.
- Seek professional advice about whether or not it is safe for your service member or veteran to drive.
- Walk closely next to your service member or veteran when out in public so that you can easily guide them around any obstacles.

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## Apraxia

Apraxia is the reduced ability to perform complex movements. A person with apraxia can often understand what to do and has the physical ability to do the task. However, their body simply has trouble cooperating with their best intentions.

### What you might see:

- Trouble using items correctly (e.g., trying to use a toothbrush to comb hair or a fork to eat soup)
- Unable to follow spoken directions accurately. For example, he or she may not give “thumbs up” when asked
- Putting clothes on backwards, upside down, or inside out



### How you can help:

- Guide your family member to complete the task the right way. For example, place your hand over your family member’s hand and move it through the correct motions to perform a specific task.
- Redirect your service member or veteran to perform other common tasks in the correct order, one step at a time.
- Write down instructions for your service member or veteran.
- Post a daily routine or schedule for hygiene and other daily tasks (e.g., dressing) and write the routine down in your service member or veteran’s calendar or memory notebook.

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## Bladder or Bowel Changes

Even bowel and bladder functions are controlled by the brain. For many people with a moderate or severe TBI, bladder and bowel functions are impaired in the early days to weeks following their injury. Health care providers expect this and are prepared to help. Urinary catheters and the use of incontinence briefs may be needed. Bladder and bowel retraining is part of the rehabilitation process. Fortunately, with time and practice, most people with TBI regain control of these body functions.

### What you might see:

- Loss of bladder or bowel control
- Increased urgency to urinate
- Incomplete bladder or bowel emptying
- Increased bladder infections
- Constipation
- Skin problems due to incontinence.

### How you can help:

- Indwelling urinary catheters followed by the use of pads or diapers are common early on. Reassure your service member or veteran that these are nearly always temporary.
- The rehabilitation nurse will teach bladder “training,” which often includes a specific fluid schedule, limiting fluids in the evening, and timed attempts to empty the bladder. Help your service member or veteran adhere to the recommended schedule and interventions.
- Bowel “training” often includes scheduled attempts, a high fiber diet, adequate fluids, physical activity, eating meals at regular times and possible use of medications—including suppositories. Help your service member or veteran to adhere to the recommended schedule and interventions.
- Monitor for skin breakdowns and report any to the health care team.



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**Changes in Swallowing and Appetite; Weight Loss or Gain**

Hemiparesis, Hemiplegia

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## Changes in Swallowing and Appetite; Weight Loss or Gain

Some people with TBI are unable to drink or eat for a period of time. Once your service member or veteran is cleared to drink or eat, he or she may only be able to consume certain types of liquids and foods. With practice, most people will return to a normal diet. Appetite can also be affected by TBI. Some people with TBI may have a reduced appetite and others may gain weight. Work with the health care team to learn how to help your service member or veteran have a healthy diet and a healthy weight.

### What you might see:

- Choking or coughing during meals
- Pocketing of food inside the mouth
- Drooling
- Decreased interest in eating
- Weight loss without trying to lose weight (possibly due to loss of taste and smell)
- Overeating, resulting in weight gain

**What Are the Physical Effects of TBI?**

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**Moderate/Severe TBI**

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**How you can help:**

- Do not offer fluids or food until your service member or veteran has been cleared to drink and eat by a doctor.
- If on a special diet with restricted fluids and foods, work with the therapists and dietitians to learn what foods are allowed. Learn how to assist your family member in eating and drinking, if special strategies are needed (e.g., eating slowly, chin tuck during swallowing, double-swallow, and following every bite of food with fluid).
- Short term changes in appetite are common. Don't worry about early weight loss. Usually, the weight is regained once the person is home.
- Monitor your service member or veteran's body weight and learn what his or her ideal weight range is from the dietitian.

- Report appetite changes to the health care team. These may be a sign of depression, general emotional distress, medication problems, or other medical conditions.
- Ask for a dietitian to review dietary intake and to learn more about meal preparation and a balanced diet.
- Talk with the dietitian about how to use spices and flavorings to perk up the taste of food.
- Work with your service member or veteran to remain physically active and engaged in outside activities to help maintain a healthy weight. Establish set meal times. Discourage overeating or too many snacks.
- Encourage your service member or veteran to be involved, as able, in grocery shopping and meal planning and preparation.
- Write meal times in a planner or memory book. Check off meals when finished.

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Spasticity

## Hemiparesis, Hemiplegia

If your service member has a severe TBI, their movement can be affected because muscle movement originates in the brain. Movement on the right side of the body is controlled by the left side of the brain, and movement of the left side of the body is controlled by the right side of the brain (“hemi” in hemiparesis and hemiplegia refers to the hemispheres of the brain).

### What you might see:

- Muscle weakness on only one side of the body (hemiparesis)
- Total paralysis of the arm, leg, and trunk on one side of the body (hemiplegia)

### How you can help:

- Your service member or veteran’s physical therapist and occupational therapist will develop leg and arm exercises. Ask to learn these exercises.
- Realize that your family member may take longer to move around. Allow extra time to get places.
- Encourage the use of prescribed assistive devices, such as a walker or wheelchair. They help your family member stay safe and independent.
- You may notice decreased sensation in affected limbs. Monitor skin for pressure points from the splints. Alert the team to areas of redness and breakdown.
- Therapists may recommend certain sleeping positions that are best for the affected limb(s). Follow their suggestions.





## What Are the Physical Effects of TBI?

### All TBI Severities

Acute and Chronic Pain

Fatigue or Loss of Stamina

Headaches

Seizures

Sensory Changes

Sleep Changes

Vestibular Effects

Visual-spatial Problems

### Moderate/Severe TBI

Apraxia

Bladder or Bowel Changes

Changes in Swallowing and Appetite; Weight Loss or Gain

Hemiparesis, Hemiplegia

**Spasticity**

## Spasticity

An injury to the brain can cause an abnormal increase in muscle tone called *spasticity*. Spasticity only occurs in those who have had a moderate or severe TBI. Spasticity is increased tension or tightness in a muscle. When the spastic muscle is stretched, the increased tension causes it to resist pull back. A spastic muscle does not easily relax the way a normal muscle does. Regular stretching, splints to keep limbs in proper position, and medications are common treatments. Severe spasticity can be painful, so pain management may be necessary.

### What you might see:

- Involuntary muscle tightness and stiffness
- Muscle contractions
- Decreased range of movement and abnormal posture

### How you can help:

- The physical therapist will develop a stretching program for your family member. Ask the physical therapist to teach you this program.
- Post diagrams of the stretches. Help your family member do the recommended stretches.
- If splints are used, learn how to apply them. Find out how long they are to be worn each day.
- Monitor your family member's skin for pressure points from the splints. Alert nurses to areas of redness and breakdown.
- Tell the health care team if the spasticity gets worse. This could be a sign of an underlying problem.
- If spasticity is so severe that it interferes with comfort, positioning, and general functioning, ask the doctor about treatment options. These may include oral muscle relaxants, injections, and, in some cases, implanting a muscle relaxant pump.



## What Are the Cognitive Effects of TBI?

*Cognition* is another term for how we think and learn. Cognitive changes, changes in thinking, are very common after a TBI. Thinking takes place in the brain. When the brain is injured, thinking is affected. Thinking may be different and harder than it used to be. Time, rehabilitation, and the natural healing of the brain all

help cognitive issues improve over time. Cognitive recovery often takes longer than physical recovery. Try to be patient. Remember that just like with physical problems, not everyone with a TBI has the same cognitive problems.



What Are the Physical Effects of TBI?

What are the Cognitive Effects of TBI?

What are the Communication Effects of TBI?

What Are the Behavioral and Emotional Effects of TBI?

Caregiver Reflections

**What Are the Cognitive Effects of TBI?****All TBI Severities****Attention Problems**

Difficulty with Decision Making and Problem Solving

Planning and Organization Problems

Slowed Speed of Processing

**Moderate/Severe TBI**

Confusion

Difficulties with Memory

**Attention Problems**

The ability to focus, pay attention for a long time and to do more than one thing at a time, is controlled by the brain. TBI can, and often does, affect all forms of attention. Attention is important because paying attention is the first step to learning and remembering.

**What you might see:**

- Short attention span, sometimes only minutes in duration
- Easily distracted
- Difficulty in attending to one or more things at a time
- Inability to shift attention from one task or person to the next
- Difficulty completing tasks

**How you can help:**

- Be sure you have your service member or veteran's attention before beginning a discussion or task. Have them focus on one task at a time. Help refocus attention to the task at hand.
- Reduce clutter at home and in the work environment. Perform tasks in a quiet environment.
- Remove distractions and noises that you don't need. As best as possible, use timers and checklists in the calendar or memory notebook to help complete tasks.
- Expect a short attention span. Schedule rest breaks and stop an activity when you notice drifting attention.
- Present verbal or visual information in limited amounts.





**What Are the Cognitive Effects of TBI?****All TBI Severities**

Attention Problems

Difficulty with Decision Making and Problem Solving

Planning and Organization Problems

Slowed Speed of Processing

**Moderate/Severe TBI**

Confusion

Difficulties with Memory

**Difficulty With Decision Making and Problem Solving****What you might see:**

- Taking a long time to make a decision
- Making inappropriate or potentially harmful decisions
- Problems reasoning
- Responding impulsively to situations
- Having a hard time recognizing problems
- Slow to think of alternate solutions to problems
- Tendency to be “concrete” in terms of problem-solving, that is, difficulty making inferences
- Taking things literally

**How you can help:**

- Avoid having your service member or veteran make decisions when they're tired, hungry or under stress.
- Help your family member to weigh the options and consequences of a decision.
- Give your service member or veteran time to make a decision. Be patient and talk them through the possible options.
- Limit the number of possible choices; two or three choices are best. Too many are often overwhelming and can increase indecisiveness.
- Avoid making last minute decisions.
- Practice identifying a problem and following through with evaluating the options.

**What Are the Cognitive Effects of TBI?****All TBI Severities**

Attention Problems

Difficulty with Decision Making and Problem Solving

**Planning and Organization Problems**

Slowed Speed of Processing

**Moderate/Severe TBI**

Confusion

Difficulties with Memory

**Planning and Organization Problems****What you might see:**

- Problems organizing time to get things done
- Problems gathering and understanding which tools are needed to complete a task
- Problems breaking down complex tasks into smaller steps



- Having a hard time getting ready for work, school, and appointments
- Being late for appointments, work, or school
- Having a hard time starting a task
- Problems making plans and completing them
- Problems setting goals
- Trouble prioritizing
- Looking disorganized

**How you can help:**

- Have a place for everything and keep everything in its place. In particular, keep your service member or veteran's belongings in certain places.
- Turn off the phone, tablet, TV, or other distractions when tasks need to be done.
- Use memory aids such as calendars and notebooks to plan, write down, and check off tasks when done.
- Use a tote bag or backpack to organize needed items for the day.
- Work with your service member or veteran to decide which information or activity has the highest priority.
- Remind your family member to use the skills they learn in therapy until they become a habit.

**What Are the Cognitive Effects of TBI?****All TBI Severities**

Attention Problems

Difficulty with Decision Making and Problem Solving

Planning and Organization Problems

Slowed Speed of Processing

**Moderate/Severe TBI**

Confusion

Difficulties with Memory

**Slowed Speed of Processing**

Many people with TBI feel that their thinking and processing of information is much slower than it used to be. This problem improves over time. It can be frustrating in today's fast-paced world.

**What you might see:**

- Taking longer to answer questions
- Confusion
- Taking longer to understand things that were easily understood before
- Taking a long time to react and respond

**How you can help:**

- Slow down and simplify information. Encourage your service member or veteran to ask others to slow down and repeat information.
- Break complex tasks and activities down into smaller steps.
- Allow extra time to respond to questions and to learn and understand new information.
- Avoid situations that are overstimulating (e.g., noise, crowds).
- Suggest a different activity or topic of conversation to help the person remain on task.

**Confusion**

Most people with TBI experience some confusion after their injury. It is expected. Sometimes confusion only lasts minutes. Other times, it can last days or even weeks.

**What you might see:**

- Disorientation (not sure of where he or she is, time of day, what has happened)
- Seems in a fog, staring blankly
- Confusing times or tasks in schedule of activities
- Confusing past and present events
- Making up convincing stories to fill memory gaps (called confabulation)

**How you can help:**

- Keep your family member oriented. Put calendars, clocks, family pictures, or a sign about where they are and what has happened to them in their room. A list of health care team members, and what each one does, may also be useful.
- Frequently remind your service member or veteran of the correct details of past and present events.
- Limit changes and provide structure in a daily routine.
- Keep your family member safe, remind them about what's going on, and offer reassurance.



## What Are the Cognitive Effects of TBI?

### All TBI Severities

Attention Problems

Difficulty with Decision Making and Problem Solving

Planning and Organization Problems

Slowed Speed of Processing

### Moderate/Severe TBI

Confusion

Difficulties with Memory

## Difficulties With Memory

Memory problems often happen after a TBI. Past memories, or long-term memory, are nearly always intact. Recent memory, called short-term memory, is much more frequently affected. Short-term memory often improves over time, but it may get worse as fatigue increases.

When someone has memory problems, he or she may start to *confabulate*. Confabulation is when a person makes up false memories. These memories could be about past events that never happened, or they could be memories of actual events that the person puts in the wrong time or place. Sometimes, these memories are very detailed, and the person honestly believes the events happened. Confabulations can be frustrating and confusing, but know that they tend to fade as memory improves.

### What you might see:

- Can't remember information from day-to-day about people, conversations, places, events, appointments, dates, and telephone numbers
- Repeating questions or the same story over and over again
- Can't learn new information and use it in everyday life
- Making up convincing stories to fill memory gaps

### How you can help:

- Teach your service member or veteran to learn memory compensation techniques. These are tools and strategies, such as writing on a calendar, providing a hint, or setting the alarm on your phone to help with memory. Most memory compensation strategies involve things we use in daily life, like digital technology (e.g. smart phone or watch), but persons with brain injury may need to use them more often or learn new ways of using them. Lists, notes, and signs with instructions can also be effective memory compensation tools.
- Get your family member's attention when you are trying to teach, do, or discuss something.
- Break new information down into categories or "chunks." List and review them in order.
- Set up a routine of daily tasks and follow it.
- Buy a pillbox and label each compartment with the time and day that medication should be taken. Write the names of medications and when to take them in a calendar or memory notebook.
- Keep personal and household items in the same place.

What Are the Cognitive Effects of TBI?

All TBI Severities

Attention Problems

Difficulty with Decision Making and Problem Solving

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Slowed Speed of Processing

Moderate/Severe TBI

Confusion

Difficulties with Memory

- Talk to your service member or veteran about the activities and events of the day to help build memory. Have them review plans for the following day as well.
- Present information in more than one way, including hearing, seeing, and doing. Each person has a different learning style. Ask the neuropsychologist how your family member learns best.
- Role-play in order to reinforce new learning.
- Get enough rest. Getting proper amounts of sleep may help with memory difficulties.
- Help your service member or veteran stay mentally active by reading, playing card games, and completing crossword puzzles.

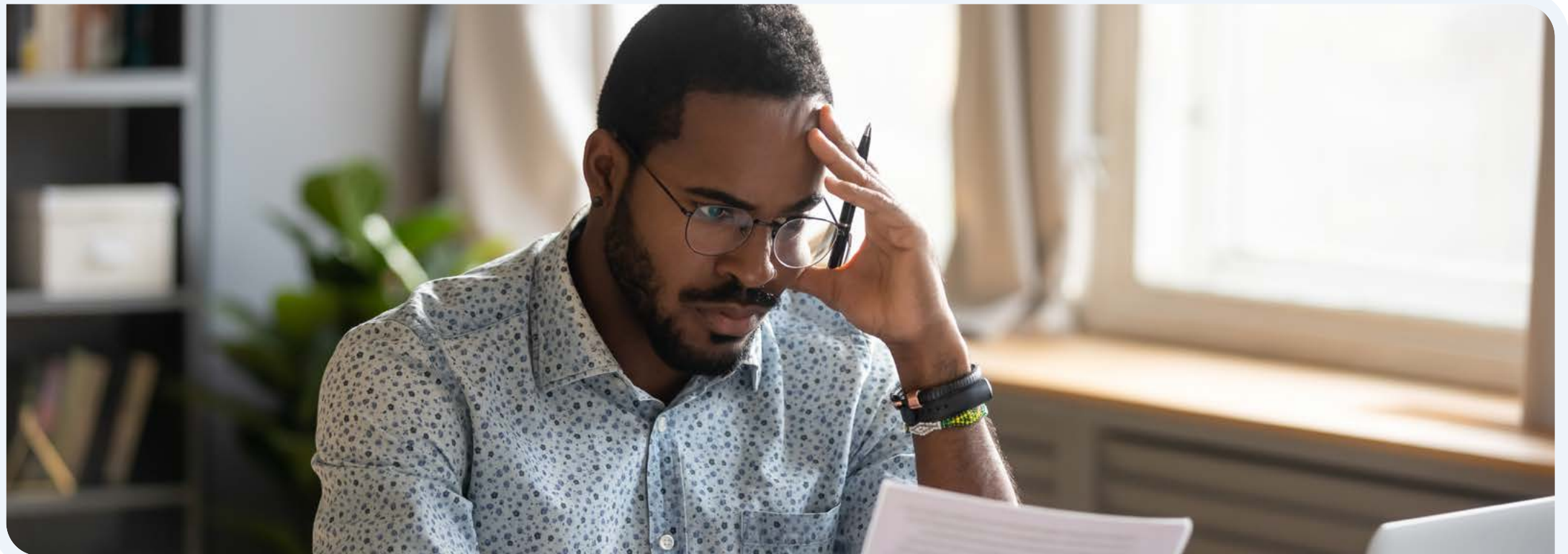
- Give your service member or veteran extra time to complete tasks. Some tasks may take them longer than they used to.
- If your service member or veteran is confabulating, gently help him or her become aware that this memory is not accurate. You can also try redirecting your family member by gently changing the topic or adding a distraction.
- Gently remind your family member of upcoming milestones such as birthdays or anniversaries.



## What Are the Communication Effects of TBI?

Communication is a complex process, which involves many aspects of behavior, thinking, memory, judgment, self-awareness, and social skills. If a TBI impairs any of these skills, the ability to communicate successfully can be affected. A service member or veteran with any severity of TBI can experience communication challenges, particularly with language. They may have difficulty exchanging information through understanding, talking, reading, and writing. These communication struggles may become worse when in stressful situations, such as at work or school.

If your family member is having communication problems, speak to a *speech language pathologist* (SLP). They can help your service member or veteran better understand and remember what is being said as well as express needs, wants, and ideas clearly to others. You may also want to check your service member or veteran's vision and hearing. This is to make sure that any hearing or vision loss is not contributing to any communication challenges.



What Are the Physical Effects of TBI?

What are the Cognitive Effects of TBI?

What are the Communication Effects of TBI?

What Are the Behavioral and Emotional Effects of TBI?

Caregiver Reflections



## What are the Communication Effects of TBI?

### All TBI Severities

Interrupting or Having a Hard Time Taking Turns in Conversation

Nonverbal Communication Issues

Problems Following a Conversation

Problems Starting a Conversation

Reading Comprehension Problems

Topic Selection Problems

Word Finding Problems

Writing Problems

### Moderate/Severe TBI

Slurred Speech

## Interrupting or Having a Hard Time Taking Turns in Conversation

### What you might see:

- Talking non-stop
- Not allowing the listener a turn to speak
- Frequent interruptions
- Inability to adjust communication style to specific situations
- Bringing up the same topic over and over again (*perseveration*)

### How you can help:

- Politely interrupt and ask for a chance to speak. Tell your service member or veteran you would like to say something.
- Develop a hand signal which would indicate to the service member or veteran that they may be taking over the conversation.
- Gently alert them to the fact that the topic change was too abrupt, or that they have interrupted and will be given a chance to say his or her piece in a moment.
- Use positive reinforcement for any attempts your service member or veteran makes at listening rather than talking.
- Your service member or veteran may be interrupting because he or she is “lost” in the conversation. Encourage them to speak up if they don’t understand what is being said.

## Nonverbal Communication Issues

### What you might see:

- Having a hard time understanding common nonverbal cues (e.g., facial expressions, hand gestures)
- Standing too close or too far from those they are speaking to
- Overly touching a person during a conversation
- Body language or facial expressions that doesn’t “match” what is being said
- Poor eye contact
- Staring at others during conversation

### How you can help:

- Politely ask your service member or veteran to stand closer or farther away.
- Explain that the behavior is making you uncomfortable.
- Tell your service member or veteran you are confused by the difference between body language and spoken message. Briefly explain what you saw and heard.
- Ask them to stop any distracting motions.
- Role-play the right way to behave in a particular setting. Work with the health care team to practice appropriate behavior.
- Talk to your family member about how to act in certain situations, before they’re in those situations.
- Give feedback on the right amount of eye contact to keep with another person. Praise all improvements.
- Decide on a signal to indicate problematic behavior.

**What are the Communication Effects of TBI?**

**All TBI Severities**

Interrupting or Having a Hard Time Taking Turns in Conversation

Nonverbal Communication Issues

Problems Following a Conversation

Problems Starting a Conversation

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**Moderate/Severe TBI**

Slurred Speech

**Problems Following a Conversation**

**What you might see:**

- Difficulty paying attention to what is said
- Misinterpreting what is said
- Being “off-topic” compared to the rest of the people in the conversation

**How you can help:**

- Try and get your service member or veteran’s attention before speaking.
- Be clear and to the point.
- Reduce distractions.
- Every so often, stop and ask your family member to restate what they heard to ensure understanding.
- Reduce your rate of speech and frequently pause to allow the person time to process and respond.
- Avoid abrupt topic changes.
- In group conversations, help set a slower pace.

**Problems Starting a Conversation**

**What you might see:**

- Unable to start or is slow to start conversations
- Long pauses
- Problems explaining what he or she means
- Doesn’t respond to another’s questions or comments

**How you can help:**

- Ask a leading question such as, “What do you think about ...?”
- Encourage your service member or veteran to talk about topics of interest or familiar topics.
- Ask open-ended questions (e.g., questions that cannot be answered with a “yes” or “no”), such as, “Tell me more about your day.”
- Give your service member or veteran your full attention.
- Give your service member or veteran time to organize their thoughts.
- Use redirection to guide conversations.
- Reinforce all efforts to start a conversation. Show that you value what your service member or veteran has to contribute to a conversation.

**What are the Communication Effects of TBI?**

**All TBI Severities**

Interrupting or Having a Hard Time Taking Turns in Conversation

Nonverbal Communication Issues

Problems Following a Conversation

Problems Starting a Conversation

**Reading Comprehension Problems**

**Topic Selection Problems**

Word Finding Problems

Writing Problems

**Moderate/Severe TBI**

Slurred Speech

**Reading Comprehension Problems**

**What you might see:**

- Problems understanding what is read
- Trouble stating the main idea or main point

**How you can help:**

- Read with your service member or veteran. Emphasize important information in the text.
- Review any reading material using the 5W strategy – Who, What, Where, When, Why:
  - Who are the characters?
  - What happened to the characters in the book? What did they do about it?
  - Where did it happen?
  - When did it happen?
  - Why did it happen?
- Have your service member or veteran write out important information or say it aloud; this uses other senses to increase comprehension.

**Topic Selection Problems**

**What you might see:**

- Problems finding good topics for conversation
- Problems keeping up when topics change
- Abruptly introducing a new topic
- Problems staying on topic

**How you can help:**

- Pick topics that your service member or veteran enjoys. Ask about their interests and opinions.
- Clarify new topics as they come up.
- Ask how their comment relates to the topic: “How does the price of gas relate to what you ate for lunch?”
- Tell your service member or veteran when you are confused or getting lost in the conversation.
- Gently but firmly alert your family member if they are bringing up a topic that may be offensive to others.



## What are the Communication Effects of TBI?

### All TBI Severities

Interrupting or Having a Hard Time Taking Turns in Conversation

Nonverbal Communication Issues

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Reading Comprehension Problems

Topic Selection Problems

Word Finding Problems

Writing Problems

### Moderate/Severe TBI

Slurred Speech

## Word Finding Problems

### What you might see:

- Problems finding the right word to describe what they are trying to say

### How you can help:

- Give your family member time to locate the word they're looking for. If they still cannot locate the word after some time, guess at what they might mean.
- Try to be patient. Think about how frustrated your service member or veteran likely feels when they know what they want to say, but cannot locate the right word or phrase.
- Encourage them to use another word that is close in meaning.
- Suggest that they use many words (or a description) instead of using a single word.

## Writing Problems

### What you might see:

- Problems expressing thoughts in writing
- Problems getting started writing
- Writing the same words or phrase over and over (*perseveration*)

### How you can help:

- Practice writing with your service member or veteran.
- Make a list of openings (e.g., Dear, Hello, Hi, etc.) and closings (e.g., Thank You, Sincerely, Yours Truly), and the reasons for selecting them.
- Suggest saying words out loud before writing them.
- Suggest reading what is written to make sure it makes sense.

**What are the Communication Effects of TBI?****All TBI Severities**

Interrupting or Having a Hard Time Taking Turns in Conversation

Nonverbal Communication Issues

Problems Following a Conversation

Problems Starting a Conversation

Reading Comprehension Problems

Topic Selection Problems

Word Finding Problems

Writing Problems

**Moderate/Severe TBI**

Slurred Speech

**Slurred Speech**

Slurred speech, or *dysarthria*, means having a hard time using the muscles needed to form words and produce sounds. This communication problem is seen most often in those with a moderate or severe TBI.

**What you might see:**

- Speech that is slow, slurred, or garbled
- Problems with intonation, the rise and fall of the voice when speaking, or inflection, changes in voice pitch

**How you can help:**

- Help your family member properly and regularly practice the exercises prescribed by a speech language pathologist to improve the muscles used in speaking. Over time, these exercises will make your family member's speech clearer.
- Encourage and allow ample time for your service member or veteran to speak.
- Inform those around your service member or veteran about the diagnosis, so they too allow the person time to express themselves.



## What Are the Behavioral and Emotional Effects of TBI?

You may notice changes in the way your family member acts. An injury to the brain, and the life changes that happen after a TBI, can cause changes in emotion and behavior. This is because our brain controls the way we act and feel.

Research has shown that changes in the emotions and behaviors of a service member or veteran after a TBI are the most difficult for a caregiver to cope with. This applies whether the service member has had a mild, moderate, or severe TBI. Try and pay attention to any

changes in how your family member acts and feels. If you notice any changes, it is important that you seek advice early on from the health care team. Remember these changes in behavior are challenging for your loved one as well. Seek help, so you can apply effective strategies through counseling, medication, or healthy coping behaviors, right away.

The next few sections will provide strategies you can use to manage common behavioral and emotional effects that you may see.

What Are the Physical Effects of TBI?

What are the Cognitive Effects of TBI?

What are the Communication Effects of TBI?

What Are the Behavioral and Emotional Effects of TBI?

Caregiver Reflections





## What Are the Behavioral and Emotional Effects of TBI?

### All TBI Severities

Changes in Self-esteem

Changes in Sexual Behaviors

Depression

Frustration, Increased Anger and Aggressiveness

Impulsivity or Difficulties with Self-Control

Increased Anxiety

Lack of Self-awareness

Less Effective Social Skills

Mood Swings (Emotional Lability)

Poor Judgment

Psychological Trauma

Reduced or Lack of Initiation

Substance Misuse

Suicide

### Moderate/Severe TBI

Repetitive Behaviors (Perseveration)

## Changes in Self-esteem

Self-esteem is feeling confidence and pride in who you are. A person's view of themselves can be negatively affected by TBI. Feelings of low self-esteem go hand in hand with depression.

### What you might see:

- Negative self-statements: "I am worthless," "I'll never be normal again," "How can you love me like this?"
- Less interest in personal appearance
- Social withdrawal

### How you can help:

- Encourage your family member to express their feelings. Try to redirect the person to more positive thoughts.
- Encourage your family member to take part in independent activities that they can feel successful in.
- Help your family member to set realistic, attainable goals. Help them choose activities that they can successfully complete.

## Changes in Sexual Behaviors

The brain regulates many aspects of sexuality. Even slight damage to these areas can affect how sexual urges are expressed and how the sexual organs will work. Sexual difficulties after TBI can be made worse by physical problems, such as pain, weakness or coordination difficulties, or by thinking, emotional, or self-esteem problems.

One of the most challenging behaviors that caregivers report after TBI is inappropriate sexual behavior by their family member. Your loved one may appear to have a greater sex drive and seem preoccupied with sex, often at inappropriate times. Try and keep in mind that this behavior is not intentional, but is most likely from damage to the part of the brain that helps them hold back impulses and urges. You may find your loved one displaying the opposite behavior; showing no desire or interest to engage in sexual activities. It is important for you to understand the reasons for such changes, so that you do not misinterpret the behavior as lack of caring.

Some TBI injuries make it difficult or impossible to engage in the same level of sexual activity as before the injury. However, a satisfying sex life for your service member or veteran can be possible.

**What Are the Behavioral and Emotional Effects of TBI?**

**All TBI Severities**

- Changes in Self-esteem
- Changes in Sexual Behaviors
- Depression
- Frustration, Increased Anger and Aggressiveness
- Impulsivity or Difficulties with Self-Control
- Increased Anxiety
- Lack of Self-awareness
- Less Effective Social Skills
- Mood Swings (Emotional Lability)
- Poor Judgment
- Psychological Trauma
- Reduced or Lack of Initiation
- Substance Misuse
- Suicide

**Moderate/ Severe TBI**

- Repetitive Behaviors (Perseveration)

**What you might see:**

- *Hyper-sexuality*, or speaking about, thinking about or wanting frequent sexual activity (e.g., masturbation)
- *Hypo-sexuality*, or a lack of interest in sex
- Difficulty becoming sexually aroused or reaching an orgasm
- Discomfort with intimacy
- Trying to kiss or touch strangers
- Making suggestive or flirtatious comments to or about others
- Disrobing or engaging in masturbation in front of others
- Thinking that they are no longer attractive, or worrying that you will be “turned off” by their injury

**How you can help:**

- Develop a “stop and think” signal to let your family member know that they are saying something inappropriate.
- Use redirection (i.e., try to change the topic or focus of interest to something else).
- Respond to inappropriate behaviors in a firm and consistent manner.
- Tell your family member that having sexual feelings is normal. Sexual behavior, however, is a private matter. Teach them what are acceptable ways to act in public.

- Find a way for your family member to express their sexual needs (i.e., in the privacy of their room).
- Communication is key in overcoming self-image barriers. Provide opportunities to reassure and support your family member.
- Try new sexual positions that will not cause pain to your partner. Discuss with the health care team the use of sexual aids. These are aids specifically developed to help people with disabilities.
- Initiate romantic activities. In many cases, an expression of interest from you is all that is needed to engage your loved one’s interest.
- Have your family member watch movies or read books with sexual content to help them become sexually aroused.
- Consider having your loved one speak to a counselor or sex therapist who can help with emotional or physical issues that are affecting sexual functioning. You can also contact a provider on the health care team to discuss medication options.

What Are the Behavioral and Emotional Effects of TBI?

All TBI Severities

- Changes in Self-esteem
- Changes in Sexual Behaviors
- Depression**
- Frustration, Increased Anger and Aggressiveness
- Impulsivity or Difficulties with Self-Control
- Increased Anxiety
- Lack of Self-awareness
- Less Effective Social Skills
- Mood Swings (Emotional Lability)
- Poor Judgment
- Psychological Trauma
- Reduced or Lack of Initiation
- Substance Misuse
- Suicide

Moderate/ Severe TBI

- Repetitive Behaviors (Perseveration)

Depression

Many people with TBI experience depression. This can be from the physical changes in the brain due to the injury, or from the emotional reactions to it. It is often hard to tell the difference between symptoms of depression and the effects of the TBI. Both people who have had a TBI and people who are depressed can have low activity levels, sleep problems, difficulty controlling emotions, loss of interest in pleasurable activities, decreased energy, changes in appetite, and lack of initiation.

If you suspect that your family member may be depressed, ask your health care team to evaluate their mental health. Remember, depression is common as a person struggles to adjust to the temporary or lasting effects of TBI. Being depressed is not a sign of weakness or anyone's fault. Depression is a medical condition, and, just like other medical conditions, it can be treated and managed. Help is available. Do not wait to call someone if you think your family member needs help.





**What Are the Behavioral and Emotional Effects of TBI?**

**All TBI Severities**

- Changes in Self-esteem
- Changes in Sexual Behaviors
- Depression**
- Frustration, Increased Anger and Aggressiveness
- Impulsivity or Difficulties with Self-Control
- Increased Anxiety
- Lack of Self-awareness
- Less Effective Social Skills
- Mood Swings (Emotional Lability)
- Poor Judgment
- Psychological Trauma
- Reduced or Lack of Initiation
- Substance Misuse
- Suicide

**Moderate/ Severe TBI**

- Repetitive Behaviors (Perseveration)

**What you might see:**

- Persistent sad, anxious, or “empty” feelings
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Irritability, anger, or restlessness
- Loss of interest in activities or hobbies once pleasurable, including sex
- Fatigue and decreased energy
- Problems concentrating, remembering details, and making decisions
- Insomnia, early morning wakefulness, or excessive sleeping
- Overeating or appetite loss
- Persistent aches or pains, headaches, cramps or digestive problems that do not ease, even with treatment
- Less attention paid to grooming and personal appearance

**How you can help:**

- Offer emotional support, hope, understanding, patience, and encouragement. Keep reassuring your family member that depression usually gets better with time and treatment.
- Don’t give up too soon. Your depressed family member may need to hear more than once, and from several people, that they deserve to feel better, and can improve with proper treatment.
- Talk to your family member and listen carefully. Acknowledge their feelings, point out realities, and offer hope.
- Get your family member involved in activities outside the house (e.g., walks, shopping, movies, church services, volunteering). If they decline, keep making gentle suggestions, but don’t insist.
- Educate yourself. Know that not everyone who experiences depression has the same symptoms. Also, it’s hard to help someone if you don’t understand the condition. Share what you have learned with your family member.
- Encourage your family member to speak to a health care provider if they experience several symptoms at the same time, if they last longer than two weeks, and if they interfere with their normal daily activities.

## What Are the Behavioral and Emotional Effects of TBI?

### All TBI Severities

Changes in Self-esteem

Changes in Sexual Behaviors

Depression

**Frustration, Increased Anger and Aggressiveness**

Impulsivity or Difficulties with Self-Control

Increased Anxiety

Lack of Self-awareness

Less Effective Social Skills

Mood Swings (Emotional Lability)

Poor Judgment

Psychological Trauma

Reduced or Lack of Initiation

Substance Misuse

Suicide

### Moderate/ Severe TBI

Repetitive Behaviors (Perseveration)

## Frustration, Increased Anger, and Aggressiveness

After a TBI, many people become frustrated more easily than before. Your family member may not be able to do things as easily as they once did, or may not know what others expect from them. They may also feel a loss of independence, fatigue, or overstimulation. These can all lead to feelings of frustration and anger. When they're frustrated, you may notice a quicker temper or unusual reactions in your loved one.

### What you might see:

- Strong reaction to minor annoyances or sources of frustration
- General lack of patience (e.g., when others don't understand the changes resulting from the injury)
- Low tolerance for change
- Unexpected outbursts of anger
- Increased irritability
- Verbal or physical demonstrations of anger
- Increased tendency towards anger when tired, in new situations, or during high levels of stress

### How you can help:

- Develop a plan to manage frustration or anger. This might mean taking a walk or going to another room and turning on the television. This can be a good signal to others in the family that your loved one needs to be alone for a while.

- Remain calm. Encourage your family member to recognize when they are becoming angry or frustrated. Help them learn to ask for a break or some space to calm down. Allow yourself to also take a break when necessary.
- Reinforce all efforts to use effective anger management strategies.
- Prepare your service member or veteran for challenging situations when possible.
- Simplify tasks.
- Provide a consistent, structured environment. Try to avoid surprises. People with TBI do better when they are prepared and can anticipate a change in plans.
- Try to consistently react to certain behaviors in a certain way. Often, a consistent approach helps to manage difficult behaviors.
- Rehearse and role-play specific situations to boost confidence in managing life outside the home.
- It is important to tell the health care team if anger increases or your family member is violent. Ask the health care team to develop a plan to manage this behavior. The rehabilitation psychologist or neuropsychologist is the team member who will work on this plan.

## What Are the Behavioral and Emotional Effects of TBI?

### All TBI Severities

Changes in Self-esteem

Changes in Sexual Behaviors

Depression

Frustration, Increased Anger and Aggressiveness

Impulsivity or Difficulties with Self-Control

Increased Anxiety

Lack of Self-awareness

Less Effective Social Skills

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### Moderate/Severe TBI

Repetitive Behaviors (Perseveration)

## Impulsivity or Difficulties With Self-Control

Many individuals with TBI react impulsively. This means they respond quickly without thinking the situation through.

### What you might see:

- Saying whatever comes to mind without thinking about how it might affect the person, themselves, or someone else
- Acting without thinking about potential consequences (e.g., crossing the street without checking traffic)
- Inappropriate comments to or about others

### How you can help:

- Use redirection (e.g., suggest a different activity or topic of conversation).
- Develop a special “stop and think” signal that you can use to alert your family member when they are doing or saying something inappropriate (e.g., raising your finger, saying a special word). It allows the person to stop, slow down, pause, and take the needed time to think about something before doing it. It allows time to develop a reasonable plan or response.
- Praise and reward desired behaviors; discuss consequences in private after the fact.
- Avoid comparing past and present behaviors.

## Increased Anxiety

### What you might see:

- Constant physical tension
- Excessive worry, racing thoughts
- Feeling jumpy, irritable, or restless
- Racing heart, dry mouth, excess sweating, shakiness, or feeling short of breath
- Feeling panic or having a sense that something bad is going to happen

### How you can help:

- Work with your family member to recognize problems that they may be worried about. Use problem-solving techniques to address them. This can help put the issues into perspective.
- Suggest that your service member or veteran write things down or keep a journal. Sometimes, this alone can be calming and can slow down racing and nervous thoughts.
- Use redirection (i.e., try to change the topic or focus of interest to something else).
- Ask your family member to talk with the doctor about options for managing anxiety, such as counseling and medication.
- The health care team may suggest other ways to reduce anxiety. These could include relaxation training, controlled breathing, and other coping strategies. If they do, practice these strategies with your family member.



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Increased Anxiety

**Lack of Self-awareness**

Less Effective Social Skills

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### Moderate/ Severe TBI

Repetitive Behaviors (Perseveration)

## Lack of Self-awareness

Self-awareness means understanding your own strengths and weaknesses. A reduced sense of self-awareness can occur after a TBI. Your family member may say very little has changed or not understand that they are having problems. Keep in mind that your loved one is not deliberately denying there is a problem but simply is unable to recognize it.

Self-awareness usually improves with time and feedback from others. People with TBI learn from their successes and failures, just as we all do.

### What you might see:

- Underestimating the problem areas related to TBI
- Not understanding why rehabilitation therapies are needed
- Not following the recommendations of the health care team (e.g., driving restrictions, no alcohol)
- Unrealistic expectations about future plans or abilities
- Inaccurate self-perception or self-image

### How you can help:

- Learn how to use safe, “supported risk taking” techniques from the health care team. This method allows people to try to do something that they think they can do, but that may be beyond their capabilities. The goal is to raise the person’s awareness through real trial and error situations.
- Work with your service member or veteran to use effective problem-solving techniques.
- Give realistic and supportive feedback.
- Help to set realistic goals. Develop plans to take steps towards larger goals.
- Use a memory notebook to track progress and setbacks.

**What Are the Behavioral and Emotional Effects of TBI?**

**All TBI Severities**

- Changes in Self-esteem
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- Increased Anxiety
- Lack of Self-awareness

**Less Effective Social Skills**

- Mood Swings (Emotional Lability)
- Poor Judgment
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- Substance Misuse
- Suicide

**Moderate/Severe TBI**

- Repetitive Behaviors (Perseveration)

**Less Effective Social Skills**

Social skills form the foundation for relationships with others. They are all of the things we do and say in order to fit in, get along with others, and read and understand the people and situations around us.

**What you might see:**

- Lack of awareness of personal space and boundaries (e.g., talking about private family matters, asking questions that are too personal, flirting with a married person)
- Reduced sensitivity for the feelings of others
- Possible disregard for acceptable standards of conduct at home or out in public
- Use of vulgar language or behavior

**How you can help:**

- Try to react calmly.
- Role-play or rehearse responses to social situations.
- Use an agreed-upon signal to let your service member or veteran know that they may be saying something inappropriate.
- Use redirection (i.e., try to change the topic or focus of interest to something else).
- Praise and reinforce appropriate behavior.



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**Mood Swings (Emotional Lability)**

**Poor Judgment**

Psychological Trauma

Reduced or Lack of Initiation

Substance Misuse

Suicide

### Moderate/ Severe TBI

Repetitive Behaviors (Perseveration)

## Mood Swings (Emotional Lability)

### What you might see:

- Laughing one minute and feeling sad or crying the next
- An emotional response that does not “fit” the situation (i.e., crying when others are laughing, laughing when receiving news about the death of a loved one)
- Frequent or unexpected shows of emotion

### How you can help:

- Reassure your family member that you understand why their display of emotion may not match the situation. Be nonjudgmental.
- Help family and friends understand sudden shifts in your family member’s mood.
- Distract your family member. Use redirection (i.e., try to change the topic or focus of interest to something else).
- If the mood swings are interfering with your family member’s everyday life, ask them to talk with the doctor. Medications may be helpful in managing mood swings.

## Poor Judgment

### What you might see:

- Inappropriate decisions; potentially harmful decisions
- Difficulty reasoning
- Ineffective problem solving

### How you can help:

- Help your service member to use effective problem-solving skills:
  - Identify the problem. If the problem has many parts, break it down into one problem at-a-time.
  - Brainstorm possible solutions together. Think of as many possibilities as you can.
  - Evaluate the alternatives. Consider the pros and cons of each possibility.
  - Choose a solution, the one that seems to fit best.
  - Have them try the solution out. Roleplay with your service member or veteran to prepare them for various situations.
  - Evaluate the solution. If it didn’t work, try another solution until they find the one that works.



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- Less Effective Social Skills
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Moderate/Severe TBI

- Repetitive Behaviors (Perseveration)

### Psychological Trauma

A traumatic event is a shocking, scary, or dangerous experience that may impact all areas of your family member’s life. Experiences like natural disasters, acts of violence, unexpected death, car crashes, and other accidents can all be traumatic. Your loved one may have experienced a trauma when the TBI occurred; they may have also had a traumatic experience during the immediate stages of recovery.

Responses to trauma can be immediate or delayed, brief or prolonged. Most people have intense responses

immediately following and often for several weeks or months after a traumatic event. Some common responses include anxiety, anger, and continually thinking about the event. For most people, these are normal and expected responses and generally lessen with time. In some cases, these responses continue for a longer period of time and interfere with everyday life. If your loved one is experiencing traumatic responses that interfere with daily life or are not getting better over time, they may have psychological stress.

#### TBI and Psychological Trauma Symptoms

##### Possible Symptoms of TBI

- Headaches
- Dizziness or balance problems
- Nausea
- Sensitivity to light and sound
- Vision changes
- Impulsivity

##### Overlapping Symptoms

- Fatigue
- Sleep problems
- Trouble with memory and attention
- Feeling depressed
- Feeling anxious
- Irritability

##### Possible Symptoms of Psychological Trauma

- On high alert
- Startled easily
- Fearfulness
- Flashbacks
- Nightmares
- Guilty feelings
- Avoidance
- Numbness
- Self-destructive behavior

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### Moderate/ Severe TBI

Repetitive Behaviors (Perseveration)

### What you might see:

- Experiencing feelings of threat or fear like those felt during the traumatic event
- Avoiding situations or people that trigger memories of the traumatic event
- Being very jumpy and easily startled
- Negative thoughts about self and others
- Crying often
- Having trouble thinking clearly
- Having nightmares or difficulty sleeping
- Becoming isolated from family and friends

### How you can help:

- Sympathize with your family member and remind them that the symptoms can get better with treatment.
- Educate yourself about trauma reactions. This can provide clarity to why your loved one may no longer have the traits you once loved.
- Don't force your family member into social activities that they do not want to participate in.
- Recognize the triggers in your family member and try to avoid those situations. This may require you changing your normal routines. Remember that flexibility is an essential part of the healthy support for your loved one.
- Listen if your loved one wants to share their feelings or experiences. Ask them what would be helpful when they become frightened, angry, or upset.
- Pay close attention to your loved one's actions and attitudes. If they have any of the common symptoms, encourage them to seek help.

## Reduced or Lack of Initiation

Your family member may seem to have lost interest in activities he or she used to enjoy or may not begin activities on their own. You may find yourself offering frequent reminders to do simple tasks, like brushing teeth or taking a bath. Try to remember that this is not from disinterest, but from injury to his or her brain.

### What you might see:

- Remaining in bed until encouraged to get up
- Spending much of the day sitting around, not actively engaged in activities
- Not speaking unless spoken to
- Problems completing tasks without a lot of supervision
- Agreeing to do something but then not following through

### How you can help:

- Set up a regular schedule for your service member or veteran to follow. The goal is to learn a routine so well that it becomes automatic.
- Post the schedule. Make sure it is in the person's calendar or memory notebook.
- Work with your service member or veteran to develop a list of goals or tasks to be completed. Help your family member check off completed tasks, so they can see progress.
- Encourage your service member or veteran to become involved. Having purpose along with structure can help.

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 Reduced or Lack of Initiation  
**Substance Misuse**  
 Suicide

### Moderate/Severe TBI

Repetitive Behaviors (Perseveration)

## Substance Misuse

Dealing with a TBI can be very challenging for your service member or veteran. Some people with TBI turn to alcohol or other substances to help them cope with the effects of their injury. This coping strategy for a person with TBI can be very harmful, and is never a good idea. After a TBI, the brain is more vulnerable to the effects of alcohol and drugs, so the person will feel these effects much more quickly.

Addictive substances change the way the brain works. Normally, a person's brain allows them to remember the activities, people, places, and things that caused pleasurable experiences. This allows a person to repeat important activities in the future. The brain also associates pleasure with the use of addictive substances. With repeated substance use, a person values using the substance over doing more important things. This uncontrolled or overwhelming need to use the substance is called addiction. Addictive substances can also cause tolerance. This is when the amount of the substance has to increase to achieve the same level of pleasurable effect.

Alcohol and other substances can slow down the recovery of your service member or veteran with TBI in the following ways:

- Make it harder for the brain to heal
- Interfere with thinking processes that are already slowed down

- Interact negatively with prescription medication
- Increase aggressive and socially inappropriate behaviors
- Increase balance problems
- Promote other risky behaviors
- Create greater risk for seizures
- Increase problems with the law involving public drinking
- Cause problems with friends and family
- Make feelings of depression and anxiety worse
- Put your family member and others at risk for falls, car crashes, and other accidents that can lead to another TBI or worse.

### What you might see:

- Using a substance in larger amounts or for longer than it was prescribed for
- Persistent desire or unsuccessful efforts to cut down or control use
- Failure to fulfill major role obligations at work, school, or home because of the substance use
- Intense desire or urge for the substance that may occur at any time



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Moderate/Severe TBI

- Repetitive Behaviors (Perseveration)

How you can help:

- Talk with them about their readiness to change drinking or drug use. Help your family member make a list of pros and cons of using substances.
- Spend time with those family and friends who are supportive of your service member or veteran not using substances. Minimize time with those who are not supportive.
- Avoid high-risk situations, such as people or places that your service member or veteran associates with drinking or using drugs.
- Develop a plan to help your service member or veteran cope with tempting situations, such as leaving the situation or calling a friend for support.
- Explore new social circles or environments that do not involve drinking.
- Encourage learning new ways to deal with stress.
- Remove alcohol and other dangerous substances from the home.
- If your service member or veteran has recently quit using substances, talk openly with them about the possibility of using again in the future, and stress that one “slip” doesn’t need to mean returning to regular use. Encourage use of support systems to help avoid a full relapse.
- Locate a local substance support group or treatment program, if advised by your health care team.



**What Are the Behavioral and Emotional Effects of TBI?**

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- Substance Misuse

**Suicide**

**Moderate/Severe TBI**

- Repetitive Behaviors (Perseveration)

**Suicide**

**What you might see:**

- Expressing thoughts of suicide or suicide attempts

**How you can help:**

- Be familiar with some of the risk factors associated with suicide:
  - Current or past depression or other mental health condition
  - Substance use disorders
  - Prior suicide attempt
  - Recent transition of care (e.g., discharge from inpatient facility, change in medication)
  - Exposure to a traumatic event
  - Social isolation
  - Loss of a relationship
  - Legal or disciplinary issues
  - Financial problems
  - History of moderate to severe traumatic brain injury
  - Access to firearms
  - Risk of unstable housing
  - Serious, life threatening illness, including chronic severe pain

- Recognize the signs of a person thinking of suicide:
  - Making a will or taking steps to get affairs in order
  - Giving away personal possessions
  - Sudden requests to visit friends or other service members/veterans
  - Purchasing a gun or stockpiling medications
  - Sudden and significant decline or improvement in mood
  - Social isolation or withdrawal
  - Talking about feeling hopeless or being a burden on others
- Writing a suicide note
- Ask the person if they have been having suicidal thoughts. If yes, ask if they have a specific plan in mind. Always take a person's threats of suicide seriously. Having a plan for killing oneself is a serious sign to get help quickly.
- Call 911 or the National Suicide Prevention Hotline (800-273-8255, then press 1) immediately.
- Make sure to remove or secure any available firearms or other harmful items in the home.



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### Moderate/Severe TBI

Repetitive Behaviors (Perseveration)

## Repetitive Behaviors (Perseveration)

*Perseveration* means getting stuck on one idea or one behavior and repeating it again and again. Injury to the frontal lobe of the brain can cause this.

### What you might see:

- Writing the same letters or words or repeating the same word or phrase over and over
- Repeating physical movements or tasks
- Getting “stuck” on one topic or theme (e.g., “when can I drive?” or “when can I go home?” or “I need a cigarette.”)

### How you can help:

- Use redirection (i.e., try to change the topic or focus of interest to something else).
- Try engaging the person in a physical task if they are verbally “stuck” on a topic.
- Try engaging the person in a conversation or thinking task, if they are physically “stuck” on a task.





## Caregiver Reflections

What Are the Physical Effects of TBI?

What are the Cognitive Effects of TBI?

What are the Communication Effects of TBI?

What Are the Behavioral and Emotional Effects of TBI?

Caregiver Reflections

*“A really super thing for us in terms of communicating with the hospital staff—and the hospital already had this installed in the room—is a big dry erase board. Some people use it, and some people don’t. We use it to make a list of all the things we want to talk about with the doctors. That way, if I’m not in the room when the doctors come by on their rotation, they’ve got the big list right there, and they can see it clearly. That helps keep the communication going.”*

Anna E.

*“He was plateauing on a therapy level. .... I said, ‘What would you want to learn first if you had to prioritize?’ Well, he wanted to learn to use the telephone, and he wanted to learn to use the remote control on the TV. We told the therapists. They got him an adaptive remote control and we got him a phone. He learned to use them both within a week. So the therapists were good. They said, ‘We’ll work with you. What do you think is going to help him?’ They didn’t know him before the brain injury, so they relied on us to give them as much information as we could on the kind of person he was, so they could determine what would work for him through the therapy. You have to educate the professionals on what he was like.”*

Pam E.

*“Sleep and fatigue were probably the biggest, most constant problems, with the other things sort of waxing and waning. And the neuropsychologist explained to me about the fatigue, that when you have cognitive deficits, your brain has to work so hard just to process something that’s just routine for the normal person that it causes a great deal of fatigue. So it took him a very long time to get over that fatigue, and he still has it at times. But when we first got home, he would be completely wiped out when he came home from work, and every single weekend was a wipe-out. And then that improved, and it was just Saturday that was the wipe-out. Now, most days are pretty normal. Most weekends are pretty normal. Every now and then, we hit a time where he just kind of crashes.”*

Caroline M.

*“I remember saying to our family therapist one day that I felt like my husband was a different person now, so I had to get to know him again. It has been a long road, but it gives me a way to explain it to him so he can understand my side a little more—some days I grieve the loss of the person I married and the life we had before all this—and that’s OK. Caregiving requires a lot of grace, for myself and others.”*

Megan P.

*“One and a half years later—he can speak now. He can have a conversation. He is just starting to spell now, which is still improving. His comprehension is very good. In the beginning, he couldn’t even understand language. He’s still having a lot of trouble reading, so we’re still working on that. He can’t read at this point. He’s never been*

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Caregiver Reflections

*embarrassed about his speech. One thing I did early on was to buy him a cell phone, and I got him to call a lot of his friends. I think that has helped, to be able to call people and talk to them. Some of them saved the first message he left them—they were just crazy. But I think that helps, just being able to stay in touch with people that are familiar and being able to communicate with them.”*

Patty H.

*“The children wanted to be involved in his recovery. They wanted to help read stories, help him with the word finding. One of the things we did was write the words on little sticky notes, and we put them on all his different things. He was really having trouble naming his workshop tools, so we labeled all of his tools. It was something the kids could quiz him on.”*

Shannon M.

*“I used to have him sit in his wheelchair once he started talking and read articles from the newspaper to me while I put on my makeup. Getting him to learn how to read and follow the line was important. If it didn’t make sense to me, I’d say, ‘Oh, wait, wait, wait, I think you missed something.’ And he’d go, ‘Oh, yeah, yeah,’ and he’d go back up. We probably did that for at least a year. Every time I’d put on makeup, he would come in and sit down and read an article to me.”*

Denise G.

*“As time went on—probably about two years after the injury—we started seeing the anger coming in. I think he started to understand the frustrations he was having...*

*the troubles. The anger got bad. Unfortunately, what I tried to do was keep it behind closed doors. The anger accelerated. Instead of trying to get help right off the bat to keep it tame, it probably took us at least a year to get it under control. He still flares up, but it’s nothing like it was before. A strategy that was suggested for dealing with his anger was to keep him abreast of everything that was going on. He couldn’t tell me he felt out of control, and still to this day, he has trouble telling me what his feelings are. So I’m trying to make sure that he’s aware of everything that’s going to go on, and we try to keep a routine. Routine is very important...it keeps him soothed. Trying to talk to him in a calm voice helps, but it’s not always easy, you know, because if you accelerate, of course they do too. The anger has gotten better over time. And now what we have is...more like frustration outbursts.”*

Denise G.

*“It’s hard to describe the things we take for granted day in and day out, just being able to take care of our own selves, like brushing our teeth, washing our hair, knowing how to do those things and when they need to be done. We take that for granted, but that’s something I’ve seen that [he] has really been able to master again. It has improved tremendously. At first, he knew what a toothbrush was for and what a hairbrush was for, but he would never have remembered, ‘Oh, I need to brush my teeth.’ He would never have thought about that. But recently, that’s something he knows. After he eats, he’ll say, ‘Oh, I need to brush my teeth.’ He’s more self-aware.”*

Meredith H.

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Caregiver Reflections

*“I know that there were times in my husband’s recovery that he and I both wrestled with a number of emotions. We definitely went through all the phases of grieving because you grieve for the loss of those characteristics and those dreams that you had before, and that’s all normal. At one point, he said to me that it would have been easier had he passed away, and there were times when I went there too, but it’s not something that you want. It’s not something that you’re wishing for. But these are feelings that I think any couple, any person that’s gone through a traumatic event like this, any*

*caregiver that’s watching a loved one suffer like that and feeling this state of entrapment or loss of control, would normally have in this situation. You need to acknowledge that you have these feelings. Not that you want to fulfill them, but just that you’re not going crazy and you’re not a bad person for having them. Just stay open and know that these feelings, and that feeling of being trapped in this sort of hopeless, hopeless place, will go away. Know that there are a lot of blessings to be found through this recovery process.”*

Anonymous





## Journal Questions

The questions below can help you reflect on your experience as a caregiver. You can write your thoughts down or reflect on these questions in your mind.

1. What physical effects have you observed in your service member or veteran? How severe is the effect?
2. Is there one particular instance that stands out for you? Describe what happened and how you reacted.
3. What impact have these physical effects had on you? On other members of the family?
4. What strategies have you tried to use to help your service member or veteran cope with physical effects? How well have they worked?
5. What strategies do you plan to try in the future to help with any physical effects?
6. What cognitive effects have you observed in your service member or veteran? How severe is the effect?
7. Is there one particular instance that stands out for you? Describe what happened and how you reacted.
8. What impact have these cognitive effects had on you? On other members of the family?
9. What strategies have you tried to help your service member or veteran cope with cognitive effects? How well have they worked?
10. What strategies do you plan to try in the future to help with any cognitive effects?
11. What communication effects have you observed in your service member or veteran? How severe is the effect?
12. Is there one particular instance that stands out for you? Describe what happened and how you reacted.
13. What impact have these communication effects had on you? On other members of the family?
14. What strategies have you tried to help your service member or veteran cope with communication effects? How well have they worked?
15. What strategies do you plan to try in the future to help with any communication effects?
16. What emotional or behavioral effects have you observed in your service member or veteran?
17. Is there one particular instance that stands out for you? Describe what happened and how you reacted.
18. What impact have these emotional and behavioral effects had on you? On other members of the family?
19. What strategies have you tried to help your service member or veteran cope with emotional or behavioral effects? How well have they worked?
20. What strategies do you plan to try in the future to help with any emotional or behavioral effects?

What Are the Physical Effects of TBI?

What are the Cognitive Effects of TBI?

What are the Communication Effects of TBI?

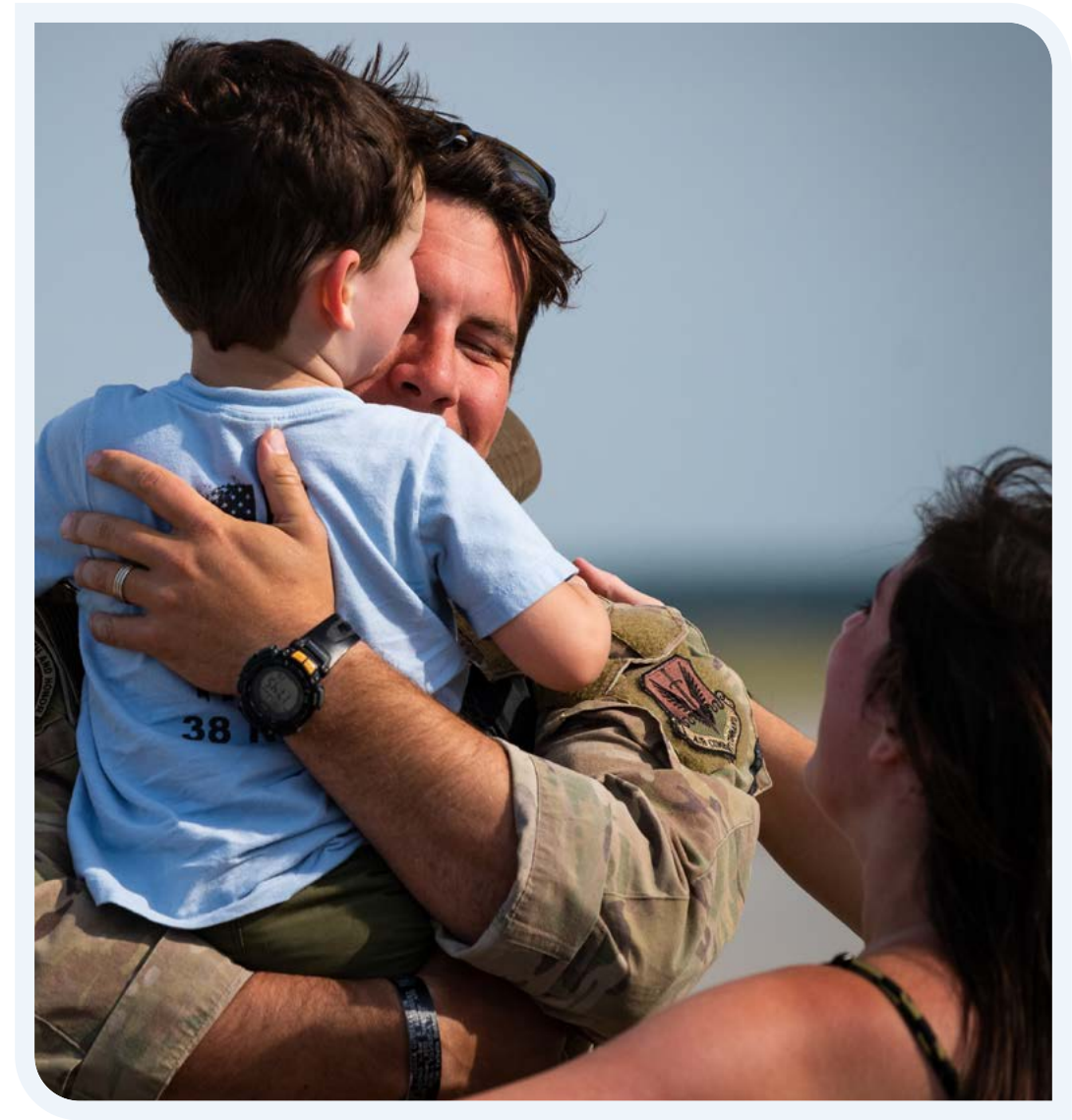
What Are the Behavioral and Emotional Effects of TBI?

Caregiver Reflections

# BECOMING A FAMILY CAREGIVER

## Starting Your Caregiving Journey

You are starting an important journey in your life—becoming a family caregiver to someone who has a TBI. A caregiver like you can help your service member or veteran recover as fully as possible. You may be feeling overwhelmed, angry, or scared. You may also feel alone and worn out by your new role. Take good care of yourself while caring for your service member or veteran. Learn as much as you can about TBI, and most importantly, keep hope alive during your caregiver journey.



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## How Long Will I Be a Caregiver?

The recovery process after a TBI will look different for each person. The effects of a severe TBI may be lifelong in some cases, while most mild TBI patients can expect the recovery process to last several weeks or months following their injury. No two brain injuries are alike, which makes it difficult to predict exactly how long the recovery process will last. Ask the health care team for their opinion on the expected recovery course of your loved one.



## How Important Is My Caregiving?

Caregivers play an important role in the recovery process. In fact, many people who work with TBI patients believe that having a caregiver just like you is one of the most important aids to the recovery process. Your job is to actively follow the treatment plan and offer guidance and help to your injured family member.

The following suggestions may help you with your journey to becoming a caregiver:

- Use this guide. It provides tips on how to be a good caregiver.
- Ask questions of the doctors, nurses, and other healthcare providers.
- Classes or online discussion groups may be helpful.



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The more organized you are, the better. Being organized will help you make decisions, have access to accurate information, reduce your stress, and have all the care-related information you need in one place.

A notebook or electronic device helps a family member with TBI and their caregivers keep information they need together in one place. You may end up with several notebooks or folders to keep track of all medical information. You may even want to enter information into a computer file. The notebook may include sections for

- **Personal information:** This includes important facts, such as your service member or veteran's Social Security number, military service record, emergency contacts, and allergic reaction to medications.
- **Military service papers:** Keep copies of military service records, medical boards, and discharge forms.
- **Medication log:** Write down all the drugs taken, dosages, dates, side effects, allergic reactions, and any other problems related to medications.
- **Medical reports, tests, scans:** Ask for copies of all reports, scans, and tests. Share these with future providers.
- **Notes and questions:** Use blank paper to take notes, and then insert the sheets in the appropriate sections of the notebook.

- **Information:** This is the place to keep all the forms and information you have received at appointments.
- **Appointment calendar:** Track all appointments on a paper or electronic calendar.

You may want to keep another notebook, folder, or file with the records needed to apply for medical and family benefits. This file could help when you apply for financial aid, a job, or additional medical care. This file could include Social Security cards, military records, insurance cards, power of attorney, living will, driver's license, birth certificate, marriage certificate, school and work records, tax returns, and assets.

If your family member with TBI can no longer handle paying the bills, consider changing the contact name on financial accounts to your name or the name of a person who has power of attorney. When accounts are in joint names or in the name of the person with TBI, it may not be easy to change names on financial accounts. You may need to obtain legal advice. A social worker can provide guidance on these matters.



## Becoming an Advocate

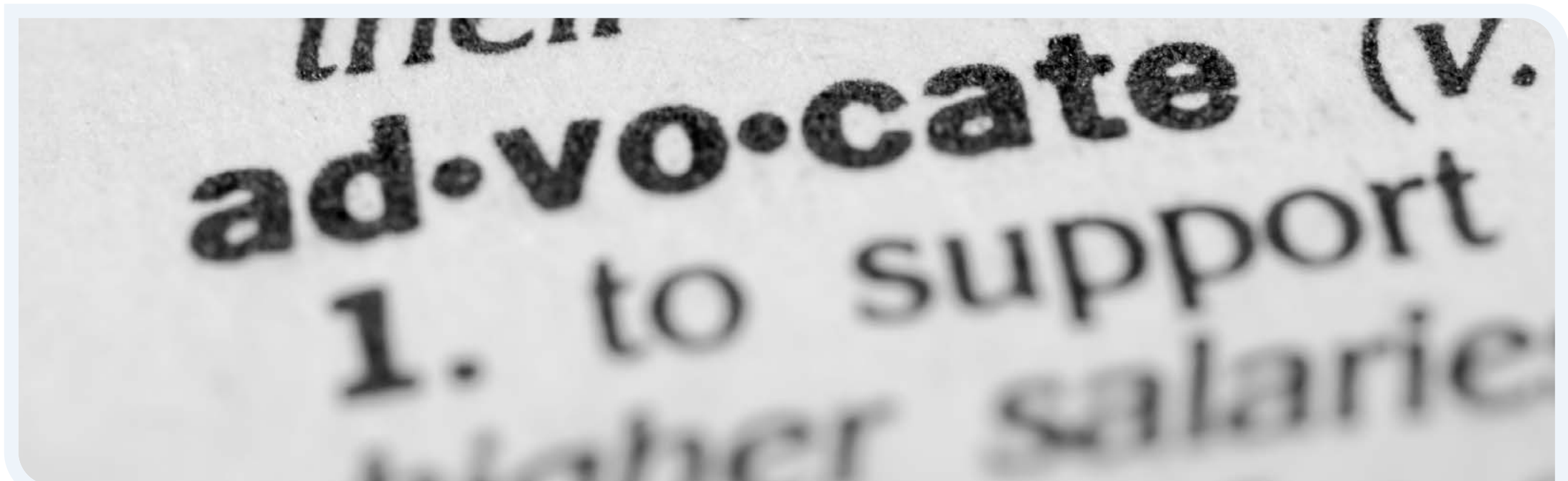
As a caregiver, you may find yourself in situations where you need to advocate for your service member or veteran with TBI or for yourself. But you may be saying to yourself: *“Who me? Advocate? I’ve always been the quiet type. I’m not comfortable demanding anything from anybody,”* or *“I don’t have the education or authority to talk back to those who hold positions of authority,”* or *“I’d rather be dead than have to speak in public.”*

You are an advocate when you speak out on behalf of someone or something that you believe in. Advocacy involves basic communication skills, such as listening to what other people have to say and talking about what is important to you. Advocacy is a form of problem solving, something you probably already do every day

in your own life. You can learn to build on the problem-solving skills that you already have. Advocacy is all about knowing what you want in a situation, getting the facts, planning your strategy, being firm and persistent, and maintaining your credibility.

You may need to use one, two, or all three of the following types of advocacy:

- **Self-advocacy:** understanding and effectively communicating your own needs to others
- **Individual advocacy:** speaking on behalf of your service member or veteran with TBI
- **Systems advocacy:** attempting to change government, organization, or agency policy, rules, or regulations



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## How Can I Speak Up When Needed?

Speaking up can be difficult for some people. Here are some important points for you to remember:

- **It is important to speak up.** No one knows your own needs and those of your service member or veteran better than you do. Don't hesitate to tell your case manager, point of contact (POC), or recovery coordinator about the unique circumstances that you are experiencing. Ask questions to make sure you understand what they are telling you. Let people know what you and your family member need to succeed.
- **Remember that this process is complex.** Don't feel as if there's something wrong with you if you don't "get it" the first time. Take time to learn about each new benefit, eligibility qualification, and application procedure. Persevere. Over time, the DOD and VA systems will become increasingly clear to you.
- **Always keep in mind that you are not alone.** Help is available. The military family that has nurtured your family member in the past will continue to provide care and support in the future. Keep hope in your heart about the recovery process, and know that excellent care and support will continue to be available.

## How Do I Advocate to the Health Care Team?

Remember, you are a member of the health care team. You know your family member best. You know when something has changed in their behavior or with their symptoms better than anyone else in the room. You are the medical team's eyes and ears when you are at home or outside of scheduled appointments. Do not hesitate to voice your concerns or speak up about the changes you have seen.

Try to learn as much as you can from the health care team about TBI and the treatment plan for your service member or veteran. Also, try to learn about the DOD and VA medical systems and how to use these services. Understanding these facts will help you communicate better.

Here are some tips when advocating with the health care team:

- If you have problems or concerns with the care your service member or veteran is receiving, identify what you think is needed and be specific. If you feel a further discussion is needed, speak to the healthcare team about the process of getting a second opinion.
- Talk about your service member or veteran's needs directly to the health care team members. Early morning is when doctors make their rounds, visiting patients. This may be the best time to talk to them.
- Be clear, persistent, and firm, but in a cooperative manner. If you don't get a response right away, keep asking.



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- If this approach does not seem to work, contact the ombudsman or patient advocate at your service member or veteran’s health care facility.
- Come prepared with a list of questions when attending care conferences. Take notes during meetings, or ask a friend or another family member to do this for you.
- Do not tell someone how to do their job. It seldom works. Instead, talk to the person as a concerned family member, and explain your worries calmly.

- Remember, the health care providers are in charge of your loved one’s care. You will be talking with them on a regular basis.
- Work with the health care providers. Remember, they are well intentioned. They might not know the exact needs of your loved one yet. You can help to inform them.
- Help the health care provider get to know your family member. Tell them about his or her stories and personality traits. Once they get to know your loved one, they may be more alert to their needs and listen to your concerns with better understanding.



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## How Do I Advocate to Employers and Others?

If your service member or veteran will be participating in workplace activities, you may need to advocate on behalf of him or her to ensure employment or access to public transportation or commercial businesses. There are often simple accommodations that can be made to help your veteran more easily navigate the workplace. You can ask one of the health care team members to write a letter for necessary accommodations or help coach your veteran to present their needs to their employer.

The Americans with Disabilities Act (ADA) requires that employers, public transportation, and commercial businesses do not discriminate against people with disabilities. It requires reasonable changes are made so that the person can work, ride on public transportation or use commercial places. If you think your service member or veteran with TBI is being discriminated against, speak up. Learn your family member's rights under the ADA and how to advocate on his or her behalf.

## How Can I Advocate to the Broader Community?

Those who have not lived your experiences may not understand what it's like to care for a loved one with TBI. You are in a unique position to educate others and raise public awareness of the impact of TBI on individuals and families through advocacy.

When you are ready, you may find it helpful to work with support groups, your local Brain Injury Association chapter or other similar organizations to find ways to share your story in the community and raise awareness of TBI. This experience may bring meaning and greater purpose to your journey. Working with others will also bring you into contact with other people who have also walked in your shoes. This may be a comforting experience.

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## What Are the Basics of Speaking Up for My Family Member?

Try using the following tips when speaking on behalf of your service member or veteran with TBI:

- **Identify yourself:** State your name and identify yourself as a caregiver.
- **Be specific:** Clearly describe the issue and state your goals. If you are advocating on behalf of proposed legislation, include the name and number of the relevant bill.
- **Make it personal:** Use personal examples and speak in your own words. The best thing you can do as an advocate is to give the issue your individual voice.
- **Be confident:** Offer yourself as a source of information. You may know more about the issue than the person to whom you are advocating.
- **Be polite:** Always work on the basis that your opponents are open to reason and discussion. If you are rude, your message will not be received.
- **Be brief:** Keep it to one issue. Limit written documents to one page. Communication that focuses strongly on one argument is the most effective.
- **Be timely:** Make it immediately relevant. Your message is more likely to be considered.
- **Be factual:** Use facts and statistics. Make sure the information you provide is accurate.





## Taking Care of Yourself

### Whose Care Comes First?

Caregiving requires you to take on new roles. You will need to learn new skills to help your family member with TBI. Keep in mind, all these new demands happen at the same time that you and your family are coming to terms with the impact of TBI on your loved one. You want to give the best possible care and support for your family member's recovery. You may find yourself spending all your time and energy dealing with your family member's needs. This may leave you feeling drained.

You may be tempted to put your own needs on hold. It's not wise to do this. While your focus is often on the care of your loved one, you must remember that your well-being is important too. You can only offer the best care to your family member when you are taking care of yourself.

### How Do I Learn to Accept the Changes in My Family Member?

You may experience many feelings as you learn about the changes that have occurred in your family member. In the first couple of months, for example, you may be feeling happy that your service member or veteran is alive and hopeful that they will recover fully and quickly. As time goes by, progress may slow and you may feel anxious and scared. Sometimes, you may think that a full recovery might happen faster, if only they would work harder at it. At other times, you may feel great joy when goals are reached, even if they seem small at the time.

As recovery progresses, you may find yourself feeling discouraged and depressed or even guilty. If the recovery process slows down, feelings of depression may progress into despair and a sense of being trapped. If your service member or veteran has sustained a severe TBI and recovery is difficult, you may find yourself experiencing a period of grief and deep mourning. Eventually—and this timeline looks different for everyone—you may get to the point of acceptance of your new “normal.” You may even find comfort and meaning in your new role.

Although you may not go through these feelings exactly, knowing what many caregivers and family members go through, as they adjust to life after TBI, can help you feel validated.

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## What Is Compassion Fatigue and Caregiver Burnout?

You want to give the best possible care and support to your family member's recovery. You may find yourself spending all your time and energy dealing with your family member's needs and may be tempted to put your own needs on hold. Although your reactions are normal, there can be harmful effects if you focus all your attention on your service member or veteran. You may experience compassion fatigue, also called the "cost for caring." It refers to physical and mental exhaustion and emotional withdrawal that is sometimes experienced by those who care for individuals in distress. You may also experience caregiver burnout, or a feeling of hopeless about your situation. Some of the signs that you may be experiencing caregiver burnout include feeling listless, isolated, or bottled up, use of alcohol or drugs to cope, maintaining poor hygiene, and having emotional outbursts.

It is important to recognize the early warning signs of compassion fatigue and caregiver burnout so that you can increase time and activities to take care of yourself while continuing to care for your loved one. Some of the signs of caregiver burnout are listed in Table B on the following page.

If you do find yourself suffering from compassion fatigue or caregiver burnout, find a friend or family member to talk to about your feelings or join a support group with other families affected by TBI. Talking with someone can relieve stress and reduce anxiety because you will learn you are not alone. If stress, sadness, or anxiety begins to feel out of control, seek professional help from a mental health provider or religious-spiritual leader. You can also consider respite care options to allow time for you to rest and recoup.

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**Table B - Warning Signs of Caregiver Burnout**

Physical	Emotional
<ul style="list-style-type: none"> <li>▪ Changes in appetite or sleep habits</li> <li>▪ Constantly feeling tired and drained</li> <li>▪ Frequent headaches and stomach or muscle pain</li> <li>▪ Lowered immunity, increased illness</li> <li>▪ Reduced efficiency and energy</li> </ul>	<ul style="list-style-type: none"> <li>▪ Decreased satisfaction and sense of accomplishment</li> <li>▪ Feeling detached</li> <li>▪ Feeling down or depressed and defeated</li> <li>▪ Hypersensitivity to emotional TV ads or shows</li> <li>▪ Increased irritability, anger, or anxiety</li> <li>▪ Increasingly cynical and negative outlook</li> <li>▪ Reduced empathy</li> <li>▪ Sense of failure and self-doubt</li> </ul>
Behavioral	Work Related
<ul style="list-style-type: none"> <li>▪ Isolating oneself from others</li> <li>▪ Procrastinating, taking longer to get things done</li> <li>▪ Strained relationships</li> <li>▪ Taking out frustrations on others</li> <li>▪ Using food, drugs, or alcohol to cope</li> <li>▪ Withdrawing from responsibilities</li> </ul>	<ul style="list-style-type: none"> <li>▪ Decreased motivation</li> <li>▪ Feeling like one has little or no control over one's work</li> <li>▪ Inability to recognize achievements at work</li> <li>▪ Increased absenteeism</li> <li>▪ Increased errors</li> <li>▪ Working too much, without enough time for socializing or relaxing</li> </ul>



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## What Are Strategies for Self-care?

It is important to take care of yourself so that you can then take care of your family member. Self-care is anything you do deliberately to take care of your physical, psychological, emotional, spiritual, personal, and professional health; something that refuels you. Everyone is different, so find what helps you.

Try some of these self-care strategies:

- **Maintain adequate sleep:** It is hard to sleep when you are worried about your family member's medical condition, unpaid bills, or legal issues. If you don't get enough sleep, you are likely to be tired and irritable during the day. You also may find it hard to concentrate. Studies show that people who do not get enough sleep are less productive, tend to overeat, and are even more likely to get in accidents. Try these tips for getting a comfortable night's sleep:
  - Establish a routine for when you go to bed and when you get up every day. This can reinforce your body's sleep-wake cycle.
  - Establish a relaxing bedtime routine. Take a bath, read a book, or find another activity that helps you shift from your busy daytime life to restful sleep.
  - Only go to bed when you're tired. If you can't fall asleep, get up and do something else until you're tired.
- Do not rely on sleeping pills. Check with your doctor before taking any sleep medications, as they can interact with other medications or a medical condition. You may have an underlying sleep disorder that requires treatment.
- Don't exercise close to bedtime. It may make it harder to fall asleep.
- Avoid too much alcohol and caffeine. Too much of either usually reduces the quality of sleep.
- Have someone stay over. They can take over the care duties during the night.
- **Eat a balanced diet:** A balanced diet is one that is low in fat, high in fiber from whole grains, fruits, and vegetables, and includes lean cuts of meat, poultry, eggs and other protein sources. It can be tempting to overeat. Do not use food as a comfort when you are stressed and sad. You may gain unwanted weight. Try to find other ways to comfort yourself, such as a hot bath or a good book.

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- **Exercise:** Exercise can relieve stress, reduce depression, make you feel better about yourself, help you maintain your weight, and give you some time alone. It doesn't have to be strenuous. A 30-minute walk on most days is usually enough to protect your health. You can break the 30 minutes into shorter 10-minute segments, if that's all the time you have. If you already have an exercise routine in place, try to stick with it. Doing things that were important to you before the TBI can help you cope and be a better caregiver.
- **Engage in relaxation:** It is important that you take breaks to relax. You can try meditation, practicing mindfulness, or listening to calming music. Finding a quiet place to read a book or write in a journal can also provide a moment of calm in your day. Try to create rest for both your body and mind.
- **Maintain and cultivate supportive relationships:** Focus on positive relationships in your life. Make an effort to stay in touch with people who have provided support throughout your journey. Take time to go out for lunch or dinner with family, friends or co-workers. Join a support group to connect with others in a situation similar to your own.
- **Minimize use of alcohol and other drugs:** When life is stressful, you may find it difficult to solve problems, make decisions, and take care of yourself. Some people turn to alcohol or other drugs to help them relax. Alcohol and drugs tend to make problems worse and can be dangerous. You can become dependent on these substances, and this will interfere with your responsibilities to your family. If you drink, do so in moderation (i.e., one drink per day for women, two drinks per day for men). Find other ways to relieve stress and to reward yourself for doing a hard job well.
- **Routine medical care:** Remember, you can't take care of someone else well unless you are strong and healthy. This includes getting routine medical and dental care, such as preventive screenings (e.g., mammograms, blood pressure checks) and regular attention to medical problems that you may have. Contact a mental health provider for yourself if you notice your mental health suffering. Both counseling and medications can effectively treat symptoms of anxiety or depression. It's okay to have your family member with TBI sit in the waiting room while you see the doctor, dentist, or other provider if they are able; otherwise, make plan for their care during your appointment.

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Your journey as a caregiver may be challenging on many levels. Along the way, you may learn that you care about your service member or veteran with TBI beyond what you realized, and your reserves of strength may surprise you—even when you’re tired and lonely. Take pride in your ability to care for another human being. Think about the ways you have changed and grown through your caregiving experience. Finding meaning in your caregiving journey will increase your sense of self and allow you to use your personal experience to give meaning to others.

Some caregivers find strength in religion or spirituality in the face of the challenges of taking care of a family member with TBI. You may find comfort in your religion or in the peace and beauty of nature. Nourish this part of your life, if it is important to you, because it may renew your spirit. Your caregiving experience may change your life and your sense of self.

Consider keeping a journal during your caregiving journey. Creating a journal will help you explore your own thoughts and feelings about what’s going on in your life. You may find that you will want to look back on this period in your life at some point in the future. Your journal will be an important guidepost to what you were thinking and feeling. It may also help you see the changes that happened so slowly that you didn’t notice them when they happened. Some find it easiest to do this using social media so that friends and family can be continually updated.





## Helping Your Children Cope With TBI

Having a parent with TBI can be frightening for a child who looks to their parent to provide strength and safety. The parent with TBI may no longer act the same as they did before the injury. Your family member—parent with TBI may be angry, depressed, or uncertain. As a result, the special parent-child bond that existed previously has changed.

Children may be confused and upset about what is going on. This could be due to worry about a parent's condition or concerns about changes in their parents' relationship. It could also be due to financial strains or simply adjusting to the new “normal.”



It is important to recognize that your children are grieving, just as you are. They may withdraw from social activities with peers, have mood swings, become withdrawn or disruptive, do poorly in school, and show other behavioral problems. Children also need time and space to be kids. Communicate with your child that they are not to blame for the TBI.

Some children may need to take on some caregiving tasks for the parent or for younger children in the family. Children who care for parents or other relatives experience considerable conflict over the reversal of roles between parent and child. Make sure any tasks that your child takes on—household chores, for example—are suitable for their age. Strive as much as possible to find other adults to help you, rather than relying on your children to play a major caregiving role. Remind your children that you are the caregiver and that they can rely on you to be a parent.

Build new family routines, and keep an eye out for signs that your child is not coping well. If your child appears to be depressed for a long time or begins taking on risky behaviors, seek professional help.

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It is difficult to explain TBI to a child, yet it is vital to tell your child what is going on. Some adults try to protect children from the truth because they think they are too young to understand. Children of almost any age are aware that something is wrong, and they want to know what is happening. Communicate in an age-appropriate way what has happened to your family member with TBI. Protecting your children by withholding information may backfire. Children have active imaginations that may create a scenario worse than reality.

**What Are Specific Ways to Explain TBI to a Child?**

Here are some ways you can try explaining TBI to your child:

- The brain is similar to the command station of a space ship. If a meteorite hit the command station, the crew would not be able to control what the space ship does. If the brain is hurt, it may send out the wrong signals to the body or no signals at all. A person with TBI may have a hard time walking, talking, hearing, or seeing.
- The brain is the computer for the body. When injured, it doesn't boot up properly, runs slower, has less memory, etc.

- A broken bone will usually heal and be as good as new. A brain injury may not heal completely. Even though the person with the injury may look the same, they may still be injured. These injuries might include having a hard time paying attention or remembering what you told them. They may get tired easily and need to sleep. They may say or do things that seem strange or embarrassing. They may get angry and shout a lot.
- Many people develop anger as a direct effect of the damage to the brain. In other words, the parts of the brain that normally stop angry flare-ups and feelings have been damaged and do not do their jobs as well. The parent with TBI may be mad because they can't do the things they used to do. Their feelings may be hurt because others treat them differently than before the injury.
- A cut may take a few days to heal, a broken bone a few weeks. Getting better after a brain injury can take months or even years. Sometimes, the person will not get 100 percent better.
- A brain injury changes people. These changes can be confusing. Try to remember that the changes you see are caused by the brain injury. You can still love and care about the person.

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What Other Ways May TBI Affect My Family?

What Can I Do If Caregiving is Just Too Much?

<b>Table C - How Can I Communicate with My Child about TBI?</b>	
<b>Age and Stage of Development</b>	<b>Communication Techniques for Parents</b>
<p><b>Age 2-3</b> Can differentiate expressions of anger, sorrow, and joy</p>	<ul style="list-style-type: none"> <li>■ Communicate using simple words.</li> <li>■ Use picture books.</li> <li>■ Create simple books with pictures of family members and simple objects that the child understands (hospital, doctor, bed, rest).</li> <li>■ Offer dolls to play with so they can recreate what is happening at home or at the doctor's office.</li> </ul>
<p><b>Age 4-5</b> More self-secure, can play well with others, tests the rules, 'magical thinking'</p>	<ul style="list-style-type: none"> <li>■ Select books with stories that mirror families like yours to help your child relate.</li> <li>■ Familiarize your child with pictures of objects and concepts related to medical care and health (hospital, gown, doctors, flowers, bed, coming home from the hospital).</li> <li>■ Incorporate play with a child's 'doctor kit' to familiarize your child and symbolize what is happening.</li> </ul>
<p><b>Age 6-7</b> Capable of following rules, enjoys having responsibility, uncertain of the relationship between cause and effect, parent is the primary source of self-esteem</p>	<ul style="list-style-type: none"> <li>■ Use interactive communication—reading books and creating stories with your child.</li> <li>■ Help your child create his/her own "this is our family" album and talk about the photographs and memorabilia.</li> <li>■ Watch movies with story lines similar to what your family is experiencing.</li> </ul>
<p><b>Age 8-11</b> Has a better understanding of logic and cause/effect, less centered on self, able to understand others' feelings, can empathize</p>	<ul style="list-style-type: none"> <li>■ Listen to your child's thoughts and opinions.</li> <li>■ Ask questions that go beyond yes and no.</li> <li>■ Depending on your child's level of development and understanding, speak with direct, reality-based explanations that include facts.</li> <li>■ Include the sequence of events involved and what to expect.</li> </ul>
<p><b>Age 12-17</b> Experience puberty and physiological changes, seek freedom and independence, acceptance by peers is extremely important, develop more intimate relationships, more thoughtful and caring</p>	<ul style="list-style-type: none"> <li>■ Speak honestly and realistically.</li> <li>■ Give facts, what is expected to happen including the diagnosis, prognosis, treatments, and expected outcomes.</li> <li>■ Talk with your children, not to them.</li> <li>■ Check in and offer time to discuss concerns frequently.</li> <li>■ Listen attentively.</li> <li>■ Ask questions that can be answered with more than 'yes' or 'no.'</li> <li>■ Stay alert for risky behaviors, acting out, or noticeably withdrawn (if this is a new behavior).</li> <li>■ If risky behaviors are present, seek professional help.</li> </ul>



**Helping Your  
Children Cope  
with TBI**[How Can I Tell My  
Child about TBI?](#)[What Are Specific  
Ways to Explain  
TBI to a Child?](#)[How Can I  
Communicate  
with My Child  
about TBI?](#)[What Are Some  
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Children Cope?](#)[How Can I Build  
Stronger Family  
Ties?](#)[How Can I Build  
on My Family's  
Strengths?](#)[How Can I Preserve  
My Marriage or  
Relationship?](#)[What Other Ways  
May TBI Affect My  
Family?](#)[What Can I Do If  
Caregiving is Just  
Too Much?](#)**What Are Some Tips for Helping Children Cope?**

Here are some tips you can use to help your child cope:

- Provide information to your children about what to expect before they are reunited with their parent with TBI. For example describe how their parent will look, behave, and react before they come home.
- Be flexible. Take your cue from your child about when they want to resume their normal routine. Encourage children to stay involved with friends and school activities.
- If your children choose to attend their activities, ask friends or relatives to take them. Ask friends to take over caregiving when you need to go to watch your son or daughter play basketball or appear in the school play.
- Encourage your children to talk about their fears, hopes, and worries. Allow safe and appropriate ways for your children to express their emotions.
- Meet with your children's teachers to explain what has happened and the effects on the family. The more the teachers are informed, the better they can support your children.
- Encourage other family members, friends, or other important adults in your child's life to share time with your child and to act as a sounding board, if needed.
- Your children may say upsetting things to you. Just listening can be the best support for them.
- Reestablish routine for your children. Consistent dinner and bed times may help. Encourage your children to talk about what familiar characteristics and behaviors of their parent they are starting to see.
- Be easy on yourself and your children. A certain amount of stress is normal.
- Be careful not to set a timeframe with your children for when recovery will occur. Children want it all to happen quickly, and it is hard to predict recovery after a TBI.
- Stay alert for changes in their behavior. Get counseling for your child to help him or her cope with grief, especially if the child appears depressed or is adopting risky behaviors.
- Recognize that some children may pull away for a while. Others may regress to younger behavior, becoming very dependent, demanding constant attention, or exploding in temper tantrums. These behaviors should return to normal over time as the child adjusts.
- Teenagers may be embarrassed about their parent with TBI. Rehearse with them how to respond to comments or questions about how their parent looks, behaves, or speaks.

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How Can I Build on My Family's Strengths?

How Can I Preserve My Marriage or Relationship?

What Other Ways May TBI Affect My Family?

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**How Can I Build Stronger Family Ties?**

It is important to have a strong family unit to best help your service member or veteran recover from TBI. Set aside some fun time each week for your family to spend together and move the focus away from TBI. Try these ideas with your family:

- Have a family meeting. Explain that you plan to set aside weekly family time together and ask if they have any ideas for when it should be and what you should do. You can take turns choosing activities.
- Turn off video, cell phone, e-mail, etc. during family time. Your goal is to enjoy and interact with each other.
- Try activities that everyone can enjoy. This might include playing board games, taking a walk or run, or baking cookies. Find activities where everyone can play a role.
- In addition to family time, schedule some individual time with each family member. Children need to have time alone with their parents. This helps them feel heard and appreciated. Plan an activity with each child—a shopping trip, movies, story time—and schedule it on a regular basis.
- To build closer family ties, encourage the children to play simple games with their injured parent. Such games may also help the injured parent practice skills to assist in recovery.



- Think about your family rituals and keep them on the schedule. If you plan elaborate holiday decorations, you may need to cut back this year, but you can still celebrate more simply.

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## How Can I Build on My Family's Strengths?

You can learn to cope with the stress of TBI by finding and building on your family's strengths. No family is perfect. As you read this section, think about your family's strengths. Then think about areas that you would like to be stronger. Discuss these with family members and choose one area that you can work on together.

Family strengths include the following:

- **Caring and Appreciation:** Looking for ways to express gratitude to your family members can make each member feel important.
- **Commitment:** One way to build commitment is to create and maintain family traditions.
- **Communication:** It's important to keep lines of communication open. Active listening is important. When the other person is telling you how they feel, try restating what they just said to see if you understand their position correctly. Also try using "I" statements to share your feelings, rather than "You" statements. For example, if you're upset because your brother didn't show up to drive you to the hospital on time, you might say: "I feel upset when you are late to pick me up. I am anxious to get to this important medical appointment on time so that I have the doctor's full attention" instead of, "You are always late." The former states your feelings; no one can argue about your own feelings. The latter attacks the other person, making him or her feel defensive and more inclined to argue with you.

- **Community and Family Ties:** Keeping close ties with relatives, neighbors, and the larger community can provide useful sources of strength and help in trying times.
- **Flexibility and Openness to Change:** A TBI in the family means that everyone's roles and responsibilities will shift. Learning to manage change can be a challenge, but it can be done.
- **Working Together:** Sharing tasks and decision making will help your home run smoothly. When important decisions need to be made, all family members should share their points of view.



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## How Can I Preserve My Marriage or Relationship?

TBI can affect the dating or marital relationships, just as it affects other areas of family life. In particular, the intimacy once enjoyed with a partner may become compromised. Intimacy is the ability to engage in, and derive pleasure from, emotional closeness and sexual activities. Sexual activities are often enhanced by the closeness of emotional intimacy.



After a TBI, couples may find it difficult to reconnect. Differences in partners' needs and desires for intimacy can lead to frustration, rejection, conflict, or withdrawal. Some may experience low sexual desire due to not feeling emotionally close to their injured partner, or by feeling angry or burdened by caregiver responsibilities. Partners with reduced sexual interest who engage just to "keep peace" may communicate that sex is simply a chore. Despite the reality that some injuries make it difficult or impossible to engage in the same level of sexual activity as before the injury, a satisfying sex life may still be possible. Communication, compassion, and creativity in finding new ways of expressing emotional and sexual needs can help couples rebuild loving and respectful relationships. These new relationships may end up being as close as, or even closer than, the ones prior to the TBI. Couples who reestablish a satisfying, intimate relationship do so by:

- **Finding ways to be close that don't involve sex:** Do thoughtful things for each other, such as leaving an affectionate note or caring for the children so your partner can have some private relaxation time. Small expressions of affection, such as a hug, kiss or touch on the shoulder, can go a long way.

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- **Spending time together doing things you both enjoy:** Plan a date night, participate in a sport or take a class together. Learning new things together can bring you closer.
- **Talking about feelings, hopes, and desires when both partners are calm and ready to listen:** Communicating, even about difficult topics, can help you feel more connected. In addition, understanding each other's perspective can help you work together to identify solutions.
- **Respecting your partner's need to have some alone time and space:** Being supportive and recognizing each other's efforts toward building your relationship is important. This may in turn encourage emotional and sexual intimacy.
- **Redefining the goal of sexual activity:** The new goal can be mutual pleasure and expression of love rather than erection and orgasm.
- **Experimenting and communicating about what is pleasurable:** Create space in your relationship to discuss pleasure possibilities. It is important to communicate changes in emotional and sexual needs and about changes in the sources of arousal. Doing so will enhance mutual understanding and foster relationship resiliency. Also try developing greater variation in sexual activities and be willing to explore together without judgment.

- **Scheduling intimate opportunities:** Depending upon energy level and emotional availability, try to schedule intimate opportunities for times when both of you are more likely to be available and ready to participate.

Pain can also interfere with the enjoyment of physical affection and intimacy. Both the injured and their partner may hold back because they are fearful of causing pain. Medications used to manage pain can affect sexual desire and sexual performance. Discuss such issues with your medical provider who may consider adjusting the medications to decrease sexual side effects. Be sure to have a discussion with your partner when the pain has decreased, or is at an acceptable level, about when intimacy and sexual activities can resume.

## What Other Ways May TBI Affect My Family?

Family members may disagree about the best plan for your injured love one, such as who is the best person to provide the caregiving or where care should be provided. If you are experiencing this kind of family conflict, try to keep in mind that everyone involved in this type of conflict loves the family member with TBI, and wants the best for them. Try to talk openly about each person's point of view. Speak to the health care team about providing education and training to all interested family members so that multiple people can help with caregiving duties.

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**What Can I Do If Caregiving Is Just Too Much?**

It is helpful to know yourself and your limits. Asking others for help is not a sign of weakness. Research shows that it is best when caregivers have a support network of family and friends who can provide relief and share in duties. Speak to the health care team about providing education and training to all interested friends and family members so that multiple people can help with caregiving duties.

When hospitalized, the goal of the health care team is to safely discharge your service member or veteran to home. In some instances, those with severe injuries and medical complications may require extensive, round-the-clock care that could be too much to handle in the home. The health care team will provide you with individualized training and support available in the system of care, but in some situations, it can be helpful to have a backup plan if necessary. Your backup plan may include finding temporary or more permanent residential care for your family member with TBI. Remember that these options are not permanent but are meant to provide the best recovery environment for your loved one. Your choices may include

- *Seeking assisted living facilities and board and care homes.* This option is best for those who have difficulty living alone but do not need daily nursing care.
- *Considering nursing homes, also called skilled nursing facilities—for individuals who need 24-hour nursing care and help with daily activities.* Skilled nursing care can also be provided at home by nurses you hire.
- *Learning which VA rehabilitation options are available besides the acute rehabilitation stay.* These programs can include the VA Transition Rehabilitation Programs (PTRP) and other unique programs throughout the VA Polytrauma Rehabilitation System of Care.

Talk with the health care team, specifically the case manager and social worker, to explore DOD, VA, and community services available for in-home care. They can help with placement options that best meet the needs of your service member or veteran.





## Transitioning to Home

The transition to home can be an exciting step, but it also can be stressful. Remember, you don't have to do it all yourself. Plan and prepare before your family member comes home.

If possible, try a practice weekend at home. A practice weekend will alert you to how much help you may need. Before your service member or veteran with TBI goes home from the hospital

- Ask the case manager(s), social worker, VA liaison, or military liaison about resources your family member may qualify for from the federal, state, and local government.
- Your family member with TBI will do the best with structure, consistency, and a schedule. With the help of your health care team, write a master schedule to follow. Try your best to stick to this schedule so you don't have to rely on your memory during this time of transition.
- Ask for a written list of all therapy and exercises (diagrams or pictures of the exercises) to be done at home.
- Ask for help. Seek out the people who offered to help, and ask them to be available.
- Identify services available in your community that you can contact for help.

- Prepare yourself and your home before your family member with TBI arrives. If your family member has physical disabilities, your health care team may be able to do a home safety evaluation. The VA and some charities have programs that will modify your home to accommodate your service member or veteran's needs.
- Make a list of the assistive devices your family member is using in the hospital. Ask the case manager if the same ones will be needed at home. If so, make sure you have prescriptions written for the devices you will need.
- Decide what projects and chores can be put off for a while; give yourself permission not to do it all.
- Know who on the health care team to call for what, and post it in a visible area of your home. You can use the [Contact Information of the Health Care Team](#) form to keep this important information organized.
- Make plans to give yourself a break each day. Have someone come to the house, so you can get out for a breather.

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Home****How Do I Manage  
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to Get Help with  
Caregiving?****How Do I Manage Care at Home?****Managing Medications**

Living with a TBI usually means taking multiple medications to treat the symptoms. It is important to keep track of what medications are being taken and when. Here are tips to manage medications and prevent mistakes:

- Always inform all the members of your health care team of any drug or Latex allergies.
- When you leave the hospital or treatment facility, be sure you get a copy of the discharge instructions. They will include a list of all the medications your service member or veteran will be taking.
- When picking up prescriptions, have the pharmacy provide written information about the current prescriptions.
- When picking up the prescription, make sure the order has your family member's name and includes the correct pills at the right dose.
- Ask the doctor or pharmacist
  - What the medication is for and what it does
  - What to do if you miss a dose
  - When and how to take it (empty or full stomach, daytime or bedtime)
  - What to do if there are side-effects



**Transitioning to Home****How Do I Manage Care at Home?****How Can I Organize to Get Help with Caregiving?**

- Make sure the doctor is aware of all other medications. This includes the supplements and herbal products that your family member takes. There might be side-effects or harmful interactions.
- Keep an up-to-date medication log with all prescription and non-prescription items. Include over-the-counter medications like antacids, pain relievers, supplements, high energy drinks, and herbal products.
- Carry the [medication log](#) with you every time you have a medical appointment. There are many other types of support tools available to help with medication management. Speak to the health care team about providing education and training on the ones that best support your needs.
- Use a pill box to help you organize the medications and ensure your family member takes them on time.
- It is never a good idea to stop medication on your own; always consult a medical provider first to discuss.
- It can also be dangerous to adjust the dosage of medications on your own without consulting the physician.
- If you are having financial difficulties that make it hard to pay for medications, contact your case manager.
- Your family member with TBI should NEVER take any medication without talking to the health care provider first.
- List side-effects of medications (date and time) in the medication log. Ask the doctor which side-effects are serious and call immediately if they occur.

- Request a printed or email copy of test results (such as blood pressure, blood sugar, or medication blood levels). If you are checking your family member's blood pressure or blood sugars at home, write down the values. Be sure to take these results to appointments with any health care providers.

**Assistive Devices and Home Modifications**

For people with TBI, it can be a challenge to accomplish daily tasks, such as talking with friends, going to school and work, or participating in recreational activities. Assistive devices can make it easier for a person with a disability to manage these activities. They are tools to help your service member or veteran live more independently. Your home may need to be altered to make it more safe and livable for your loved one. Home modifications may be relatively minor, such as installing handrails, ramps, or shower seats. Others may require more major remodeling, like installing elevators, enlarging doorways, or modifying kitchens. Don't rush into major modifications because your service member or veteran's needs may change over time. Before discharged to home, ask the health care team which assistive devices or home modifications may be needed. The health care team can also connect you to the appropriate supports and benefits to ensure your loved one has independence and that your home is ready and safe, prior to leaving the hospital. Depending on your service member or veteran's VA benefits, home or vehicle modifications may be covered by the VA.



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**How Can I Organize to Get Help With Caregiving?**

Here are some steps to consider in organizing your home life:

- Don't feel like you need to do everything! It is important to accept help because it's not likely that you can do it all by yourself. Identify a home-care team to help you. This includes friends, family, and the members of the community who will help you do all that needs to be done at home to care for your family member with TBI.
- If you do not have time, ask a friend or adult family member to read this section and assume the role of coordinating the home-care team. Even if it is short-term help, this can relieve some of your immediate needs. You can work together to get the outside help you need. If possible, ask your family member with TBI which people they would like involved.
- Outline your tasks. Not just the tasks to take care of your service member or veteran with TBI, but tasks that lighten the load for you and other members of the family.
- Your new "normal" day will now consist of your usual everyday tasks, plus the care and treatment for your family member with TBI. These care and treatment tasks may take up much of your time. Your home-care team may be able to help you with many everyday tasks, and possibly some of your family member's care. If you ask your children for help, be sure the chores you give them are age-appropriate.

Here are some tips to use when asking others for help:

- Some people find it really tough to ask for support. If that's you, put yourself in the shoes of another family who needs assistance. You would most likely be willing to help them if the tables were turned. So, tough as it may be, let them assist you. If you're too stressed to even think about organizing others to help, ask a friend to take on this role.
- Make a list of everyone close to you and your service member or veteran who can be part of your caregiving team. Also, write down the names of those who have already offered to help.
- Once you have your list of names, create an email group so you can easily contact everyone.
- As you schedule others to help, jot down their names and the tasks they will do. Do not rely on your memory.
- Ask for specific help. For example, ask someone to go grocery shopping or come over to spend time with your service member or veteran while you go out to do something for yourself.

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**Coordinating Your Home-care Team**

Consider holding a meeting for all home-care team members to discuss specifics, such as

- Current needs of your service member or veteran with TBI and the rest of your family
- The roles or tasks each team member can take. Ask for the members' availability and tasks they are willing to do (write these down). Manage home-care team schedules on a master calendar.
- Exchange of contact information
- Identify a team leader to make phone calls to team members during emergencies or to reorganize schedules.
- Invite potential home-care team members to the hospital or rehabilitation center to learn more about TBI and your family member's specific needs.
- Have some cash available for helpers in case of emergencies, an extra set of house keys, and a spare set of car keys.
- Have an easily visible list of important information:
  - Location of preferred pharmacies
  - Preferred grocery stores
  - Medical information
  - List of phone numbers of people to contact in an emergency

**Time Management**

There may be more to do than you have time and energy to complete. Decide which tasks need to be done right away and which can wait until later. Prioritizing allows you to focus on what absolutely needs to be done and allows you to delegate non-urgent tasks to your home-care team members.

**Respite and Home Health Care**

The demands of being a caregiver may cause many challenges. Respite care, planned or emergency care to a child or adult with special needs that provides temporary relief to a family caregiver, can help both the caregiver and service member or veteran with a TBI. Respite care offers a break and allows you time for yourself.

Respite may be provided inside the home, with a companion, or outside of the home in an adult day care, assisted living, or nursing facility. It can range from a few hours per day or week to short-term placements. Home health care is assistance provided for your family member with TBI from a qualified aide, nurse, or therapist in your home. The case manager or social worker can help you through this process by considering your individualized needs.



## Moving Forward

Each person's experience with the effects of TBI is unique. Most effects improve with time, although some may linger for a lifetime. As you are now aware, brain injury presents many challenges for survivors and their families. For some, recovery will extend over a lifetime. There is no "normal" time frame for recovery. However, many family members with severe injury surprise doctors with an unexpected degree of improvement.

Many factors, such as any co-occurring behavioral health issues, determine the extent of recovery. Generally, the more severe the damage to the brain there is, the greater the likelihood of long-term challenges. However, with the passage of time, a dose of patience, and a strong support system, most individuals will go on to live productive and fulfilling lives. Returning to the community, to family, and to school or work following a TBI can be challenging, but it is possible. Addressing any of your loved one's mental health needs is critical to achieving successful reintegration and independent living.

For most of us, a "normal" and fulfilling life can include living independently, spending time alone, working, attending school, volunteering, driving, doing household chores, parenting, dating, and participating in social and leisure activities of our choosing. For a person who has recently experienced a TBI, some or all of this may not be possible right away. The hope is always there that much will become achievable, over time.

Moving back home is an exciting step in the recovery process! Although the transition to home is certainly positive, it is important to be aware that it may also be stressful at times. With time, most people with TBI and their families successfully adjust to life at home.

Some families report that, during the first few days or weeks at home, their loved one with TBI actually seemed to have taken a step or two backwards. Your family member needs more time than they used to in order to adapt to a new environment, even if it's a familiar one. Returning to the community, to family, and to a familiar setting requires thoughtful planning to ensure that the transition goes smoothly. It is important that you work closely with the rehabilitation team to prepare a discharge plan.

Skills that your service member or veteran acquired or relearned in rehabilitation will not easily transfer into a home setting without a great deal of support and reinforcement. The therapy team will spend weeks to months preparing you and your family member for this step. You will both have many opportunities to practice and to identify what the challenges might be before your loved one goes home.

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**How Can I Protect the Safety of My Service Member or Veteran with TBI?**

**Can My Family Member with TBI Drive?**

**How Can My Family Member Avoid Another TBI?**

Remember that those with TBI prefer structure. They adjust better and thrive when there is some routine and predictability to their days. It is helpful to add structure right away at home by scheduling activities and rest breaks, much like the schedule observed in rehabilitation. Over time, as everyone adjusts to being home and your service member or veteran continues to recover and gain skills, the need for so much structure may lessen, with more flexibility possible.

Your family member may be concerned that they cannot easily make comfortable relationships with other people because of the cognitive and communication effects of TBI. You may be worried they will behave inappropriately or unsafely because of reduced judgment or impulsiveness. Role-play potential social situations with your family member with TBI before they venture into community settings. This helps with understanding appropriate behavior. Recreational and occupational therapists are your best allies in this effort, and they will work closely with you to practice community reentry.

**How Can I Protect the Safety of My Service Member or Veteran With TBI?**

Your physical therapist (PT) and occupational therapist (OT) will work with you to decide if you need to make safety modifications to your home. Be sure to remove or secure items that could result in harm to your family member with TBI. For example, keep car keys in a safe place if your family member is not cleared to drive. If possible, remove guns, knives, or other weapons from the house.

When your service member or veteran with TBI begins expanding their activities beyond the house, it is important that they carry identification at all times. Some may choose to continue wearing dog tags but, other forms of identification should be carried, such as a Medic Alert bracelet or necklace. This will help ensure that all medical information is readily accessible to emergency medical personnel, if it is needed.

Removing clutter and simplifying your home environment can help the person with TBI. Clutter, or too many things in the visual environment, can contribute to a sense of overstimulation. It also raises the likelihood that your family member may trip, especially if they are experiencing balance, vision, or perception problems. Ask the OT or PT to help with fall prevention, if your family member has trouble with dizziness, balance, or vision.

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the Safety of My  
Service Member or  
Veteran with TBI?

Can My Family  
Member with TBI  
Drive?

How Can My Family  
Member Avoid  
Another TBI?

## Can My Family Member With TBI Drive?

Driving is a key mark of independence in our society. Your family member may be eager to get behind the wheel again. A professional should evaluate their ability to drive. This evaluation is usually done by an occupational therapist, physical therapist, neuropsychologist, or a certified driving evaluator. Good vision and good perceptual skills, such as the ability to judge distances between cars, are required to drive safely.



The evaluation will address the following skills as they relate to driving:

- **Physical skills:**

- Ability to physically steer and brake the car and control speed
- Assessment of need for assistive devices for driving
- Ability to get in and out of the car

- **Visual and spatial skills:**

- Assess need for corrective lenses
- Be able to concentrate attention in their central vision
- Good peripheral vision

- **Perceptual skills:**

- Ability to judge distances between cars on the road and space in parking lots
- Ability to integrate complex visual and verbal information, such as following directions to a store
- Recognize shapes and colors of traffic signs
- Awareness of left and right, no drifting to one side of the road

- **Speed of motor responses:**

- Reaction time
- Ability to brake or change lanes safely within a reasonable amount of time
- Ability to process a large amount of information and react quickly

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**• Judgment:**

- Adequate decision-making skills in an emergency
- Possess a healthy self-awareness and an understanding of their strengths and weaknesses

As cognitive skills improve, driving skills may be re-evaluated. Many people with TBI do eventually return to driving and drive safely. Driving skills affected by TBI can be improved through training that focuses on visual scanning, attention skills, and spatial perception.

In some situations, the loss of skills needed to drive safely may prevent the person from driving again. When this occurs, it is important for the doctor or other appropriate professional to ensure that the service member or veteran with TBI and other family members understand the reasons. The family must be diligent about enforcing the “no driving” rule. For example, you may need to keep close control of the family’s car keys.

If your family member cannot drive a motor vehicle safely, there are other transportation options. Public transportation (bus, train, or subway) may be available. Resources for transportation to medical facilities for appointments, or to obtain medications or other needs, may be obtained from a variety of sources. Consider driving assistance from family members, friends, and church or community groups.

**How Can My Family Member Avoid Another TBI?**

Repeated blows to the head result in further damage to the brain. The effects of repeated injuries to a brain that has sustained a previous injury tend to add up, causing greater damage than the initial injury. For this reason, it is best for people with TBI to exercise caution and avoid another TBI, if possible.

You can help your family member with TBI avoid another injury by

- Safeguarding your home
- Insisting on the use of safe practices (e.g., wearing seatbelts in the car)
- Following the recommendations of the health care team on activity restrictions (e.g., no contact sports)





## Addressing Everyday Issues

### What Is the Family and Medical Leave Act?

Thanks to the work of several caregiver advocacy organizations, great strides have been made to provide flexibility in the workplace for those caring for a loved one at home. The *Family and Medical Leave Act* (FMLA) provides eligible employed spouses unpaid leave to care for seriously injured services members or veterans without risk of losing their jobs or health insurance.

Check with your company's human resources department about your eligibility for unpaid leave under the FMLA. Know your company's caregiver leave policies. Explore alternative working arrangements, such as flexible hours, working from home, reduced hours, etc. Some states and employers have more extensive policies regarding leave for caregiving. To see what your state policies are, check out your state-specific websites or offices.

### Can I Receive Public Benefits If I Lose My Job?

If you lose your job because caregiving is demanding too much of your time, check out unemployment benefits. They can provide some income while you look for other work. You may also be eligible for other public benefits, such as Temporary Assistance for Needy Families (TANF), the Supplemental Nutrition Assistance Program (SNAP, formerly Food Stamps), and Women, Infants, and Children (WIC) supplemental food benefits (if you have children up to age 5).

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**Can I Get Help in Finding a Job?**

You and your injured family member can get help and support finding a job. This support recognizes the important contribution that both you and your family member have made in service to the United States. Start by checking with your installation's support services or the *National Resource Directory*. Depending on your service member or veteran's service branch, your Fleet and Family Support Center, Marine Corps Community Services, Airman and Family Readiness Center, or Army Community Service Center can provide you with information and support.

If your family member with TBI is rated with a 100 percent, service-connected disability, the federal government considers you to be an "other eligible," providing you the same resources, rights, and services that are available to veterans and disabled veterans. This includes priority for Labor Department-funded employment and training programs, as well as expedited recruitment and selection for federal civil service positions. The VA also has caregiver programs to support caregivers in finding employment.

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## How Can I Balance Work and Caregiving?

It can be difficult to balance the dual responsibilities of a job and caregiving. Talk to your supervisor about your caregiving responsibilities so that they understand your need for flexibility. Learn about your company's caregiving policy. If your firm has an employee assistance program, you may be able to obtain counseling, legal assistance, or referrals to community resources.

At home, prioritize what needs to be done. Delegate tasks to others and don't ignore your own needs. Remember that if you don't take care of yourself and get run-down or sick from too much stress, it will be difficult to take care of your family member. If you are not able to work full-time because of caregiving tasks, look into part-time jobs, flex-time options, or job-sharing.





# Legal Planning

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There are several legal issues you should know about to protect your family and service member or veteran with TBI. You may need to consider these issues to make good decisions about your family's future. This section provides the basics of each legal concept. Each state has its own set of rules regarding these

legal documents. You will need to find out what the rules in your state are from someone with legal expertise. You may want to discuss your personal situation with an attorney or social worker-case manager who has experience with legal matters.

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## What Is Guardianship?

Guardianship is a legal arrangement under which one person, the guardian, has the legal right and duty to care for another, the ward. If your service member or veteran is severely injured and unable to manage his or her own affairs and property, you may need to be appointed to guardianship.

There are three categories of guardians:

- A **guardian of the person** ensures the physical care and rehabilitation of the disabled individual.
- A **guardian of the estate** (also called a conservator) manages the financial affairs and property of the disabled person.
- A **plenary guardian** does both.

Guardianships are covered under state law. To obtain guardianship over your family member with TBI, you will most likely need a lawyer to represent you in court. You will be required to submit periodic reports and a doctor will need to periodically recertify that the guardianship is still needed.

## What is Power of Attorney ( POA)?

A power of attorney (POA) is a written document in which a competent person, the principal, appoints another person, the agent, to act for them in legal and financial matters. Because of decreased cognitive and functional abilities, your family member with TBI may need you or another person to be named power of attorney. A power of attorney is created when the principal (your family member) signs a notarized document that legally authorizes another person to act on their behalf.

There are different types of POAs:

- A **general power** allows the agent to perform any act or exercise any power on the principal's behalf. Only use a general power when a special power is insufficient.
- A **specific or special power** limits the agent's authority only to the act or acts listed in the POA document.
- A **durable power** of attorney permits the agent to continue to act on the principal's behalf if they are incapacitated.

Most POAs last from a definite start time to a specific end time, but they may be created to last for an indefinite period. A POA can be revoked at any time for any reason. A guardian can override or revoke a POA.



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There are two ways to revoke a POA:

- By destroying the original document
- By executing a *revocation of power of attorney* form and sending a certified copy to any financial institution or company where your agent has conducted business on your behalf

**What Is a Medical Power of Attorney?**

A durable power of attorney for health care is also known as a *medical power of attorney*, or health care proxy. It appoints a primary and secondary agent to make decisions about medical care, including end-of-life issues, in the event that the principal is unable to make those decisions.

**What Is an Advanced Medical Directive or Living Will?**

A *living will* is often called an *advance directive*. It provides a person's written instructions on providing or withholding life-sustaining care or procedures when they are in a terminal or permanently unconscious condition. It is not required to have a living will to receive medical care. Many people use a living will, along with a medical power of attorney, to make their wishes known about medical treatment and health care.

If your family member with TBI is your spouse, and is unable to make decisions regarding your estate or the care of your children, you may wish to consult your lawyer and make changes to your will. This may involve naming a guardian for your children, or your assets, or both in the event of your death. You may also wish to discuss creating a trust as an alternative estate planning tool.



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## What Do I Need to Know About Trusts?

A trust is a document used in estate planning. It is a written legal agreement between the individual who creates the trust (called the grantor, settlor, or creator) and a trustee, the person or institution who is named to manage the trust assets. The trustee holds legal title to the assets for the benefit of one or more trust beneficiaries. The ideal trustee has personal knowledge of the grantor and investment expertise. A trustee team, composed of an individual trustee who knows the grantor well and an institutional trustee with investment knowledge, is a workable solution for some people.

There are different types of trusts. The basic categories include

- A **revocable living trust** is one that can be changed or cancelled at any time.
- An **irrevocable living trust** cannot be changed.
- A **testamentary trust** is one that is irrevocable upon the person's death.

Within these basic categories are a number of types of trusts. The following two may be of interest to families who have a service member or veteran with TBI.

- A **“special needs” trust** is one that is created by a parent or other family member of a person with a disability who is the beneficiary of the trust. This can be either a living trust or a testamentary trust. The trust may hold cash, personal property, or real property, or be the beneficiary of life insurance proceeds. The disabled person cannot have any control over these assets.
- A **qualified income trust**, also called a *Miller trust*, is used in states where there is a limit on the amount of income allowed for Medicaid nursing home eligibility. Some nursing home residents may have retirement incomes at, or above, the level that disqualifies them for Medicaid, yet they do not have enough money to privately pay for a nursing home. Section 1396p of Title 42 of the United States Code permits the creation of an income diversion trust that allows pension, Social Security, and other income to be placed in an irrevocable trust. Upon the death of the beneficiary, the state receives all amounts remaining in the trust equal to the total medical assistance paid by Medicaid on behalf of the beneficiary.

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*“Try never to despair. I know that everybody has moments and walls or the black day that you feel is the end of the world. The truth is that each day is a new day and you can look for the little moments.”*

Lee Woodruff, wife to newscaster Bob Woodruff who sustained a TBI while covering Operation Iraqi Freedom. Co-author with her husband of *In an Instant: A Family’s Journey of Love and Healing*.

*“As caregivers for my brother, my family and I were his voice when he could not speak. This could be anything from hanging signs in his room that reminded nurses and therapists where [he] was missing his skull, to helping with rehab, to filling out paperwork, to going to JAG officers to discuss power of attorney issues. Every day, seven days a week, it became our lives. It’s easy to fall into a groove. Sometimes that groove is comforting, but sometimes it makes you complacent. It’s important to stay on top of the situation and not take things for granted.*

*As a caregiver, you know your loved one and his or her treatment plan the best. You can easily recognize when something is working well or when something is wrong. Never hesitate to acknowledge improvement or voice a concern, always ask questions about a procedure with which you are unfamiliar, and continually seek out benefits to which your loved one is entitled. Information is not always volunteered to you; if you don’t ask, you might not receive.*

*Being a caregiver means being an advocate. You’ve already committed yourself to caring for your loved one; it comes naturally that standing up for him or her should be part of that care.”*

Liza B.

*“I went and saw a psychologist and that was probably one of the best things I did. It was for two days a week, an hour each session, and she was just... a neutral person. I could come in and say all this stuff was going on, and she would actually help me make decisions as to where to go next or what things to do for [him]. She could stand back, look at everything, and help me make sense of it. That was a huge help for me. It was an hour that was just about me, and we could talk about what was going on. She could put things in perspective for me when I couldn’t. I probably saw her for six months.*

*We got involved in the community. We found a church, and that was a great blessing because the people in the church really supported us while we were there. They invited us to do things in the community away from the hospital. I also joined the women’s soccer team.*

*The hospital provided a place for [him] to be on Tuesday night, and I could get away and play. Later on, I needed a reason to go to the gym, so we put together a team to run the Army 10-miler for [him]. I had a reason to go to the gym because I needed to train. It’s something for me—I did it last year, I ran 10 miles! We are doing it again this year.”*

Patty H.

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*“When [he] was starting to read and do word finding, those games were fun activities for the kids to do with him. They took part in his recovery, and I think that involvement was probably the key factor that kept the children from getting resentful, from being isolated. The kids have told me since then that they had wanted to know about things sooner. They thought that we kept a lot of things from them.*

*I still think that there are some things kids at that age don't really need to know, and they learned things along the way that they were ready for. But they did want to know. They're very intuitive. Sharing age-appropriate information meant that they still had a little control in their lives, too. They could then process why Mommy and Daddy had to be away and not go to the dark side of their imagination thinking their worlds were falling apart and not have a clue as to why. I think not discussing the issues is probably the worst thing you can do for your children. They don't like being left in the dark.”*

Shannon M.

*“You know—it's still a daily thing. TBI is definitely a hard thing to grasp. I think the hardest thing, especially for our teenage son, because maybe he is older, is that his Dad is 37 on the outside, but on the inside, he's younger. Our son is going to continue to get older and get more mature and grow up, and his Dad is kind of where he's going to be.*

*I just think a lot of communication is the key. Ask them: Do you have questions? What are you struggling with today? What don't you understand? We also go to therapy. I stressed to our son that this isn't going to go away. This is a lifelong disability. We have to learn to deal with it and cope with it, and you can't do it on your own. You cannot do it on your own.*

*Getting plugged in to support groups that are geared for TBI, seeking out counselors that know TBI and can give you strategies on how to deal with situations, those things are important. That's what it's about for us right now. It's about getting the mental help and the feedback that we need and realizing that, really, we're not alone.”*

Anonymous

*“Intimacy is something that I think a lot of couples with TBI have trouble with. Some too much, some too little—but certainly changes from pre-injury. In our case, there were periods of more emotional withdrawal, whether from the medications or the injury itself. For me personally, helping other families has filled that emotional void. Focusing on the children and focusing on my husband has filled that emotional void in a different way. Physical touch, I've found that massage really helps. When I'm feeling like I'm just out there on my own, sometimes if I go get a massage, then that sort of relieves that physical tension.”*

Anonymous



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*“I think that one of the hardest things is that with a brain injury, you step into the role of being a caregiver... I’ve ended up feeling like mom pretty much and not so much a wife, if that makes sense. That’s been hard for me because another issue that we have is his judgment sometimes, the things he does. I feel like I end up being mom. ‘No, you can’t go spend all your money at once.’ I hate that feeling because he views me in that way now. I don’t want to be mom to him. So that’s really hard.*

*Sometimes I just wish he would go get more counseling for himself. You know how some of these guys are. [Some feel like it’s]. like a sign of weakness to go talk to somebody about things, especially being in the Army. They don’t want to admit something is wrong. I’ve tried to tell him, I can’t handle everything myself. So that’s been an issue.”*

Anonymous

*“The biggest challenge? Just the stress of being the only person. It’s hard most days. Being everybody’s memory and being everybody’s person that does everything, that cooks and cleans, and makes sure everybody gets where they need to go, and everybody remembers where they need to go. It’s overwhelming for the most part.*

*You kind of wish that you had more of a partner than somebody you’re taking care of, but it’s not their fault. They can’t help it. They were just doing their job.”*

Emily S.

*“It does get better. I don’t know if it gets better because you get used to it or because they are making improvements. [He] has definitely made improvements.*

*We’ve kind of fallen into a routine, and I guess when you fall into a routine, then you know what to expect. I guess that makes it easier. It does get easier just because they’re getting better, and they do get better.”*

Pam E.

*“Nobody chooses this. If I could have chosen for him not to be injured, definitely. But you just take what you’re given and make the best of it. Other people don’t even get to come home. Their families don’t even get them back. So we still feel lucky.*

*Initially, the injury is devastating. You don’t feel safe anymore. You kind of feel injured yourself. You just don’t really have any faith in a lot of things, and you just kind of navigate forward.”*

Emily S.

*“Caregiving is a privilege. I never expected to be caring for my husband in this capacity, but it is my honor to serve him in this way after he so courageously served his country. Some days are hard and can be exhausting. Other days, I can see the glimpse of the man he was prior to being injured and that’s what keeps me going. No matter what the future holds, I know that I wouldn’t want to be anywhere else but by his side.*

Tiffany B.

*“Caregiver peer support continues to be the best long term plan I have for my caregiver journey. Connecting with others helps me not feel alone. I appreciate the practical tips offered and continue to keep hope in my heart.”*

Melissa C.

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## Journal Questions

The questions below can help you reflect on your experience as a caregiver. You can write your thoughts down or reflect on these questions in your mind.

1. What are the main sources of stress in my life? How do I handle them? How could I handle them better?
2. Other ideas for emotional self-care that I will try include:
3. Ideas for taking care of myself physically that I plan to do include:
4. What questions have your children asked? How are they adjusting to the changes in the family?
5. What new routines do you think your family would enjoy that would help your family adjust to the new normal?
6. How has your relationship with your service member or veteran with TBI changed?
7. Are you experiencing conflicts with other family members? Describe each person's point of view in the conflict. List strategies that you could use to resolve the conflict.
8. What legal issues concern you most? Why? How do you plan to find answers to your questions and concerns?

# CAREGIVER RESOURCES

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The [National Resource Directory](#) (NRD) is a collaborative effort between the Departments of Defense, Labor, and Veterans Affairs. The directory is a web-based network of care coordinators, providers, and support partners with resources for wounded, ill, and injured service members, veterans, their families, families of the fallen, and those who support them.

The directory offers more than 10,000 medical and non-medical services and resources to help service members and veterans achieve personal and professional goals along their journey from recovery through rehabilitation to community reintegration. Resources are consistently vetted, reviewed, and maintained.

The NRD is organized into ten major categories:

- Benefits and Compensation
- Education and Training
- Employment
- Family and Caregiver Support
- Health
- Housing
- Transportation and Travel
- Homeless Assistance
- Military Adaptive Sports Programs
- Other Services and Resources

To help with navigating the site, the NRD offers easy tips to quickly get to the important information you need. Click here to learn more:

[nrd.gov/misc/HowToUseThisSite](http://nrd.gov/misc/HowToUseThisSite).

Here are several caregiver resources you can start your NRD search with:

- **AARP Military Caregiving Guide:** Offers five key tips and details to provide caregivers with the tools and resources needed to help with the caregiver journey.
- **Brain Injury Association of America:** Offers a nationwide network of chartered state affiliates providing support and advocacy for individuals living with brain injury, their friends and family, professionals, and the general public. They also provide the latest brain injury research, treatment options, resources, and information on local support services.
- **Caregivers On The Homefront:** Provides in-person and online support groups, educational workshops, and mental health-wellness restorative weekends. They also advocate for the caregiver at the local, state, and national level.
- **Center of Excellence for Medical Multimedia:** Provides education and tips to help caregivers understand their role in taking care of service members or veterans with TBI during recovery as well as lifelong care.



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- **Cohen Veterans Network:** Works to strengthen mental health outcomes and complement existing support by providing low to no-cost mental health care for eligible veterans and their families, including access to comprehensive case management support and referrals to deal with other stresses, like unemployment, finances, housing, and legal issues.
- **Elizabeth Dole Foundation:** Offers support to military and veteran caregivers at local, state, and national levels. The Elizabeth Dole Foundation and the VA created the Campaign for Inclusive Care, a national initiative, to integrate military and veteran caregivers into their veteran's care team from day one of the care process.
- **Integrated Disability Evaluation System (IDES):** Describes the joint DOD and VA disability evaluation process that determines if ill or injured service members are fit for continued military service, as well as providing disability benefits to service members and veterans, if appropriate. Service members found fit for duty continue their military service. Service members determined to be unfit for duty receive a single set of disability ratings to determine the appropriate level of DOD and VA disability benefits. Integration with the VA provides medically separated or retired veterans timely access to their VA Benefits.
- **Military Caregiver Resource Directory:** Provides information about national resources and programs supporting the caregivers of wounded, ill, or injured service members. The concept of the directory is to connect communities with caregivers—building public awareness and support for caregivers.
- **Military & Veteran Caregiver Network:** Offers peer support and services to connect caregivers with resources and mentors to reduce isolation and increase connection, engagement, knowledge, skills, and hope.
- **Operation Family Caregiver:** Provides returning service members free and confidential support to the families of returning service members and veterans with a personalized program that teaches them how best to navigate their challenges. It is a program of the Rosalynn Carter Institute for Caregiving.
- **Operation First Response:** Provides personal and financial services for wounded military and their families from the onset of injury throughout their recovery period, and along their journey from military service to civilian life. Financial aid services offered by Operation First Response vary as each case is based on individual needs ranging from rent, utilities, vehicle payments, groceries, clothing, and travel expenses.

- **PsychArmor:** Provides a library of online education courses with information, resources, and strategies on how to manage the demands and stress involved with caregiving. They also offer online training courses at no cost, and other resources to support military service members, veterans, and their families.
- **Psychological Health Center Of Excellence:** Provides information and resources to help service members, veterans, and their families with psychological health care, readiness, and the prevention of psychological health disorders.
- **Traumatic Brain Injury Center of Excellence:** Collaborates with the DOD, VA, civilian health partners, local communities, and families and individuals with TBI to promote TBI care from point-of-injury to reintegration. Helps Service Members, Veterans and their families to prevent and mitigate the consequences of mild to severe TBI.
- **TRICARE's Plans and Eligibility:** Provides TRICARE beneficiaries with coverage information including health plans, special programs, prescriptions, and dental plans. Also provides access to TRICARE's program manuals.
- **VA Caregiver Support:** Its Program of General Caregiver Support Services (PGCSS) provides resources, education and support to caregivers of veterans. The veteran does not need to have a service-connected condition for which a caregiver is needed, and may have served during any era.
- Its Program of Comprehensive Assistance for Family Caregivers (PCAFC) is for eligible veterans who have incurred or aggravated a serious injury in the line-of-duty. In addition, this program provides a financial stipend, health insurance, and beneficiary travel to eligible caregivers.
- **VA's Eligibility for Healthcare:** Provides veterans and their families with the information they need to understand VA's health care system—eligibility requirements, health benefits and services available to help veterans, and copayments that certain veterans may be charged.
- **VA Polytrauma & TBI System of Care:** Offers an integrated network of specialized rehabilitation programs dedicated to serving veterans and service members with both combat and civilian related TBI or polytrauma.
- **Wounded Warrior Programs:** Various programs that provide support and help with applications for federal assistance to wounded warriors, veterans in crisis and their families.
- **Yellow Ribbon Fund:** Provides housing, transportation, caregiver; and family support to severely wounded, ill, and injured post-9/11 service members from every branch of the United States military following unexpected medical crises. They also offer recreational and respite events to caregivers.



## Glossary

Terms that are located within the text are linked (in blue) below.

**Abscess:** A collection of pus that has built up within the tissues of the body. A brain abscess is a collection of pus enclosed in the brain tissue.

**Acute Care:** Emergency medical treatment and time in the intensive care unit (ICU), for serious illness or traumatic injury.

**Acute Pain:** Mild-to-severe pain that comes on suddenly and lasts anywhere from a few seconds to several months.

**Acute Rehabilitation:** Intensive inpatient rehabilitation. Rehabilitation is conducted two-to-six hours daily.

**Advanced Medical Directive:** Wishes and preferences about medical treatments and interventions. When a person is incapable of making their own medical decisions, a health care proxy (a designated person) can act on that person's behalf to make decisions consistent with, and based on, the patient's stated will.

**Alteration of Consciousness (AOC):** Feeling dazed, confused, or "seeing stars."

**Amnesia:** A loss of memory.

**Antibiotics:** Medications that fight bacterial infections.

**Apraxia:** The reduced ability to perform complex movements. A person with apraxia can often understand what to do and has the physical ability to do the task. However, their body simply has trouble cooperating with their best intentions.

**Arachnoid Mater:** Protective membrane covering the brain and spinal cord. This membrane is located between the dura mater and the pia mater.

**Axon:** A long threadlike extension of a nerve cell that conducts electrical impulses away from the neuron's cell body. Axons are the primary transmission line of the nervous system.

**Basilar Skull Fracture:** A break in the bone at the base of the skull. Clear fluid may drain from the nose or ear due to a tear in the covering of the brain.

**Blast Wave:** Intense over-pressurization created by a detonated high-order explosive (HE).

**Blood Clots (Thrombus):** A clump of blood that has changed from a liquid to a gel-like or semisolid state. Clotting is a necessary process that can prevent blood loss in certain instances, but when it forms inside of a vein, it can be dangerous.

**Brain:** The main organ of the central nervous system (CNS). It is divided into the cerebrum, brainstem and cerebellum. The brain regulates virtually all human activity.

**Brain Cells:** The brain has different cell types, each with its own unique properties. The most common brain cells are neurons and glial cells.



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**Caregiver Burnout:** State of physical, emotional, and mental exhaustion. It may be accompanied by a change in attitude, from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able. Caregivers who are "burned out" may experience fatigue, stress, anxiety, and depression.

**Cerebellum:** The base of the brain (cerebrum) involved with coordinating movement and maintaining posture and balance.

**Cerebrospinal Fluid (CSF):** A colorless fluid that is found around and inside the brain and spinal cord. It offers some protection and cushioning to the brain.

**Cerebrum:** The largest part of the brain. It is composed of right and left hemispheres, or halves. The right hemisphere controls the left side of the body, and the left hemisphere controls the right side of the body. The cerebrum is divided into four lobes: the frontal, parietal, temporal, and occipital. The cerebrum performs higher functions like interpreting touch, vision, and hearing, as well as speech, reasoning, emotions, and learning.

**Cervicogenic Headache:** A type of headache that occurs when there is injury to the muscles and soft tissues in the neck and back of the head. Many nerves located in the neck travel to the skull and can cause these headaches.

**Chronic Pain:** Ongoing pain that usually lasts longer than six months.

**Closed Head Injury:** A blow or jolt to a person's head causes the brain to shake violently inside of the skull. This causes the soft brain to hit the hard skull resulting in bruising and tearing of brain tissue and blood vessels that do not result in an opening to the skull.

**Cognition:** The process of acquiring knowledge and understanding through thought, experience, and the senses.

**Coma:** A period of prolonged unconsciousness in which a person is neither aware of the environment nor able to perform voluntary actions.

**Community Reentry:** Programs that can help prepare for return to independent living and if possible return to work or school.

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**Compassion Fatigue:** A condition characterized by emotional and physical exhaustion leading to a diminished ability to empathize or feel compassion for others.

**Computerized Tomography Scan (CT scan):** A computerized x-ray that doctors use to view the brain and look for areas of bleeding and bruising.

**Consciousness:** A state of awareness of the self and the environment.

**Concussion:** Also known as a mild traumatic brain injury, it is characterized by loss of consciousness lasting for up to 30 minutes, alteration of consciousness for up to 24 hours, or post-traumatic amnesia for up to 24 hours.

**Confabulation:** It is when a person makes up false memories. These memories could be about past event

that never happened, or they could be memories of actual events that the person puts in the wrong time or place. The memories can vary, and the person honestly believes that the events are real.

**Contusion:** A bruise to the brain itself.

**Coup-Contrecoup Injury:** When an impact or violent motion causes the brain to rock back and forth inside of the skull, causing damage.

**Deep Vein Thrombosis (DVT):** A blood clot in one or more of the deep veins in the body, usually in the legs. DVT can cause leg pain or swelling, but it can also occur with no symptoms.

**Depressed Skull Fracture:** Part of the skull is sunken in from the trauma, which may be seen with or without a cut in the scalp.

**Diffuse Axonal Injury (DAI):** The pulling, stretching, and tearing of the brain's long connective nerve fibers (axons). It happens when the brain is injured as it shifts and rotates inside of the bony skull.

**Diffuse:** Widely spread.

**Diffuse Brain Injury:** Injury to the cells in many areas of the brain rather than in one specific location.

**Disorder of Consciousness:** Is caused by a severe injury to the brain and diagnosed when someone has difficulty maintaining wakefulness or has impaired awareness.

**Dura Mater:** The tough outermost membrane protecting the brain and the spinal cord.

**Dysarthria:** Occurs when the muscles used for speech are weak, or there is difficulty controlling them. Dysarthria often causes slurred or slow speech that can be difficult to understand.

**Edema:** Swelling due to excess fluid trapped in your body's tissues. Cerebral edema, also known as brain swelling, occurs when the brain contains more fluid than normal. The fluid increases the pressure inside the skull.

**Epidural Hematoma:** Bleeding into the area between the skull and dura mater.

**Family and Medical Leave Act (FMLA):** A law that entitles eligible employees to take unpaid, job-protected leave for specific family or medical reasons with continuation of health insurance coverage under the same terms and conditions as if the employee had not taken leave.

**Fisher House Foundation:** A “home away from home” for families of patients receiving medical care at major military and VA medical centers. The homes are normally located within walking distance of the treatment facility or have transportation available.

**Frontal Lobes:** Located at the front of the brain, they are involved in planning, organizing, problem-solving, selective attention, personality, and a variety of “higher cognitive functions.”

**Guardianship:** A legal arrangement under which one person (the guardian) has the legal right and duty to care for another (the ward).

**Hematoma:** A collection of blood caused by rupture or tearing of blood vessels.

**Hemiparesis:** Weakness of one side of the body.

**Hemiplegia:** Paralysis of one side of the body.

**Herniation:** Compression of brain tissue caused by high pressure inside of the skull that can lead to death if not aggressively treated.

**Heterotrophic Ossification:** Formation of bone in an unnatural location, such as in soft tissue or muscle. It mostly occurs in the hips and knees.

**Home Health Care:** Care by a qualified aid, nurse, or therapist in a person’s home.

**Hydrocephalus:** Also known as “water on the brain,” it happens when there is an increased build-up of cerebrospinal fluid (CSF) within the brain cavities. This condition can lead to increased pressure in the brain.

**Hyper-sexuality:** Thinking about or wanting frequent sexual activity.

**Hypertension:** The medical term for high blood pressure.

**Hypo-sexuality:** Lack of interest in sex.

**Hypotension:** The medical term for low blood pressure.

**Improvised Explosive Devices (IEDs):** An IED can be almost anything with any type of material or initiator. It is a “homemade” device that is designed to cause death or injury by using explosives alone or in combination with toxic chemicals, biological toxins or radiological material. IEDs can be produced in varying sizes, functioning methods, containers and deliver methods. IEDs can utilize commercial or military explosives, homemade explosives or military ordinance and ordinance compounds.

**Impulsivity:** The tendency to act without thinking.

**Increased Intracranial Pressure (ICP):** Increased pressure in the brain to dangerous levels after a traumatic brain injury, which can cause decreased blood flow to the brain. Increased ICP can cause a midline shift or brain herniation.



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**Indwelling Urinary Catheter:** A flexible plastic tube (a catheter) inserted into the bladder that remains there to provide continuous urinary drainage.

**Infection:** Invasion of the body by a pathogen such as a bacterium, fungus, or virus. Infections can be localized or widespread (sepsis), and they are often accompanied by fever.

**Insomnia:** Sleep disorder in which a person has trouble falling or staying sleep.

**Intracerebral Hematoma:** Bleeding within the brain tissue itself.

**Intracranial:** Within the skull.

**Intracranial Hematoma:** Bleeding in or around the skull.

**Intraventricular Hemorrhage:** Bleeding goes into the ventricles (butterfly-shaped spaces) of the brain.

**Laceration:** Tears in brain tissue caused by a foreign object or from a sunken bone fragment after a skull fracture.

**Linear Skull Fracture:** Break in the skull resembling a thin line or crack that does not splinter, cave in, or change the shape of the skull.

**Living Will:** A written document that specifies what types of medical treatments are desired should the individual become incapacitated. A living will can be very specific.

**Lobe:** A part of the brain located in each of the two hemispheres. Each hemisphere of the brain is divided into four sections known as the frontal lobe, the parietal lobe, the occipital lobe, and the temporal lobe.

**Long-Term Care:** A facility that provides ongoing skilled nursing care for those who sustained a severe brain injury and need lifelong care.

**Long-Term Memory:** Memory that involves the storage and recall of information over a long period of time (such as days, weeks, or years).

**Loss of Consciousness (LOC):** Loss of awareness of oneself and one's surrounding. It can be brief or for an extended period of time.

**Magnetic Resonance Imaging (MRI):** Shows detailed images of the brain using magnetic energy rather than x-ray technology.

**Medical Power of Attorney:** A primary and secondary agent appointed to make decisions about medical care (including end-of-life issues) in the event the principal is unable to make those decisions.

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**Meninges:** The covering of the brain that consists of three layers; the dura mater, the arachnoid mater, and the pia mater. The primary function of the meninges and of the cerebrospinal fluid is to protect the central nervous system.

**Meningitis:** A bacterial, viral, or fungal infection of the fluid surrounding the brain and spinal cord that causes swelling of the membranes.

**Migraine Headaches:** Migraines can occur when an area of the brain becomes irritated. Migraines cause pain that is throbbing or pulsating.

**Mild Traumatic Brain Injury:** Also known as a concussion. Characterized by loss of consciousness lasting for up to 30 minutes, alteration of consciousness for up to 24 hours, or post-traumatic amnesia for up to 24 hours.

**Midline Shift:** A midline shift of the brain develops when pressure on one side of the brain pushes it out of alignment.

**Mindfulness:** The act of being intensely aware of what you are sensing and feeling in the moment without interpretation or judgment. Practicing mindfulness involves breathing methods, guided imagery, and other practices to relax the body and mind and to help reduce stress.

**Moderate Traumatic Brain Injury:** Loss of consciousness that lasts more than 30 minutes but less than 24 hours, alteration of consciousness that lasts more than 24 hours, or post-traumatic amnesia that lasts one to seven days.

**Neurons:** Cells located in the brain.

**Neuropathic Headaches:** A type of headache caused by an injury to the soft tissue of the scalp or neck that can damage nerves located in these areas and cause pain.

**Neurotransmitters:** Often referred to as the body's chemical messengers, these molecules are used by the nervous system to transmit messages between neurons, from neurons to muscles, and from neurons to gland cells.

**Obstructive Sleep Apnea (OSA):** When someone periodically stops breathing while sleeping, which causes sleep to be fragmented.

**Occipital Lobes:** Located in the back of the brain, the occipital lobes are the primary portion of the brain responsible for receiving and processing all information from the eyes.

**Open Head Injury:** Trauma to the brain that occurs from a skull fracture or penetrating injury.

**Outpatient Care:** Medical care on an outpatient basis, including diagnosis, observation, consultation, treatment, intervention, and rehabilitation services.

**Parietal Lobes:** Located above the temporal lobes and between the frontal and occipital lobes, it contains the part of the brain primarily responsible for movement and the sense of touch.

**Penetrating Head Injury:** A brain injury in which an object pierces the skull and enters the brain tissue.

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**Pia Mater:** The innermost membrane enveloping the brain and spinal cord.

**Pneumonia:** Infection in one or both of the lungs.

**Polytrauma:** Injuries to multiple organs or body parts.

**Post-Acute Care:** Focuses on gaining as much independence as possible by learning new ways to compensate for potentially long-term or permanent disabilities. Sometimes called transitional rehabilitation.

**Post-Concussion Syndrome:** Symptoms that persist beyond the expected recovery period of 1-3 months. It includes headaches, dizziness, fatigue, irritability, anxiety, insomnia, loss of concentration, memory loss, and noise sensitivity.

**Post-Traumatic Epilepsy:** Recurrent and unprovoked seizures that begin at least one week after a traumatic brain injury.

**Post-Traumatic Stress Disorder (PTSD):** A behavioral health condition that is triggered by a terrifying event. Symptoms may include flashbacks, nightmares, and severe anxiety, as well as uncontrollable thoughts about the event.

**Post-Traumatic Amnesia (PTA):** Not being able to remember what happened after a trauma.

**Power of Attorney (POA):** A written document in which a competent person (the principal) appoints another person (the agent) to manage legal and financial matters.

**Rancho Los Amigos Revised Scale (RLAS-R):** A scale that describes the cognitive and behavioral patterns found in brain injury patients as they recover from their injury.

**Redirection:** Shifting a distressed person's attention away from the situation that is causing anger, anxiety, or unsafe behavior to a more pleasant emotion or situation.

**Rehabilitation:** Relearning skills needed for everyday life to improve function and quality of life.

**Respite Care:** It provides a short-term break for a primary caregiver. It can be arranged for just one afternoon or for several weeks. Care can be provided at home, in a health care facility, or at an adult day center.

**Seizure:** Uncontrolled electrical disturbance in the brain. It can cause changes in behavior, movements, feelings, or levels of consciousness.

**Severe Traumatic Brain Injury:** Loss of consciousness that lasts more than 24 hours, alteration of consciousness that lasts more than 24 hours, or post-traumatic amnesia that lasts longer than seven days.

**Short-Term Memory:** Memory that involves recall of information for a relatively short period of time, such as minutes to hours.

**Skull Fracture:** A break, split, or crack in the skull.



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**Spasticity:** Abnormal muscle tightness. The muscle remains contracted and resists being stretched.

**Spatial Awareness:** The ability to perceive where you are in space in relation to other items in the environment.

**Subarachnoid Hemorrhage:** Bleeding between the arachnoid mater and the pia mater.

**Subdural Hematoma:** Bleeding that occurs between the dura mater and the arachnoid mater.

**Supplemental Nutrition Assistance program (SNAP):** A federal program that provides benefits to eligible low-income individuals and families via an Electronic Benefits Transfer card. This card can be used like a debit card to purchase eligible food in authorized retail food stores.

**Temporal Lobe:** Located below the parietal lobes and in front of the occipital lobes, the temporal lobes are involved in speech, memory and hearing.

**Temporary Assistance for Needy Families (TANF):** It provides families with financial assistance and related support services. State-administered programs may include childcare, job preparation, and work assistance.

**Tension Type Headaches:** Headaches often associated with muscle tension or muscle spasms and stress.

**Tinnitus:** The perception of noise or ringing in the ears.

**Traumatic Brain Injury (TBI):** A blow or jolt to the head, or exposure to an external force (such as a blast wave) that disrupts the normal function of the brain. At least one of the following needs to occur to be considered a TBI:

- **Loss of consciousness (LOC):** This means loss of awareness of oneself and one's surroundings. It can be for a brief or an extended period of time.
- **Alteration of consciousness (AOC):** This means feeling dazed, confused, or "seeing stars."
- **Post-traumatic amnesia (PTA):** This means not being able to remember what happened after a trauma.

**Trust:** A document used in estate planning. A trust is a written legal agreement between the individual who creates the trust (called the grantor, settlor, or creator) and a trustee (the person or institution who is named to manage the trust assets).

**Ventilator:** A machine that helps you breathe or breathes for you.

**Ventricles of the Brain:** Four butterfly-shaped spaces located within the brain that contain cerebral spinal fluid (CSF).

**Ventricular Drain:** A tube placed inside a ventricle of the brain that is connected to an external drainage container. The drain can monitor the pressure inside the brain as well as drain blood and cerebrospinal fluid (CSF) to maintain normal intracranial pressure (ICP), or pressure within the brain.

**Vertigo:** Having the feeling of spinning or moving even when someone is perfectly still.

**Vestibular System:** A sensory system that is responsible for providing our brain with information about movement, head position, and spatial orientation. It also allows us to keep our balance, stabilize our head and body during movement, and maintain posture. The vestibular system is important for normal movement and equilibrium.

**Visual-Spatial Problems:** Trouble understanding where objects are in space; unsure how close objects are to one another.

**Whiplash:** An injury to the neck caused by the head being violently thrown back and forth, such as in a rear end car collision.



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# Printable Forms

## Contact Information of the Health Care Team

Professional – Name	Contact Information
Audiologist	
Blind and Low Vision Specialist	
Case Manager	
Chaplain	
Department of Defense Military Liaison	
Dietitian	
Neurologist	
Neuro-ophthalmologist or Neuro-optometrist	
Neuropsychologist	
Neurosurgeon	
Occupational Therapist (OT)	
Palliative Care Team	
Physiatrist	

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Home Safety Checklist

Safety Plan Worksheet

Professional – Name	Contact Information
Physical Therapist (PT)	
Primary Care Provider or Primary Care Manager	
Psychiatrist	
Recreational Therapist (RT)	
Rehabilitation Nurse	
Rehabilitation Psychologist	
Social Worker	
Speech Language Pathologist (SLP)	
VA, DOD Liaison for Healthcare or VA, DOD Polytrauma Rehabilitation Nurse	
Veterans Benefits Associate (VBA)	
Vocational Rehabilitation Counselor	





## Caregiver Support Worksheet

Caregiving Task	Who Can Help	Contact Information
<b>Everyday Tasks:</b>		
Meal Planning		
Lawn Care		
Grocery Shopping		
Meal Preparation		
Light Housekeeping		
<b>Transportation for:</b>		
Other Family Members		
Shopping & Errands		
<b>Child Care</b>		
<b>Pet Care</b>		
<b>Care Tasks:</b>		
Coordinating Home Care Team		
In-home Supervision or Companionship		
<b>Transportation for:</b>		
Medical Appointments		
Support Group or Counseling		
<b>Care Team Meetings or Dinner</b>		

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Caregiving Task	Who Can Help	Contact Information
<b>Personal Hygiene:</b>		
Bathing		
Other, e.g., hair, nails, skin		
<b>Hands-on Medical Treatments, Exercise or Therapy</b>		
<b>Scheduling Medical Appointments</b>		
<b>Managing Medications</b>		
<b>Recreation Activities:</b>		
For the Service Member or Veteran		
For the Family Caregiver		
For Other Family Members		
<b>Finances or Legal</b>		
Banking		
Paying Bills		
Managing Military or VA Benefits		
Managing Insurance Claims		
Handling Legal Matters		
Finding Community Services		

## Home Safety Checklist

This checklist focuses on safety issues that commonly apply to individuals with perceptual and cognitive problems.

### How To Use This Checklist

Take this checklist with you as you WALK through your home with your service member or veteran, carefully check “yes” or “no” for each item on this list.

Any item scored “no” is a safety concern and should be corrected.

General Home Safety Checklist for Individuals with Perceptual and Cognitive Problems		
Area of Focus	Yes	No
1. While cooking, is a timer available to help you keep track of items cooking on the flame? (attention and memory problems)		
2. Do you use a “whistling” teakettle? (attention and memory problems)		
3. Are commonly used items kept in the same location? (attention and memory problems)		
4. Have commonly used telephone numbers been pre-programmed into the phone, posted near the phone, or both? (memory problems, sequencing problems)		
5. Do you use a calendar or scheduling book to help remind you of important events? (attention and memory problems)		
6. If necessary, have you posted signs by the door to help remind you to Lock the front door when you leave Turn off appliances when you finish using them Take out the garbage (attention, memory problems)		
7. Is your front door house key color coded for easy identification? (memory problems, distractibility)		



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Safety Plan Worksheet

General Home Safety Checklist for Individuals with Perceptual and Cognitive Problems		
Area of Focus	Yes	No
8. When the doorbell rings, do you use the peep hole to identify who it is before opening the door to let the person in? (impulsivity, decreased judgment)		
9. When necessary, do you use checklists with correct steps and sequences for household tasks, such as the laundry or making a bed? (poor attention, memory problems, sequencing problems)		
10. Are directions for multi-step tasks posted at appropriate locations (e.g., near washing machine)? (sequencing problems, difficulty initiating tasks, attention and memory problems)		
11. Are sharp utensils separated from other items and arranged in a kitchen drawer with handles pointing towards you? (perceptual impairments, impulsivity)		
12. Are toxic household cleaning fluids kept separate from other items to avoid potential confusion? (perceptual impairments, attention problems)		
13. Have unnecessary items been removed from the living environment to decrease confusion and distraction? (perceptual impairments, attention problems)		
14. Are commonly used items kept in a consistent, prominent place? (memory and attentional problem)		
15. Are cabinets labeled to assist in locating objects? (memory and attentional problems, safety)		
16. If you are “neglectful” of one side of your body, are objects placed and positioned where you can see and reach them? (perceptual impairments)		
17. Do you use a watch with an alarm and calendar display? (memory problems)		
18. Are the most “taxing” household activities planned for the time of day when you feel most alert and attentive? (attentional problems, fatigue)		
19. Do you have a “Medi-Alert” system in place? (safety, language difficulties)		
20. Does a family member or friend have a key to your home in case of emergencies? (safety)		

If you have answered “YES” to all these items on this checklist, your home appears to be relatively safe. Any items scored “NO” should be corrected to promote a safe home environment. Remember to check with your health care professional to identify any potential safety issues that might be particular to your individual needs.

### Safety Plan Worksheet

**Purpose:** Providers and patients complete Safety Plan together, and patients keep it with them.

Contact Information of the Health Care Team

Medication Log

Caregiver Support Worksheet

Home Safety Checklist

Safety Plan Worksheet

**Step 1.** Warning signs (that I might be headed toward a crisis and the Safety Plan should be used):


**Step 2.** Internal coping strategies (things I can do to distract from my problems without contacting another person):



**Step 3.** People, places, and social settings that provide healthy distraction (and help me feel better):

Name and phone number:	
Name and phone number:	
Place:	
Place:	

**Step 4.** People I can contact to ask for help (family members, friends, and co-workers):

Name and phone number:	
Name and phone number:	
Name and phone number:	
Name and phone number:	

- Contact Information of the Health Care Team
- Medication Log
- Caregiver Support Worksheet
- Home Safety Checklist
- Safety Plan Worksheet

<b>Step 5. Professionals or agencies that can help me during a crisis:</b>	
Clinician/Agency (Name, phone, pager, emergency contact number)	
Clinician/Agency (Name, phone, pager, emergency contact number)	
Clinician/Agency (Name, phone, pager, emergency contact number)	
Other (Name, phone, pager, emergency contact number)	
 <p><b>Military/Veterans Crisis Line:</b> Dial 800-273-TALK (8255), press 1 for military, or text 838255 or live chat at <a href="http://militarycrisisline.net">militarycrisisline.net</a> for 24/7 crisis support.</p>	<p><b>National Suicide Prevention Lifeline:</b> Dial 800-273-TALK (8255) or live chat at <a href="http://suicidepreventionlifeline.org">suicidepreventionlifeline.org</a> for 24/7 crisis support.</p>
<b>Step 6. Making my environment safe (plans for removing or limiting access to lethal means):</b>	
<b>Step 7. My reasons for living (things that are most important to me and worth living for):</b>	

Department of Veterans Affairs and Department of Defense employees who use this information are responsible for considering all applicable regulations and policies throughout the course of care and patient education.

Reference: Stanley, B. & Brown, G. K. (2012). Safety planning intervention: A brief intervention to mitigate suicide risk. *Cognitive and Behavioral Practice*, 19, 256–264.

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