

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



**Understanding the Effects of
Traumatic Brain Injury and What
You Can Do To Help**

| 2



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



Module 2 Summary

This module is about the ways that a moderate to severe traumatic brain injury (TBI) may change a person's body, thinking, acting, and feelings.

Some of the information you will read may be true for your service member/veteran. But some of it will not. Each person is unique and each person's effects from TBI will also be unique.

Many people with TBI have similar patterns of recovery. But everyone recovers at a different pace. There is no way to "hurry up" the recovery from TBI.

There are, however, many things you and the health care providers can do to create the best possible recovery.

Remember, you are not alone. There are thousands of other military families who are struggling to cope with many of the same changes from TBI that you and your service member/veteran are experiencing.

Doctors at the Departments of Defense (DoD) and Veterans Affairs (VA) are learning more every day about how to effectively treat the effects of TBI. Your service member/veteran will benefit from new medical knowledge based on other service members' experiences. His or her experience will add to doctors' knowledge about how to treat TBI.

Most effects of TBI fade over time. Keep hope in your heart as you move forward into the future.



TBI Effects and Treatment

This module is about all the effects that people with TBI may experience. You may notice some of these changes in your service member/veteran with TBI.

The module explains what you can do to help your service member/veteran manage these effects. This information will be especially helpful when he or she comes home from the hospital.

Please keep in mind—**your service member/veteran is likely to experience some—but not all--of these effects**. Many effects are common right after the injury. Many are likely to improve over time.

Though we know more now about TBI than ever before, no one can say with certainty just what effects each injured person will have.

We do know that most people with TBI can and will make improvements. Proper diagnosis, treatment, and follow-up care helps. So do a supportive family and community.

You Are Not Alone

TBI is the “signature” injury of the conflicts in Iraq and Afghanistan. As many as one in five service members with injuries returning from these war zones have been diagnosed with a TBI.

Blasts from grenades, improvised explosive devices (IEDs), and land mines caused most of these TBIs. Gunshot wounds, falls, and motor vehicle accidents also cause TBI.

Because TBIs from blast injuries are common, the DoD and VA are focused on how to help the injured and their families manage the effects of TBI. More is learned every day about how to do so.

The good news is that you are not alone. There are skilled health care providers and excellent resources to help you and your service member/veteran with TBI manage the effects of TBI.

There are things you can learn to do to manage these effects at home. There are other caregivers who are learning about the effects of TBI too, and who can share their experiences and ideas with you (see Module 3).

Learning about Effects

The very first effect of a TBI could be loss of consciousness or a dazed feeling. Some effects are most visible just after the injury. For most people, these effects will generally fade as time goes by.

A blast is an explosion. There is often a loud noise, waves of air pressure, shaking, and flying objects. People in a blast may get thrown out of their vehicles.

What is a TBI?

A traumatic brain injury (TBI) is a direct blow or jolt to the head, penetrating head injury, or exposure to external forces such as blast waves that disrupts the function of the brain. Not all blows to the head or exposure to external forces results in a TBI. The severity of TBI may range from “mild”— a brief change in mental status or consciousness—to “severe,” an extended period of unconsciousness or confusion after the injury.

Post-traumatic stress (PTS) is anxiety that can develop if you are exposed to or witness a traumatic event (like combat) that threatened or caused great physical harm to self or others.

The kind of effects that your service member/veteran with TBI will have depends on what part of his or her brain was injured. (You can learn more about the parts of the brain in Module 1.)

Understanding the brain injury can help you make sense of what doctors tell you. It can also help you cope with changes you observe.

Service members sometimes have several injuries, including TBI. It is often hard to sort out which effects are due to TBI alone, and which result from other injuries.

Emotional conditions like **post-traumatic stress (PTS)**, post-traumatic stress disorder (PTSD), and depression also make it hard to tell if an effect is due to TBI.

The health care team is familiar with all of these conditions. They will develop the

proper treatment plan. They will also teach you about how you can help.

You will see sections in this module about physical effects, cognitive effects, communication effects, and so on. It’s important to remember that many effects of TBI are inter-connected. For example:

- Sleep problems can affect how quickly someone thinks.
- Sensory changes can affect how someone focuses and learns.
- Fatigue can make it hard to safely move about.
- Memory problems can make it hard to communicate with others.
- Visual problems can make it hard to learn.

The changes that result from TBI are the direct result of the injury, and not a result of your loved one intentionally trying to act or think in a way that may be different from how he or she used to act and think.

What are the Phases of Treatment?

If your injured family member was deployed, treatment began immediately. The military health care team stabilized your service member so he or she could be moved to the next level of care.

From Iraq and/or Afghanistan, most service members go to Landstuhl Army Regional Medical Center in Germany for **acute care**. Those stationed outside of the United States may return to their home base. Others may go directly to a military hospital in the United States.

You will be informed about where your service member is and when he or she will return to the United States. If your family member is going to be in Landstuhl for awhile, you may receive Invitational Travel Orders to pay for you to fly to Germany.

Once the service member's injuries are under control, he or she is transported back to the United States for continued **inpatient care** and **rehabilitation**.

Medical treatment and rehabilitation may continue for several months in a military treatment facility (MTF), such as Walter Reed Army Medical Center, National Naval Medical Center, or Brooke Army Medical Center. Rehabilitation may continue at a VA Polytrauma Rehabilitation Center or Polytrauma Network Site.

The final phase of treatment is often at home and in the community. In this phase, you may be the primary caregiver for your service member/veteran with TBI. Therapy often continues on an **outpatient** basis in a hospital or clinic closer to home.

Each injured service member will have his or her own pattern of care. Those stationed outside the United States may not return stateside for care. Some service members 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.

The health care team will tell you the type of care your family member needs. They will explain when it is time to move to another level of care, and why.

Throughout treatment, you are an important member of your service member/veteran's team. The more you know about TBI, the more easily you can work with the health care team. The more you know, the better able you will be to help your service member/veteran recover from TBI.

Acute care is short-term treatment for a serious injury or illness.

Inpatient care is care provided to a person staying in a hospital.

Rehabilitation means re-learning old skills.

A military treatment facility (MTF) is a military hospital. You can find a list of MTFs in Appendix B.

Outpatient care means living at home and going to appointments at the hospital or doctor's office.

What is the DoD System of Care?

There is a network of military treatment facilities (MTFs) across the country. They are operated by the Department of Defense (DoD). The DoD and the Department of Veterans Affairs (VA) Polytrauma Centers work together to manage the care of injured service members.

Check www.tricare.mil/mtf to locate the military treatment facilities.

DoD also provides health care through TRICARE (see Module 4).



*Department of Defense Medical Centers
(source: www.tricare.mil/mtf)*

What is the VA Polytrauma System of Care?

If your service member/veteran needs long-term care and rehabilitation, he or she may go to a center that is part of the **Department of Veterans Affairs (VA) Polytrauma System of Care (PSC)**.

The PSC is a comprehensive, integrated system of rehabilitation care for veterans and service members with polytrauma and TBI.

The PSC is a tiered system of care which includes:

- Four TBI/Polytrauma Rehabilitation Centers (PRC) located in Richmond, VA; Tampa, FL; Minneapolis, MN; Palo Alto, CA (a fifth PRC in San Antonio, TX is scheduled to open in 2011). The PRCs provide the most intensive specialized care and comprehensive acute, inpatient TBI rehabilitation care.
- 22 Polytrauma Network Sites (PNS) which provide a full range of inpatient and outpatient TBI rehabilitation care in regional areas closer to home.
- 81 Polytrauma Support Clinic Teams (PSCT) which provide local outpatient, specialty rehabilitation care, and long-term TBI management.
- 49 Polytrauma Points of Contact (PPOC) located at VA medical centers across the country. PPOCs coordinate case management and referral within the PSC and provide referrals for local community services.

*VA is the
Department of
Veterans Affairs.*

*Polytrauma
means more than
one injury.*

*Learn more about
the VA Polytrauma
System of Care at
[www.polytrauma.
va.gov](http://www.polytrauma.va.gov).*



Department of Veterans Affairs PRCs and PNSs

Polytrauma Rehabilitation Centers (PRCs)

Your service member/veteran may transfer from a military hospital to a VA PRC for additional inpatient care and TBI rehabilitation. The health care teams at the military hospital and PRC work together to plan the move.

At the PRC, your family member will receive specialized medical and rehabilitation treatment for all the effects of TBI (and other serious injuries) that you will read about here.

The PRC offers a program where injured service members/veterans learn how to live as independently as possible after TBI. Each PRC also has military liaisons on site. Through regular meetings, the liaison helps your family member stay connected with his or her military community and makes sure that all service-related needs (e.g., orders) are addressed.

Polytrauma Transitional Rehabilitation. For those who have completed inpatient care but are not yet able to live independently, Transitional Rehabilitation offers a progressive return through a structured program focused on restoring home, community, and vocational skills in a controlled, therapeutic setting. A transitional rehabilitation program for veterans and active duty service members with TBI is located at each of the four PRCs.

Case management is the coordination of services to meet the patient's needs.

VBA stands for Veterans Benefits Administration. It is the government agency that offers insurance and other benefits to veterans and eligible service members.

Case management is an integral part of PSC services. A clinical case manager works with your service member/veteran to help with:

- Transition from military hospital to VA medical center
- Communication between service member/veteran, family, and the VA rehabilitation team
- Identification of various VA, DoD, and community resources.

There are also **VBA** counselors to help you find and apply for VA benefits.

The DOD and VA systems of care have many levels of service. That's because your family member's need for care will change as he or she gets better over time. There are also services to give you the education and support you need as a caregiver.

“My goal—and I’ve made this clear to the team—is for Mike to go to the transition program, where they have to live basically on their own. They have to be able to take care of all their living skills, and be able to get in and out of their bed, and to and from therapy, and that kind of thing. I would really like for him to get to that point because I would like for him to prove to himself that he’s able to stay alone and take care of himself and prove to me that he’s able to stay alone and take care for himself for a short time.”

- Meredith H.



Family Support Services

Families are valued members of the treatment team at the PRC and throughout the VA Polytrauma System of Care. VA rehabilitation team members work with family members and caregivers to provide education, training, and information on:

- Caregiver role and caregiver tasks
- TBI rehabilitation process and recovery
- VA and community support services
- How to take care of yourself and stay well.

Each PRC has a Voluntary Services office. This office can help you find resources near the PRC, including places of worship, shopping centers, and other local services.

All four PRCs have a Fisher House on site that offers housing for family members while their service member/veteran is receiving care.

*Learn more about
Fisher House at
www.fisherhouse.org.*

Who is on the Health Care Team?

Your service member/veteran's health care team includes members with different skills and training. The team may include:

- **Your service member/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. It also drives recovery.
- **You, the caregiver—the one who knows your service member/veteran best!:** Your role is to pay attention to what your family member is experiencing. Report problems to the health care team. This helps the team develop the best treatment plan.
- **Audiologist:** A team member who evaluates and treats hearing loss and related disorders, including balance (vestibular) disorders and tinnitus (ringing in the ears).
An audiologist fits and dispenses hearing aids and other assistive devices for hearing.
- **Case Manager/Care Coordinator:** A case manager may be a social worker or Registered Nurse (RN) who works at the MTF or VA center. He or she is the family's Point of Contact (see Module 4). This is the person who will be the liaison between you and the health care team. The case manager learns about the needs (medical, financial, emotional) of your service member/veteran and your family. Then, he or she plans for your family member's move to the next level of care. The case manager is available throughout treatment. She or he can share information to help your family manage the challenges you experience.
- **Chaplain:** The chaplain is a member of the clergy. He or she can counsel you and your family member about how to accept and cope with the changes that a TBI may bring. The chaplain also offers spiritual comfort.
- **Department of Defense Military Liaison:** The team member who helps with questions about benefits and other military-related issues. (See Module 4 to learn about benefits.)
- **Dietitian:** This team member reviews your family member's diet and develops a nutritional plan based on his or her medical needs.
- **Neurologist:** A doctor who treats disorders of the brain, spinal cord, nerves, and muscles. Neurologists are often called upon to manage seizures and headaches.



“The whole team would come in almost every morning to discuss the day and how he was and what was going on. Then they’d have a big weekly meeting. So I felt very involved with his care and I felt like I understood what was going on, on a daily basis. That gave me a lot of comfort.”

- Patty H.



- **Neuro-ophthalmologist:** A doctor who treats visual problems related to the nervous system (that is, vision problems that do not come from the eyes themselves). He or she tracks changes in vision, perception, and the need for lenses.

- **Neuropsychologist:** A licensed clinical psychologist with special training in how the brain affects a person’s behavior.

This team member gives and evaluates certain types of cognitive and emotional tests.

Neuropsychologists may serve as the rehabilitation team leader. They can help both service members/veterans and family members cope with life after TBI.

- **Neurosurgeon:** A doctor who performs surgery on the nerves, brain, and/or spine.

- **Occupational Therapist (OT):** A therapist who helps with “activities of daily living,” like eating, grooming, dressing, and bathing.

OTs also help injured people to re-learn or adapt skills they need to return to work or school. This may include skills such as shopping, cooking, and money management.

OTs provide adaptive equipment and make suggestions for changes in the home.

OTs provide cognitive rehabilitation. They also may help treat swallowing problems.

- **Physiatrist (Physical Medicine and Rehabilitation Specialist):**

A doctor who is often the leader of the health care team. As the leader, he or she directs and coordinates rehabilitation care.

Physiatrists treat problems of all the major systems in the body.

- **Physical Therapist (PT):** A team member who provides services that help restore body function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities from injury.
PTs also determine the patient's level of independence and ability to re-enter the community or workplace after injury.
They teach service members/veterans to use assistive and adaptive devices, such as crutches, prosthetics, wheelchairs, and specialized equipment.
- **Primary Care Provider:** The team member who coordinates the ongoing care of all your family member's general medical needs. Primary care providers may include Family Practice Physicians, Internal Medicine Physicians, Clinical Nurse Practitioners, and Physician Assistants.
- **Recreational Therapist (RT):** A team member who helps service members/veterans become independent in leisure activities and with social reintegration. RTs help with re-entering the community by applying practical skills to real-life situations.
- **Rehabilitation Nurse:** A nurse who specializes in rehabilitation. Rehabilitation nurses educate service members/veterans and their families about TBI and safety, skin care, toileting, medication, and other issues. They 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/veterans and their families (i.e., coping and adjustment problems related to chronic or traumatic injury). They work to help achieve the highest level of functioning after injury.
- **Social Worker:** A team member who may help 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, a team member who specializes in evaluating and treating both expressive and receptive speech and language problems. SLPs may be involved with evaluating and treating swallowing problems. Cognitive rehabilitation is another area of assessment and treatment for SLPs.
- **Vocational Rehabilitation Counselor:** This team member may help your service member/veteran prepare for or retrain for employment.



“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.



The next chapters describe many possible effects of TBI. These include physical, cognitive, communication, and behavioral/emotional effects

If you notice any change in any effects of TBI in your service member/veteran, alert the health care team immediately.



“He was plateauing on a therapy level. We realized that what the therapists were doing—you know, they had a book and they were going through checklists—was like being in school to him. So we suggested that the therapists try working with him on something he wants to learn. They said fine, tell us what he wants to do. So I asked him one night. I said, ‘Jason, 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.

Physical Effects

This chapter is about possible physical effects from TBI.

Module 1 is about how the brain works. It explains that there are areas in the brain that control our ability to perform physical tasks.

After a TBI, the nerve cells in the brain may no longer send information to each other the way they normally do. This is why people with a TBI may have changes in their physical abilities.

A brain injury can affect physical abilities, such as:

- balance
- mobility
- coordination
- muscle strength, tone, and control.

It may also affect the body's senses, including:

- hearing
- vision
- smell
- touch
- taste.

A TBI can cause **fatigue** and conditions such as seizures, **spasticity**, and bladder, bowel, and swallowing difficulties.

Some of these effects will get better quickly, others will take time, and still others may become a lasting problem.

Every person with TBI has a unique set of physical effects. Each person has a unique pace of recovery.

This chapter describes many physical effects that people with a TBI may experience. **Some information in this chapter may apply to your service member/veteran, but other information may not. Some information may apply now, but not in the future.**

With the help of the health care team, many physical effects can be treated or managed with positive results.

You can help your service member/veteran with TBI by following through on treatment plans from the health care team. You can also use the suggestions in this chapter. But first, check these ideas out with the health care team.

The health care team will have many more suggestions and treatments than are listed here. Talk to the team members about "what to do" if

Fatigue is being very tired or weary.

Spasticity is increased tension or tightness in a muscle. When such a muscle is stretched, the increased tension causes it to pull back (resist).

your service member/veteran begins to have new symptoms or problems, or reacts differently to treatments than he or she has been.

What are Common Physical Effects of TBI?

Headaches

Headaches are common following TBI. Some people have a headache all the time, and some people's headaches come and go.

Fatigue, stress, and a history of migraines make these headaches worse.



"He deals with migraines right now on a daily basis, and I think that stress plays along with it. He can't deal with too much at one time. He's overwhelmed. But he deals with the fatigue factor. He's on limited hours right now, so he can only work four hours out of the day. It's very light duty. That's where we're at, right now."

- Meaghan L.

Fortunately, post-TBI headaches usually improve over time.

Treatment Options

Medication: It can take some trial and error to find the right medicine to treat post-TBI headaches. Your family member should take all medications exactly as the doctor directs. He or she should talk with the doctor before changing how much medicine he or she takes, or how often.

Other options: Stretching and strengthening exercises may help. Follow the directions of the health care team on these. Exercise, such as swimming in warm water, can help loosen the muscles that cause headaches. Acupuncture, occipital nerve blocks, biofeedback, Botox®, and physical therapy are possible treatments.

How you can help:

- Ask your service member/veteran to lie down in a dark and quiet place; sleep can relieve a headache.
- Use heat or ice as directed by the doctor.

- Encourage your family member to:

- Avoid bright sunlight, especially going from a dark building into bright sunlight (may need to wear very dark sunglasses).
- Avoid alcohol.
- Avoid foods that trigger headaches. These include cold foods, aged hard cheeses, or chocolate.
- Manage stress. Take breaks during activities, practice deep breathing exercises, exercise, and have some fun.
- 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 medications at the same time every day.

If headaches do not improve or worsen, call the doctor. Your service member/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.

Sleep Changes

Altered sleep patterns are very common after TBI. This problem is usually worst in the first several weeks to months after injury.

Many people with TBI sleep during the day and are awake at night. They may nap now, when before they did not.

Stay hopeful. Most people with TBI do usually resume a more normal sleep routine similar to the one they had before the injury.

Time, patience, and some creative problem-solving help. Developing a consistent routine, using medications on a temporary basis, and changing the bedroom can improve sleep.

What you might see:

- Difficulty falling or staying asleep (insomnia)
- Awake at night, sleeping during the day
- Frequent naps
- Sleeping too much or too little.

How you can help:

- Work with the health care team to establish healthy sleeping patterns.
- Encourage your service member/veteran to:
 - Limit daytime naps (talk to the health care team first).

- Avoid caffeine (coffee, tea, energy drinks, dark soda) after the morning.
- Exercise during the day; avoid exercise too close to bed time.
- Avoid fluids two hours prior to 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 use of bed for activities other than sleep and sex (e.g., watching TV).
- If worrying or nightmares are contributing to poor sleep, consult a doctor or nurse.
- Monitor the bedroom: turn the clock away from the bed, use room darkening shades. Most people sleep better in a cooler environment.
- If your service member/veteran simply cannot fall or stay asleep, have him or her get out of bed and watch TV or read (if easy to do without assistance) until he or she feels tired and is ready to try again.
- Talk with your service member/veteran's doctor about temporarily using sleep medication or complementary/alternative therapies to help establish a sleep schedule.
- Make sure to tell your doctor if your service member/veteran is taking an over-the-counter medication.



"He had tremendous sleep problems, which is extremely common. He met other people who were in similar situations. They'd all be up on the computers or watching TV in the middle of the night, doing things that make their symptoms worse. We went for 25 years with no TV in our home so we're not TV watchers. He would sit and channel surf. And the reason he channel surfed, he said, was because he couldn't concentrate long enough to watch anything very long. He was just going from one thing to another."

- Caroline M.

Fatigue/Loss of Stamina

Fatigue is a common complaint among people with TBI. The body needs a vast amount of energy for healing after traumatic injuries. Sleep is often disrupted in the hospital.

Usual patterns of rest and activity are often very different for many weeks to months after TBI. Confusion can make fatigue worse.

Central fatigue is the major type of fatigue in TBI patients. Central fatigue affects thinking. Working harder to learn and stay focused can make your family member mentally tired. In some people, central fatigue causes them to be irritable or have headaches.

Stamina is having the physical strength to keep on going.

Central fatigue is fatigue of the central nervous system.

“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.

Peripheral fatigue is also reported by many. Peripheral fatigue is physical. It can make pain, thinking, and mood worse.

Fatigue reduces the speed and quality of rehabilitation. Fatigue can also 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 just not what it used to be. They have to pace themselves more than they used to.

Peripheral fatigue is muscle fatigue.

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. Make sure it includes enough rest/sleep. Use a calendar to help your service member/veteran follow the schedule.
- Reduce family and social demands.
- Help your family member to pace him or herself.
- Ask your family member to conserve energy for important tasks in the day.
- Help your family member to have an active lifestyle. Regular exercise increases stamina. The physical therapist can develop a safe exercise program.
- Allow time for undisturbed rest during the day. A nap is usually 30-60 minutes.
- Schedule important appointments for times of the day when your family member is most awake.
- Learn the signs of fatigue in your service member/veteran. Ask him or her to do the same. Make a list of the signs and keep it in his or her calendar/memory notebook.
- Inform the health care team about changes in sleep patterns or stamina.
- Ask the health care team to rule out other causes of fatigue. Common causes of fatigue are endocrine abnormalities, sleep disorders, mood disorders, diabetes, substance abuse, electrolyte imbalances, and nutrition deficits.

Dizziness

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 increased tendency to fall when dizzy or lightheaded.

Dizziness is often an early effect. It frequently goes away during the first weeks following injury.

“He had severe dizzy spells and vertigo from the head injury. Driving in a car was really hard for him. The dizziness in the car went on for three or four months. It slowly started to go away.”

- Emily S.



If dizziness does not go away on its own, there are therapies and medications that may help. These must be used under the supervision of the health care team.

What you might see:

- Complaints that the surroundings are spinning or moving (vertigo)
- Loss of balance, unsteadiness
- Nausea
- Wooziness, lightheadedness
- Blurred vision during quick or sudden head movements.

How you can help:

- Be aware of the possible loss of balance. This can lead to falling and serious injury.
- Fall-proof your home: Remove area rugs and electrical cords that someone could slip on. Use non-slip mats on your bath and shower floors.
- Have your service member/veteran:
 - Sit for a few minutes before walking. This gives the brain time to adjust.
 - Sit or lie down as soon as he or she feels dizzy.
 - Avoid driving a car if frequent dizziness or lightheadedness is present.
 - Use good lighting when getting out of bed at night.
 - Walk with a cane, walker, or other assistive device for stability.
 - Avoid sudden movements or bending over.

- Work closely with the health care team to manage symptoms effectively.
- Talk with the doctor about therapies or medications that improve symptoms.

Balance Problems (Tendency to Fall)

The brain controls our physical movement and our balance. A TBI can affect balance.

Balance problems are often an early effect after TBI. They go away over time and with physical therapy.

What you might see:

- Unsteadiness when walking
- Inability to walk or sit without assistance
- Falls
- Holding onto furniture, walls, other objects when walking.

How you can help:

- Encourage proper use of aids such as walkers or canes, if prescribed, in all settings (community and home).
- Remove throw rugs from your home.
- Work with the physical therapist to learn how to assist your service member/veteran while he or she is sitting or walking.
- Falls are the leading cause of non-combat TBI. Provide or arrange for supervision once you are home to prevent falls and another TBI.



“He was dizzy. He had balance problems. In the first four months, maybe six months after the injury, we just never knew what was going to happen from one moment to the next, and it was like a light switch going on and off. One minute he would be pretty normal, and the next minute it was like somebody flipped a switch and he was dizzy and losing his balance and nauseated and couldn’t remember things, and he was confused. It was the darndest thing.”

- Caroline M.

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. There is often not much to be done about these changes in the first year after injury.

Doctors often use a “wait and see” approach with the hope that sensory changes will go away on their own.

“He had visual field deficits right after the injury. They’ve since gotten a little bit better, but he still has visual field deficits. He lost hearing in his right ear, so he can’t hear sometimes when I’m trying to talk to him.”

- Aimee W.



For some sensory changes that don’t go away over time, surgery may help. For others, therapy and learning to live with the effect will be in order.

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:

- A neuro-ophthalmologist can evaluate visual changes. A neurologist can evaluate other sensory changes.
- Reinforce wearing of an eye patch or special glasses if ordered for double vision.
- Ask your service member/veteran to avoid alcohol. It may increase sensitivity to light and noise.
- Seek professional advice about whether or not it is safe for your family member to drive if he or she is having a change in vision.
- Have his or her 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 if his or her sense of smell has been lost.
- Try to be patient. Sensory changes can improve over the first several months or years after TBI. Work with the health care team to track how the senses are working. Seek further evaluation and treatment options as needed.



“He’s getting a laptop and he’ll be using a special program on it, which the vision therapy here has provided for him. It magnifies everything.”

- Meredith H.

What Physical Effects May Be Less Common?

Spasticity

Spasticity is increased tension or tightness in a muscle. When the spastic muscle is stretched, the increased tension causes it to resist, pull back.

An injury to the brain can cause an abnormal increase in muscle tone called **spasticity**. A spastic muscle does not easily relax the way a normal muscle does.

This effect is most common with a severe and/or penetrating head injury.

Regular stretching, splints to keep limbs in proper position, and medications are common treatments.

Severe spasticity can be painful so pain management may be in order.

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.

“My son’s biggest problem was the spasms. My son was very tight. All his muscles were contracted. He slept with his foot on the floor, because his leg would not stretch out. His arm was contracted to him, against his body. You couldn’t pull it apart from his body. His fingers were tight and closed. He could not open his hands.

They gave him a muscle relaxer. My son’s legs now move. He’s completely relaxed, completely relaxed. It’s amazing what it does for my son.”

- Nellie B.



- 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 include implanting a muscle relaxant pump.

Hemiparesis, Hemiplegia

Muscle movement originates in the brain. A TBI can affect movement.

You may remember from Module 1 that movement of 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.

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/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.

The “hemi” in hemiparesis and hemiplegia refers to the hemispheres of the brain.

- Encourage use of prescribed assistive devices, such as a walker or cane. 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.

Bladder/Bowel Changes

Even bowel and bladder functions are controlled by the brain. For many people with TBI, bowel and bladder functions are impaired in the early days to weeks following injury. Health care providers expect this and are prepared to help. Urinary catheters and use of diapers or pads may be needed. Bowel and bladder 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
- Memory and cognitive problems such that the person does not recognize the need to urinate/defecate or recall when he or she last did so
- 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/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/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/veteran to adhere to the recommended schedule and interventions.

- Monitor for skin breakdown and report it to health care providers.

“He had to learn bladder continence all over again, and that was really tough. I bought a bunch of pants that snapped down the side, the kind the basketball players wear. So he’d be sitting in his wheelchair and right there was the urinal. It was very accessible—those snap pants were a lifesaver. It took a lot of time and patience. Every so often we’ll have an accident, and it’s just like, okay, things happen.”

- Anonymous

Changes in Swallowing and Appetite; Weight Loss or Gain

Many people with traumatic injuries do not drink or eat for a period of time. As a result, they lose weight.

Once the person is fully awake and able to follow directions, swallowing can be evaluated. It is important to fully evaluate swallowing before the injured person drinks or eats.

The purpose of evaluating the person’s ability to swallow is to make sure that what he or she eats goes into the stomach, not into the lungs. When food or fluid slips into the lungs, it often results in pneumonia.

A speech or occupational therapist evaluates swallowing. This may be done in the person’s hospital room.

If not, the therapist may escort your family member to the x-ray department for a video fluoroscopy. Your family member will consume a barium-laced liquid or food that will light up on an x-ray. The x-ray helps the therapist to see precisely where it is going.

Once your service member/veteran is cleared to drink or eat, he or she may only be able to consume certain types of liquids and foods. Most people do best with medium consistencies, rather than thin fluid or very chewy, tough foods.

With practice, most people will return to a normal diet.

Appetite can be affected. Some people with TBI complain of a reduced appetite. Others gain weight due to boredom, memory problems, and an increased appetite.

Work with the health care team to learn how to help your service member/veteran have a healthy diet and a healthy weight.

What you might see:

- Choking or coughing during meals
- Pocketing of food inside the mouth and/or 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
- Memory problems: failure to remember when to eat or when last ate.

How you can help:

- Do not offer fluids or food until your service member/veteran has been cleared to drink and eat.
- 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 to drink and eat if special strategies are needed (i.e., eat slowly, chin tuck during swallow, double swallow, follow every bite of food with fluid).
- Short term changes in appetite are common. Don't worry about early weight loss. Most often, the weight is regained once the person is home.
- Monitor your service member/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.
- It is common to have reduced taste and smell following TBI. Talk with the dietitian about how to use spices and flavorings to perk up the taste of food.
- Weight gain following TBI is common. It is usually due to lack of physical activity. But sometimes it is due to boredom. Work with your service member/veteran to remain physically active and engaged



in outside activities. Establish set meal times. Discourage overeating or too many snacks.

- Encourage your service member/veteran to be involved, as able, in grocery shopping and meal planning/preparation.
- Write meal times in the planner/memory book. Check off meals when finished.

Visual Spatial Problems

Visual **spatial** abilities begin in the brain. They include blind spots and/or changes in the brain's ability to understand what the eyes see.

The ability to perceive where you are in space and in relation to other items in the environment may also be affected by TBI. This is called **spatial** awareness.

Injury to the right side of the brain in particular can lead to difficulties in these areas.

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
- Turning head towards the unaffected side
- 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:

- Ask for a neuro-ophthalmologist to identify your service member/veteran's specific visual and/or visual spatial problems.
- Stand on and place objects on the affected side. Encourage your service member/veteran to look to that side (this is called visual cueing).
- Remind your service member/veteran to frequently look around the environment, especially toward the affected side (this is called visual scanning).

Spatial refers to understanding where you are in the space around you.

- 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/veteran around new places several times. Avoid sending him or her to new places alone.
- Limit clutter in the house. Try not to move items around.
- Remind your service member/veteran to use handrails when available.
- Provide gentle reminders that 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/veteran to drive (see Module 3).



“As far as training him for his left side neglect, when we would eat, he would put everything on the right side, and I would move everything to the left side to help him learn that. In the bathroom, I moved everything to the left side of the counter. So that was definitely a suggestion from the staff, to get everything to the left side so that he’s using that training.”

- Sandy M.

Apraxia is the reduced ability to perform complex movements.

Apraxia

A person with **apraxia** can often understand what to do and has the physical ability to do the task. However, his or her body simply has trouble cooperating with his or her best intentions.

This is a direct result of injury to the brain, often to the parietal lobe (see Module 1).

People with apraxia may have trouble using items correctly.

What you may see:

- 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, inside out.

How you can help:

- Guide the person 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/veteran to perform other common tasks in the correct order, one step at a time.

"He has what they call apraxia, which is one of many cognitive deficits that have occurred. He has issues with sequencing; for example, if he were going to make a sandwich, he wouldn't know how to put these things in order like you and I would, he would get confused. He wouldn't know what to do first, what to do second, like when to cut a sandwich in half and how to pick it up... the sequencing."

- Cindy P.



-
- Write down instructions for your service member/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/veteran's calendar/memory notebook.

Seizures

Seizures happen when the electrical system in the brain misfires.

Seizures can be frightening to watch.

Two kinds of seizures may occur following a severe TBI:

- Early seizures—also called “generalized seizures” or “Grand Mal seizures”—typically happen during the first week after an injury.
- Later seizures usually occur after the first week of injury in individuals who have never had a seizure before. People who have late-onset seizures are more likely to have a penetrating injury or one that causes a large amount of bleeding in the brain.

Seizures can be temporary or chronic. Late-onset seizures carry a greater risk of future seizures than do early seizures.

Chronic means ongoing.

A neurologist is the member of the health care team who usually diagnoses seizures. He or she will treat seizures with medications.

What you may see:

- Generalized shaking or jerking of the arms and legs
- Loss of consciousness
- Altered attention, emotion, sensation, or movement
- Strange odors or sensations.

Late-onset seizures can also cause changes in smell, behavior, or personality. Sometimes, people mistake a seizure as a psychiatric disorder.

Ask your doctor early on about how to recognize a seizure and what to do if one occurs.

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.
- During a seizure:
 - 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 the 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/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.

Some things are triggers for seizures. These include:

- Stress
- Overuse of alcohol and/or other drugs
- Being overworked and/or tired.

Help your service member/veteran to avoid these triggers.

"I wish the doctors had educated me about seizures early on, because the likelihood of him having seizures was pretty high given the type of injury he had, and I had no education. And the first seizure he had, I thought he was dying. I had no idea what was going on.

There are some things--like if you lack sleep or if you have too much caffeine or if you drink alcohol--that may be triggers for some people. I think there should be education, too, about the different kinds of seizures, like what they are and what they look like... for me, it was very scary the night Pat had a seizure. Everyone has a seizure threshold, but, for some people, once you have a brain injury it can drop way down. They're more concerned about seizures in the first three weeks because those can be more dangerous. It's important for family members to know you're not out of the woods even after the first few weeks. Pat's was at four months and the husband of one of my friends developed seizures almost a year after his injury."

- Patty H.



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 he or she has a seizure disorder.

Heterotrophic Ossification

Heterotrophic ossification (HO) happens when bone forms in an unnatural location, such as in soft tissue or muscle.

What you may see:

- Swelling, warmth, limited range of motion, pain in soft tissue areas or a muscle.

How you can help:

- Rest the arm or leg where the pain is. Ask for physical therapy to maintain range of motion.

With the health care team's help, many physical effects can be treated or managed with positive results.



Journal

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

*What physical effects have you observed in your service member/veteran?
How severe is the effect?*

Is there one particular instance that stands out for you? Describe what happened and how you reacted.

What impact have these physical effects had on you? On other members of the family?

What strategies have you tried to use to help your service member/veteran cope with physical effects? How well have they worked?

What strategies do you plan to try in the future?



Cognitive Effects

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.

In most cases, cognitive problems improve over time. Time, rehabilitation, and the natural healing of the brain all help thinking to improve.

Cognitive recovery often takes longer than physical recovery. Try to be patient. Remember that it is an injury to a specific part or parts of the brain that causes cognitive problems.

This chapter reviews cognitive changes your family member with TBI may experience. Strategies are listed that may help you and your service member/veteran with TBI to make up for the loss of some thinking skills.

Just as with physical problems, not everyone with a TBI has the same cognitive problems. The neuropsychologist, OT, and speech language pathologist are the health care team members who identify and treat cognitive problems.

What is a Neuropsychological Evaluation?

Module 1 described tests—like MRIs and CTs—that doctors use to examine the brain and its physical injuries.

There is a different test to figure out how well the brain is working, i.e., how well the person is thinking. This test is called a neuropsychological evaluation. A neuropsychologist conducts this test.

First, the neuropsychologist will learn as much as possible about the person and what he or she was like before the injury. He or she may ask you questions about your family member.

Next, the neuropsychologist will use a number of different tests to see how the person's brain is working and where there are cognitive problems.

Testing may measure:

- attention span
- orientation
- memory
- concentration
- language (receptive and expressive)
- new learning

- mathematical reasoning
- spatial perception
- abstract and organizational thinking
- problem solving
- social judgment
- motor abilities
- sensory awareness
- emotional characteristics
- general psychological adjustment.

These tests can take several hours to complete.

Based on what the tests show, the health care team will develop treatment plans to improve cognitive problems. Occupational therapists (OTs) and speech language therapists are the members of the health care team who do this work.

What are Common Cognitive Effects?

Confusion

Most people with severe TBI experience some confusion after their injury. It is expected.

Sometimes confusion only lasts minutes. Other times, it can last days or even weeks.

Keeping your family member safe, reminding him or her about what's going on, and offering reassurance are important during this stage of recovery.

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/tasks in schedule of activities
- Confusing past and present events
- Making up convincing stories to fill memory gaps (This is called confabulation. See page 43 to learn more.)



How you can help:

- Keep your family member oriented. Put calendars, clocks, family pictures, and/or a sign about where he or she is and what has happened, in his or her room. A list of health care team members and what each one does may also be useful.
- Use a notebook to plan for and log events. Have your family member refer to it for details of daily events.
- Frequently remind your service member/veteran of correct details of past and present events.
- Limit changes and provide structure in a daily routine.

Slowed Speed of Processing

Many people with TBI complain 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.

Slowed speed of processing can add to confusion.

What you might see:

- Taking longer to answer questions
- 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.
- Break complex tasks and activities down into smaller steps.
- Allow extra time to respond to questions and to comprehend and learn new information.

“Processing is very slow, just taking things in—he would repeat things over and over.

You try to do everything for them. They’re trying to do things and you’re tired... then you start over again trying to do everything for them to speed things up, which doesn’t help. They need to do things for themselves as much as possible. Rehab is the main thing.”

- Denise G.



- Avoid situations that are overstimulating (e.g., noise, crowds).
- Suggest a different activity or topic of conversation to help the person remain on task.
- Encourage your service member/veteran to ask others to slow down and repeat information.

Attention Problems

The ability to focus, to 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.

It is not uncommon for a person with a severe TBI to only be able to attend for a few minutes at a time in the beginning.

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:

- Focus on one task at a time.
- Be sure you have your service member/veteran's attention before beginning a discussion or task.
- 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 (watches, PDAs, or other devices) and checklists in the calendar/memory notebook to help with completion of tasks.
- Refocus attention to the task at hand.
- Expect a short attention span. Schedule rest breaks and/or stop an activity when you notice drifting attention.
- When signs of distraction arise, insert a rest break ("Let's do this for another 5 minutes and then take a 15 minute break.").
- Present verbal or visual information in limited amounts.



Difficulties with Memory

Memory problems happen often after a TBI. Past memories or long-term memory is nearly always intact. Recent memory, called short-term memory, is much more often affected.

Short-term memory often gets worse as fatigue increases.

Short-term memory usually improves over time.

Memory **compensation** means learning to use memory tools, such as a calendar, planner, organizer, or memory notebook.

Signs with instructions, lists, and notes are other effective memory compensation tools.

Ask the health care team about which memory tools would be helpful for your family member.

Compensation means finding another way to do something. For example, if you can't remember something in your head, write it down.

"He has severe memory issues. He has a PDA to keep him straight on what appointments he has, what medications he needs to take, things like that. That's helped him a lot."

- Meaghan L.



These tools may also help you remember everything you need to do!

What you might see:

- Can't remember information from day to day about people, conversations, places, events, appointments, dates, and telephone numbers
- Keys, wallet, etc. are frequently lost or misplaced
- Repeating questions or the same story over and over again
- Can't learn new information and use it in everyday life.

How you can help:

- Get the person'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.



- Help your family member use memory aids on a regular basis. Write down tasks on a calendar or notebook. Check tasks off when done.
- Explore use of “high tech” memory aids. Personal digital assistants (PDA), wristwatch alarms, and cell phones can remind your family member when to do a task, such as taking medication. Before spending money on these devices, ask the OT or speech pathologist whether your family member can learn to use the technology.
- Buy a pill box and label each compartment with the time and day that medication should be taken. Write the names of medications and when to take them into the calendar/memory notebook.

- Keep personal and household items in the same place.
- Try to pair new information with things the person is able to recall.
- Provide verbal cues for recall and help fill in memory gaps.
- Talk to your service member/veteran about the activities and events of the day to help build memory.
- Have your service member/veteran review plans for the following day.
- Learn and use a **cueing** system (see section on cueing at the end of this chapter).
- 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.



To cue is to instruct or prompt someone to do something.

Planning and Organization Problems

Organization and planning skills are often affected by TBI.

These skills improve over time. The health care team will work with your family member to develop better organization and planning skills.

You may need to remind your family member again and again to use the skills he or she learns in therapy until they become a habit.

"His biggest problem is naming. He has a hard time naming anything. So we have picture cards. We go through the cards all the time, just to get him to name an object. We can even go through the house or if we take a walk, I ask him to name things... what is this? This is a sidewalk. What is this? This is a tree. What sort of tree?"

- Patty H.



"He has a PDA, and he does make lists, but that's a battle in itself. Early on I had sticky notes everywhere and lists of things that he needed to do when he got up in the morning, things that he would need to get before he left for his therapy, that kind of thing.

And over time I see that we're regressing in that department, so I'm actually in the process of getting those lists back out because he definitely has a memory issue, even with taking his medication every day. There will be times that he forgets."

- Sandy M.

What you might see:

- Problems organizing time to get things done
- Problems understanding which tools are needed to complete a task and getting them together
- Problems breaking down complex tasks into smaller steps
- Having a hard time getting ready for work, school, and appointments
- Being late for appointments and 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:

- Begin with small, realistic tasks.
- Work with your family member to get organized at home. Keep a family calendar posted on a wall. Use reminder notes and cue cards (example at the end of the chapter).
- Have a place for everything and keep everything in its place. In particular, keep your service member/veteran's belongings in certain places.
- Turn off the radio/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/veteran to decide which information or activity has the highest priority.



"He has his talking watch because he has some issues with his vision. So his watch tells the date and the time. And he also has a beeper that's preset by speech therapy, and it goes off five minutes before he has an event, like therapy or something scheduled. The beeping, the auditory cue, lets him know to look at his book, which is just a three-ring binder notebook. It has his schedule, like Monday through Friday and a time on one side. So he picks the day and then looks at the time according to what his watch says, and then he knows where he's supposed to be."

- Meredith H.

Difficulty with Decision Making and Problem Solving

Making decisions and solving problems take a lot of thinking. Both can be hard for people with TBI.



Simple decision making and problem solving are easier than more complicated decision making and problem solving.

What you may see:

- Taking a long time to make a decision
- Making inappropriate and/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/veteran make decisions when tired, hungry, or under stress.
- Help your family member to weigh options and consequences of a decision.
- Give your service member/veteran time to make a decision. Be patient and talk him or her through the possible options.
- Limit the number of possible choices. Two or three choices is 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 (see tips for problem solving at the end of the chapter).

Confabulation

Confabulation is a memory problem. It happens when a person with a brain injury 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.

Confabulation is the direct result of injury to the brain. It may go away on its own.

The health care team will work with your service member/veteran to reduce the effect by helping him or her to become more aware of it.

What you may see:

- Making up convincing stories to fill memory gaps.

How you can help:

- Don't accuse your family member of lying.
- Gently help your family member become aware that this memory is not accurate.

How Can You Help to Build Thinking Skills?

Occupational therapists (OTs) and speech language therapists are the members of the health care team who teach cognitive skills.

They teach memory compensation skills. They also develop systems for cueing and providing feedback to your service member/veteran.

You can learn a lot from these therapists about how to use these techniques. The more everyone uses these techniques, the more benefit to your family member.

Compensation Strategies

Compensation strategies are ways to help your family member manage cognitive changes. They build on the person's strengths. At the same time, they make up for deficits in thinking caused by the TBI.

Each person is unique. A compensation approach that works for one person might not work for another. What works during structured inpatient rehabilitation may not work in the same manner at home. Try approaches out with your service member/veteran with help from your health care team. If an approach does not work well, review it with a provider and try other strategies. Continue to use your health care team as experts in designing compensation approaches most likely to work for your service member/veteran with TBI.



The OT, PT, and speech language pathologist are the health care team members who assess how well your family member is thinking. They will develop a cognitive rehabilitation program for your family member. Their assessments will pave the way for return to the community and will help decide if your family member can return to duty, work, or school.

“We would play Trouble, where you have to count how many squares you move. We would play Connect 4. We played Phase 10, Skippo, Uno, and sequence games. We played board games where you have to count your spaces. In the beginning, one of the things we did was we got the little children’s blocks where four blocks make a picture, and then another four blocks make another picture. In the beginning, he couldn’t put the four blocks together to make a picture. He couldn’t figure out what picture went with what. I mean, he’d have an airplane with a ladybug. He also had trouble putting the shapes into the right size hole. When you think about it, you’re thinking this is very easy, but it definitely was a challenge for him.”

- Sandy M.



Cueing

Cueing means to give a signal to begin a specific action. Cueing prompts your service member/veteran to stop and think before acting.

Cueing strategies are best learned from the therapists working with your service member/veteran. Attend therapy and observe how they cue the person. The goal of progressive cueing is to move your service member/veteran from having to be “told what to do” by you and rehabilitation team members to being able to independently cue, or remind, him or herself what he or she needs to do. Learning how to self-cue increases self-reliance. Consistency in approach increases the odds of success.

Try the following methods for cueing your service member/veteran with TBI:

- Guide your service member/veteran by asking questions.
 - Ask questions that will help the person find a solution, such as “What could you do to help yourself next time?”

- Avoid asking questions that do not help solve the problem, such as “Why did you do that?”
- Provide verbal or nonverbal cues.
 - An example of a verbal cue is to say “Stop and think, what else could you do?”
 - An example of a nonverbal cue is pausing or not acting immediately to help the person recognize the need to use a strategy such as “stop and think.”
 - Use a signal you have agreed upon ahead of time, such as a raised finger or a head nod.

CUE CARD - Preparing a Meal

- Decide on a menu
- Count number of people eating
- Look at the needed ingredients
- Look in the pantry for what you have
- Prepare shopping list and shop
- Follow recipe instructions and organize time
- Serve and eat meal
- Clean up

- Types of cues:
 - **Direct Cue** – a specific prompt. For example: “Did you look in your calendar?”
 - **Indirect Cue** – a general prompt: For example: “Where could you find that information?”
 - **Self Cue** – “Where could I find that information?”

CUE CARD - Thinking Strategies

- Slow down, pause, STOP and THINK
- Take my time
- Don’t assume
- Check things off as I go along
- Ask questions to make sure I understand
- Repeat back what I heard
- Take notes
- Underline important information
- Double check my work
- Write down information in my own words
- Ask myself, “Do I want to be quick or accurate?”
- When I get bored – stretch, take a short break, walk around
- When I get angry – doodle, take a break, and then come back





5W Strategy

Therapists may also teach the 5W strategy to help your service member/veteran learn more efficiently. Learning in the face of a short-term memory deficit can be challenging. This technique will help as it allows the person to save time. Instead of reading information over and over again, the person is taught to focus and pick out the main points of what he or she is reading.

Read and Remember

- Who
- What
- Where
- When
- Why

Why 5W Strategy Works:

Writing out or saying something out loud reinforces accurate memory. The 5W strategy also simplifies the information so main points can be recalled.

Your service member/veteran may have difficulty at first but practice helps.

Example of the 5W strategy:

Making/taking a message – write down all 5 points (W's) of the message

Who: Mom
What: Call about lunch
Where: Meet at our favorite restaurant
When: Friday at noon
Why: To talk about vacation plans

Feedback

Feedback means giving information to your family member about how he or she is doing. A brain injury can make it hard for a person to fully understand how he or she is behaving. Feedback from others can help the person see what is going on.

The best time to give feedback is right away, just after the situation happened. If your family member has memory problems, it can be hard for him or her to remember what happened for very long. So prompt feedback is best.

You need to give feedback in a firm but gentle manner. This may be hard at first, but keep practicing. It will get easier. A direct and supportive approach works best.

Consistency is another key. Attend therapy as much as you can to learn how to provide feedback to your service member/veteran. You can also learn how your service member/veteran tends to respond to different types of feedback. The more consistent the approach, the more likely the feedback will have a positive impact on the thinking and behavior of your service member/veteran.

Problem Solving

Learning how to be a good problem solver can help you and your service member/veteran cope with stress and reduce anxiety. Therapists will often work closely with your service member/veteran to improve problem-solving skills. The following simple problem-solving steps can be effective in helping to break down problem solving into a more manageable task. Writing down the answers can be helpful and allow the person to better “see” options. Reinforcing use of this technique is one way you can help with problem solving, both in the rehabilitation setting and when you get home.

- Identify the problem. If the problem has many parts, break it down into one problem at a time.
- Brainstorm solutions. 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 for you.
- Try the solution out.
- Evaluate the solution. If it didn't work, try another solution until you find the one that works.



Here are some examples of problem solving. Fill in the worksheet with examples from your own experience.

Problem Solving Worksheet

The Problem	Potential Solution	How It Worked
<i>Sallie has to be at school at 8:15 and Don's medical appointment is at 8:30 across town. I can't be in both places.</i>	<i>Ask Terry's mom if I could drop off Sallie at her house early and she could drive Sallie and Terry to school together.</i>	<i>Worked great!</i>
<i>I can't remember what the doctor told me to do about John's memory problems.</i>	<i>Ask again at the next appointment.</i>	<i>I still forgot—he's not the only one with memory problems!</i>
<i>Nothing's changed—I still can't remember what to do.</i>	<i>Next appointment, I will take a notebook with me and write down his answer.</i>	<i>Now I can refer to my notes and don't feel so worried about it.</i>



"The most important piece of equipment he has is his cell phone. I said, 'How are you going to have a phone if you can't read and you can't do the numbers?' And he said, 'Mom, you use call voice command.' I'm thinking, gee, who has the brain injury here?"

He had to tell me, and I thought, oh, my gosh, you're absolutely right, Shane. He's the one that came up with that. Not even the doctors brought that up.

We do have to key in the phone numbers. If he wants a friend's number or asks for that, he'll say, 'Okay, here's my phone number. Call me. When you call me, I'll know that's you and then I'll have my mom key in your name. Or here's my phone, put in your name and key in your number so I can call you.' And it works.

And that is our safety net because whenever he is away with someone that I'm not really sure about, I make sure that I call or he calls so that we keep that open line of communication."

- Cindy P.



Journal

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

*What cognitive effects have you observed in your service member/veteran?
How severe is the effect?*

Is there one particular instance that stands out for you? Describe what happened and how you reacted.

What impact have these cognitive effects had on you? On other members of the family?

What strategies have you tried to use to help your service member/veteran cope with cognitive effects? How well have they worked?

What strategies do you plan to try in the future?



Communication Effects

A TBI can cause changes in a person's communication skills. These changes vary from person to person.

How severe the injury is and its location affect these changes.

Factors that play a role in communication problems include:

- behavior
- memory, attention, and other thinking skills
- judgment
- social skills
- self-awareness.

Communication skills are very important in everyday life. Your family member may not be able to use words to express him or herself well. This can be very frustrating. Many people with TBI do well speaking in non-stressful situations. But your service member/veteran may not be able to use these speaking skills during a stressful situation at school, work, home, or in the community.

Language problems can lead to miscommunication and confusion. This may make it harder than it used to be to make new friends and maintain old relationships. A positive note: Most people with a TBI do, in fact, speak again. Most make notable progress in the other areas of communication over time.

A speech language pathologist (SLP) is the team member who treats communication problems. Your service member/veteran may be able to speak, but may need training to:

- understand and remember what is being said
- express needs, wants, and ideas clearly to others.

The SLP treats problems with speech, voice, and memory.

What are Common Communication Effects?

Language and thinking are linked. Language involves understanding, talking, reading, and writing.

In this chapter, you will read about some common communication effects from a TBI. You will also learn about ways that you can help your family member with these effects.

Each person with a TBI will have different communication problems. Some are more severe than others.

Communication problems occur when the frontal and temporal lobes of the brain are injured.

Hearing or vision loss make it harder to communicate well. If your family member is having communication problems, his or her hearing and vision should be checked.

Use this chapter as a guide. Talk to the speech language pathologist, neuropsychologist, and doctor about the specific areas that are hardest for your family member.

Feedback is important to help improve your family member's communication.

"When he started to speak again, his speech was impaired, wasn't good. The first time he said a word, one day, like a Friday, he was saying a word. On Saturday, he was doing phrases. And on Sunday, he was doing sentences.

To me, he does not sound like he did before the brain injury. He's clear. He can carry on a conversation with you. If you talked to him, you would probably think he was just fine. I know there's a difference in his speech, but it's not enough that an average person would know he's got a brain injury."

- Pam E.



Does Not Speak Clearly

What you might see:

- Slurred speech
- Speaking too loudly or softly
- Speaking too rapidly.

How you can help:

- Tell your family member that you did not understand what he or she said. Ask him or her to say it again more slowly.
- Use a consistent cue or gesture to let him or her know you did not understand. For example, cup your hand over your ear as a reminder to speak louder.
- Allow time for your service member/veteran to express him or herself.

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
- Does not respond to another's questions or comments.

How you can help:

- Help your service member/veteran start a conversation by asking a leading question such as, "What do you think about ...?"
- Encourage your service member/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/veteran with TBI your full attention.
- Give your service member/veteran time to organize his or her thoughts.
- Use redirection, if necessary (e.g., "So what do you think about....?")
- Reinforce all efforts to start a conversation. Show that you value what your service member/veteran has to contribute to conversations.

"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 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.



Word Finding Problems

What you might see:

- Problems finding the right word to describe what he or she is trying to say.

How you can help:

- Give your family member time to locate the word he or she is looking for.
- If he or she still cannot locate the word after some time, guess at what he or she might mean. Or ask him or her to write it down.
- Try to be patient. It can be very frustrating for your service member/veteran when he or she knows what he or she wants to say but cannot locate the right word or phrase.
- Encourage him or her to use another word that is close in meaning.
- Suggest that he or she use many words (or a description) instead of using a single word. (This is called circumlocution, a strategy speech language pathologists will often teach.)



“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.

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:

- Get your service member/veteran’s attention before speaking.
- Be clear and to the point. Keep it simple.

- Reduce distractions.
- Every so often, stop and ask your family member to restate what he or she heard to ensure understanding.
- Reduce your rate of speech and pause frequently to allow the person time to process and respond.
- Avoid abrupt topic changes.
- In group conversations, help set a slower pace of conversation.

“To improve our communication, I had to learn to make shorter sentences. I ramble a lot. So I had to learn not to ramble... to ask myself, what am I thinking? I had to really consolidate my thoughts before I approached him on a subject. That has helped our communication a lot because he’s not way out there in left field zoning out because I already lost him at sentence two.”

- Shannon M.

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/veteran.
- Review the 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?
- The 5W’s should be related, that is, they should refer to the same characters or portion of the story.

- Your service member/veteran can write out important information or say it out loud; this uses other senses to increase comprehension.
 - Emphasize important information in the text.
-



"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.

"He couldn't read or write. He can now, after two years of therapy--it's a very slow process, but he can recognize signs, and in time he was able to write his name and his Social Security number and his phone number. Now, mind you, if you show him a sign and it has numbers on it, it takes him a while to even understand what that is. He learns with repetition and sometimes those signs have no meaning to him, especially if there are words with the pictures.

Now, he can see that's the McDonald's sign, that's a Wendy's sign, and he surprises me sometimes. He'll say, 'Well, that's so and so.' 'Now, how did you know that?' And he says, 'Well, it just looks like it is.'"

- Cindy P.

What Communication Effects Are Less Common?

Dysarthria

Dysarthria means having a hard time using the muscles needed to form words and produce sounds.

What you might see:

- Speech is often slow, slurred, and garbled
- Problems with intonation or inflection.

How you can help:

- The speech language pathologist will prescribe exercises to improve the muscles used in speaking. Over time, these exercises will make your family member's speech more clear. Help him or her to do these exercises properly and regularly.
- Allow ample time for your service member/veteran to express him or herself.
- Encourage him or her to take time to speak.
- Inform those around your service member/veteran about the diagnosis so they too allow the person time to express him or herself.

"While in the hospital, he stuttered when he would get angry or frustrated. He would often forget his thoughts. He would be on a train of thought and he'd just forget where he was going, which caused him to be frustrated. So you really couldn't have a two-sided conversation with him early on because he'd want to be talking the whole time, and God forbid he loses his thought."

- Kristen S.



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 for the situation
- 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/veteran you would like to say something.
- Ask your service member/veteran to please make it brief.
- Develop a hand signal which indicates to the service member/veteran that he or she may be monopolizing the conversation.
- Gently alert him or her to the fact that the topic change was too abrupt or that he or she has interrupted and will be given a chance to say his or her piece in a moment.
- Use positive reinforcement for all attempts at listening rather than talking.
- Your service member/veteran may be interrupting because he or she is “lost” in the conversation. Encourage him or her to let you know if he or she doesn’t understand what is being said.

Topic Selection Problems

What you might see:

- Problems finding good topics for conversation
- Problems keeping up when topics change
- Introducing a new topic abruptly
- Problems staying on topic.

How you can help:

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





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/veteran. For example, write letters to friends or relatives.
- Make a list of openings (i.e., Dear, Hello, Hi, etc.) and closings (i.e., 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.

Nonverbal Communication Issues

What you might see:

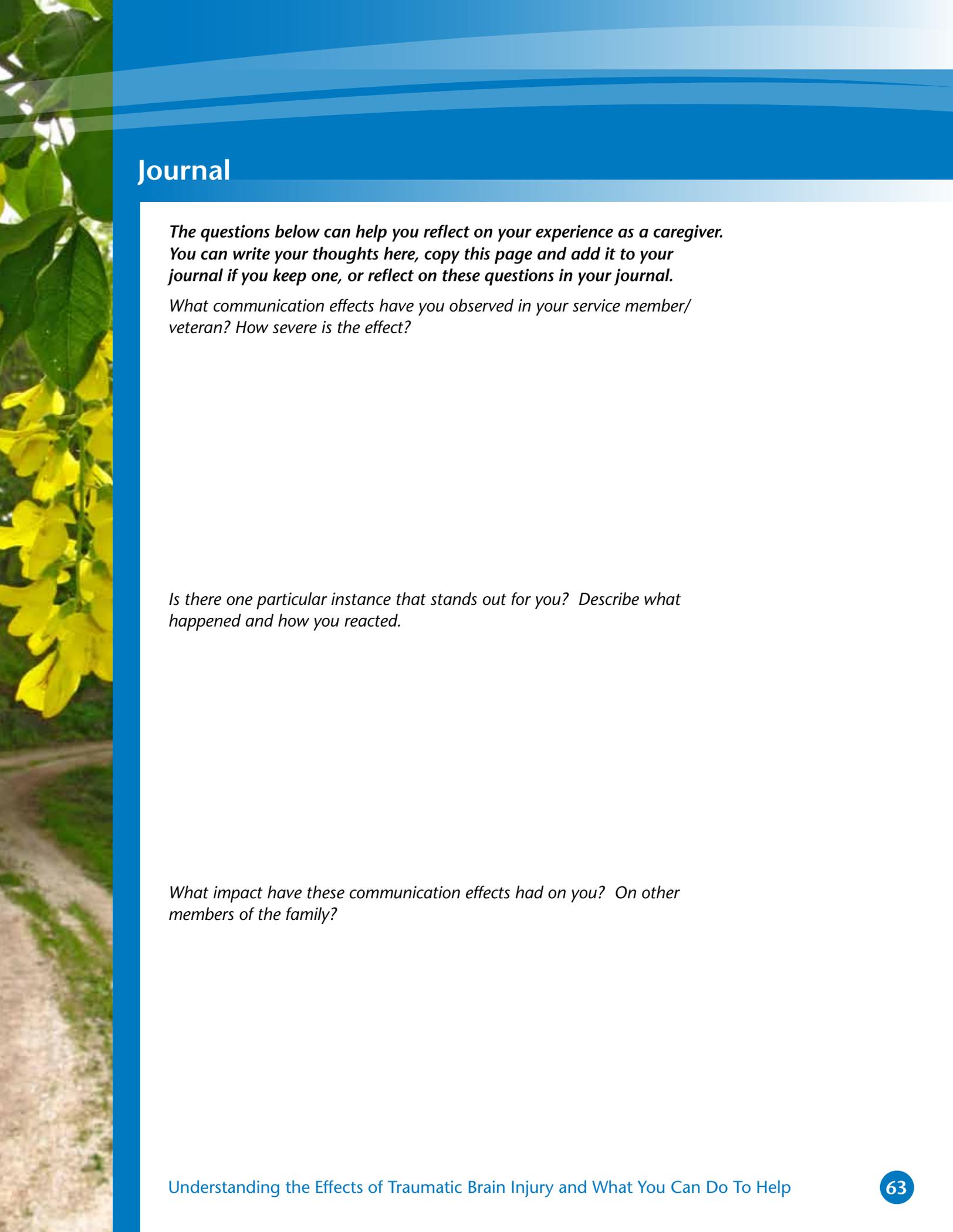
- Having a hard time understanding common nonverbal cues (e.g., facial expressions, hand gestures)
- Standing too close or too far from those he or she is speaking to
- Uncomfortable number/type of physical contacts
- Body language that doesn't "match" what is said
- Facial expressions that don't "match" what is said
- Poor eye contact
- Staring at others during conversation.

How you can help:

- Politely ask your service member/veteran to stand closer or further away.
- Explain the behavior is making you feel uncomfortable.
- Tell your service member/veteran you are confused by the difference in body language and spoken message. Briefly explain what you saw and heard.
- Ask him or her 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. This will help decrease behavior that causes problems.

- Talk to your family member about how to act in certain situations, before he or she is 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.





Journal

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

What communication effects have you observed in your service member/veteran? How severe is the effect?

Is there one particular instance that stands out for you? Describe what happened and how you reacted.

What impact have these communication effects had on you? On other members of the family?

What strategies have you tried to use to help your service member/veteran cope with communication effects? How well have they worked?

What strategies do you plan to try in the future?



Behavioral and Emotional Effects

You may notice changes in the way your family member acts. People with a TBI may have many emotional and behavioral effects.

That's because our brain controls the way we act and feel. An injury to the brain—usually an injury to the frontal lobe—causes changes in emotion and behavior. The life changes that happen after a TBI also affect how people act and feel.

Changes in behavior may include:

- frustration, increased anger/aggressiveness
- impulsivity or difficulties in self-control
- faulty or poor judgment
- decreased ability to initiate conversation or activity
- repetitive behaviors (perseveration)
- less effective social skills
- changes in sexual behaviors
- impaired self awareness about how TBI impacts him/herself and others.

Emotional effects may include:

- depression
- increased anxiety
- mood swings (emotional lability)
- changes in self-esteem.

Pay attention to changes in how your family member acts and feels. Ask the health care team for advice. They can help your family member manage these changes through counseling, medication, and healthy coping behaviors.

“He’s very blessed that he has retained his personality and his speech. He does have anxiety--with the anxiety comes a little depression. He also has a short fuse and frustration. Sometimes we still see some PTSD mixed in there, and that kind of intertwines with the TBI. Some of those symptoms kind of intertwine.”

- Cindy P.



What Are Common Behavioral Effects?

Frustration, Increased Anger/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 he or she once did. Sometimes, he or she may not know what others expect. This can be frustrating.

You may notice a quicker temper or a tendency to fly off the handle more easily.

Loss of independence, fatigue, overstimulation, or cognitive problems can also lead to feelings of frustration and anger.

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, and 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.



"If I try to talk to him about issues with our family or the relationship or whatever, he can't handle it. Emotionally, he just can't deal with that kind of stuff. He does have mood swings occasionally, some of which have not been so pretty. I think sometimes the fight or flight kind of thing kicks in, and then sometimes he has actually left the house. Little things that might sit normally and not aggravate someone will aggravate him and he'll get upset about it."

- Aimee W.

This can be a good signal to others in the family that your family member needs to be alone for awhile.

- Remain calm. Encourage your family member to recognize when he or she is becoming angry or frustrated. Help him or her learn to ask for a break or some space to calm down.
- Reinforce all efforts to use effective anger management strategies.
- Prepare your service member/veteran for challenging situations when possible.
- Simplify tasks and 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.
- Approach challenges calmly and allow yourself to take a break when necessary.
- If your family member is often angry, 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.

“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,

(continued)



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.

Tell the health care team if anger increases or your family member is violent. You do not have to tolerate verbal or physical attacks.

Your family member is no more comfortable with this behavior than you are. Get help. There are effective medications and behavior management approaches to help manage angry outbursts.

Impulsivity means responding quickly, without thinking the situation through.

Impulsivity or Difficulties in Self-Control

Many individuals with TBI react before thinking. "Stop and think" is a good way to help a person make up for various cognitive problems. It allows the person to stop, slow down, pause, and take the needed time to think about something before doing it. This allows time to develop a reasonable plan or response.

What you might see:

- Saying whatever comes to mind without thinking about how it might affect the person him/herself 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 he/she is doing or saying something inappropriate (e.g., raising your finger, saying a special word).
- Suggest that your family member stop and think, slow down, and consider options.
- Praise and reward desired behaviors; discuss consequences in private, after the fact.
- Avoid comparing past and present behaviors.

“People just don’t know a lot about brain injury, and I try to educate them in the sense that there’s a lot of things emotionally that Jason doesn’t have control over, and you have to learn to not take it personally because it’s not a personal attack. It is what it is. Not that it’s excusable or that it is acceptable, but Jason is also learning good public behavior: what’s okay to say, what’s not okay to say, and when enough is enough. That’s definitely where I come in with the cueing.”

- Sandy M.



Poor Judgment

Sometimes it’s hard for a person with TBI to analyze a situation and understand what could happen.

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.
- Role play with your service member/veteran to prepare him or her for various situations.
- Have him or her try the solution out.
- Evaluate the solution. If it didn't work, try another solution until he or she finds the one that works.

"I think that early in his injury--especially with severe TBI--to me, watching him go through his recovery was like watching a child go through a really rapid growth phase. He went through that toddler phase when he was just learning his ADLs (Activities of Daily Living). Then he went through the adolescent phase where he was gaining some independence and learning his bounds. Then he went through that teenage phase where he was trying to take control of his life and impulsivity became a real issue. Finally, now we are in the adult phase where things have begun to balance out. There are still good days and bad days, but more good days as we move forward."

- Shannon M.



Initiation means "get up and go." A person who initiates is a self-starter.

Reduced or Lack of Initiation

Your family member may seem to have lost interest in activities he or she used to enjoy. You may find yourself offering frequent reminders to do simple tasks, like brushing teeth or taking a bath.

Your service member/veteran may not begin activities on his or her own. This is not laziness. Injury to the brain is the reason.

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/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/veteran to develop a list of goals or tasks to be completed. Help your family member check off completed tasks so he or she can see progress.
- Encourage your service member/veteran to become involved. Having purpose along with structure can help.

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 is the cause.

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?", "when can I go home?", "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 he or she is verbally "stuck" on a topic.
- Try engaging the person in a conversation or thinking task if he or she is physically "stuck" on a task.

Less Effective Social Skills

Social skills 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.

Social skills form the foundation for relationships with others. They include:

- Thinking of topics for a conversation

- Listening to the other person without interruption
- Keeping the conversation going
- Reading the facial and verbal cues that the other person sends and responding to them
- Knowing when and how to end a conversation.

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:

- React calmly.
- Role play or rehearse responses to social situations.
- Use an agreed-upon signal to let your service member/veteran know that he/she 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.

Changes in Sexual Behaviors

Many people with TBI change how they act during intimate moments.

Those with moderate to severe TBI may sometimes act in sexually inappropriate ways. These behaviors can often be managed over time. It takes patience, feedback, and a consistent approach.

What you might see:

- Hypersexuality (thinking about or wanting frequent sexual activity, e.g., masturbation)
- Hyposexuality, or a lack of interest in sex
- 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.





How you can help:

- Develop a “stop and think” signal to let your family member know that he/she is saying something inappropriate.
- Use redirection (i.e., try to change the topic or focus of interest to something else).
- Talk to your family member about what are and are not acceptable ways to act in public.
- Tell your family member that having sexual feelings is normal. Sexual behavior, however, is a private matter.
- Find a way for your family member to express his or her sexual needs (i.e., in the privacy of his or her room).
- Emotional changes and physical symptoms can affect desire for intimacy and sex. Ask your family member to discuss concerns with the doctor or counselor. (See Module 3.)

Lack of Self-Awareness

Your family member may not be aware of how the TBI has affected him or her. He or she may also not understand how it affects others.

Self-awareness means understanding our own strengths and weaknesses. Our sense of self-awareness is housed in the frontal lobe of the brain.

A reduced sense of self-awareness is a hallmark effect of TBI. Your family member may say very little has changed. He or she is not deliberately denying there is a problem. People with TBI simply do not understand that they are having problems.

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 (i.e., 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 the person to try to do something that he



“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 Mike 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.

thinks he can do but that may be beyond his capabilities. The goal is to raise the person’s awareness through real trial and error situations.

- Work with your service member/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 Common Emotional Effects?

Emotions start in the brain. Emotional self-control may be more difficult following a TBI. TBI can affect the complex neurochemistry system in the brain. This can lead to changes in emotional functioning.

Depression

Many people with TBI become depressed. This depression comes from both the physical changes in the brain due to the injury and the emotional reactions to it.

It is sometimes hard to tell the difference between symptoms of depression and effects of the TBI. For example, depressed people and people with TBI may have:

- low activity level
- sleep problems

- 
- difficulty controlling emotions
 - lack of initiation.

Men and women often have different symptoms of depression. They also have different ways of coping with the symptoms.

Men often report symptoms of:

- fatigue
- irritability/anger
- loss of interest in pleasurable activities
- sleep disturbances.

Men are more likely than women to use alcohol or drugs when they are depressed. They may engage in reckless, risky behavior. Men also tend to avoid talking about their feelings of depression with family or friends.

Women are more likely to talk about depressive symptoms to others. They often report feelings of:

- persistent sadness
- anxiety
- excessive crying
- feelings of guilt/worthlessness
- decreased energy
- increased appetite
- sleep problems
- weight gain.

In severe cases, both men and women may experience thoughts of suicide.

If you suspect that your family member is depressed, ask your health care team to evaluate his or her mental health. This is very important.

Depression can be treated with counseling and medication. If the depression is affecting the family, marriage and/or family therapy can help.

What you might see:

- Persistent sad, anxious, or “empty” feelings
- Feelings of hopelessness and/or pessimism
- Feelings of guilt, worthlessness, and/or helplessness
- Irritability, anger, 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
- Thoughts of suicide, suicide attempts.

How you can help:

- Offer emotional support, understanding, patience, and encouragement. Remind your family member that depression usually fades with time and treatment.
- Talk to your family member and listen carefully.
- Acknowledge 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 he or she declines, keep making gentle suggestions but don't insist.

Module 4, Chapter 5 provides information on suicide prevention resources.

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. It is not anyone's fault. Help is available...do not wait to call someone if you think your family member needs help.

Know the signs of a person thinking of suicide:

- making a will
- 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
- a sudden and significant decline or improvement in mood
- writing a suicide note.





Call 911 immediately or bring your family member to the closest hospital if you have any suspicion about suicide. It is perfectly fine to directly ask the person if he or she has been having suicidal thoughts. If yes, ask if he or she has a specific plan in mind. Having a plan for killing oneself is a serious sign to get help quickly.

Always take a person's threats of suicide seriously. Get immediate help. Call the health care team or an emergency hotline (DoD/VA: 1-800-273-TALK) right away. Make sure to remove or secure any available firearms.

"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

Increased Anxiety

People with TBI often become anxious. Anxiety sometimes goes hand in hand with depression.

What you might see:

- Constant physical tension
- Excessive worry, racing thoughts
- Feeling jumpy, irritable, 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 he or she may be worried about. Use problem-solving techniques (page 48) to address them. This can help put the issue into perspective.
- Suggest that your service member/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).

“You know what? I think that a big key in rehabilitation is to keep him busy because what happens when he’s not, he gets very down. He sometimes feels hopelessness because he can’t drive and he can’t just get in the car and go.

These guys are used to being on the go 24/7, being in the Army and part of the war itself, and to come back and have to sit in a wheelchair and have to depend on your mom or your spouse to take you everywhere--you know, you can’t just go in the car and get a hamburger.

It’s very difficult. What keeps him sane and keeps him going is sports. He’s on a sled hockey team, the San Antonio Rampage, and he travels. Sports have been a huge, huge outlet.”

- Cindy P.



- Ask your family member to talk with the doctor about medications for anxiety. Counseling may also help.
- 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.

Mood Swings (Emotional Lability)

It can be frustrating and embarrassing when you can't control your emotions. It can make it hard to participate in social situations.

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, unexpected shows of emotion.

How you can help:

- Reassure your family member that you understand that his or her display of emotion may not match the situation. Be nonjudgmental.
- Help family and friends understand sudden shifts in your family member's mood.

Emotional lability is a term for sudden mood swings.

"He was very emotional, and still is when he stops and thinks too much about stuff. But he was very, very emotional. He would hear a song and just cry for no apparent reason.

That was kind of hard to deal with because all you can do is comfort. "

- Sandy M.



-
- 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 him/her to talk with the doctor. Medications may be helpful in managing mood swings.

Self-esteem is feeling confidence and pride in who you are.

Changes in Self-Esteem

A person's view of him or herself 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 his or her feelings. Try to redirect the person to more positive thoughts.
- Encourage your family member to spend time with others. Encourage him or her to take part in independent activities.
- Help your family member to set realistic, attainable goals. Help him or her to choose activities that he or she can successfully complete.

Should I Stay in Touch with the Health Care Team?

Your health care team is your best resource for support and education. It is important that you tell the health care team about the emotional and behavioral effects that you observe. This is particularly true as these effects change over time.

Remember, many TBI effects improve over time. Until they do, the health care team can help manage the challenges that your family member is facing. Rehabilitation, counseling, and medication are tools that the team can use.



“Ultimately, you will end up being the therapist. You will end up being the caregiver. But they do make improvements and you will see plateaus, and then all of a sudden you’ll see improvements again and then plateaus.

When they’re making a lot of improvements, work it. Work it hard. Just do whatever you have to do, if it’s physical or mental. I mean, work it. And then when they plateau off, don’t get discouraged and think, oh my God, everything’s gone again. You might take a couple of steps backward, but you will hopefully, eventually make some more steps forward. The brain is just amazing.”

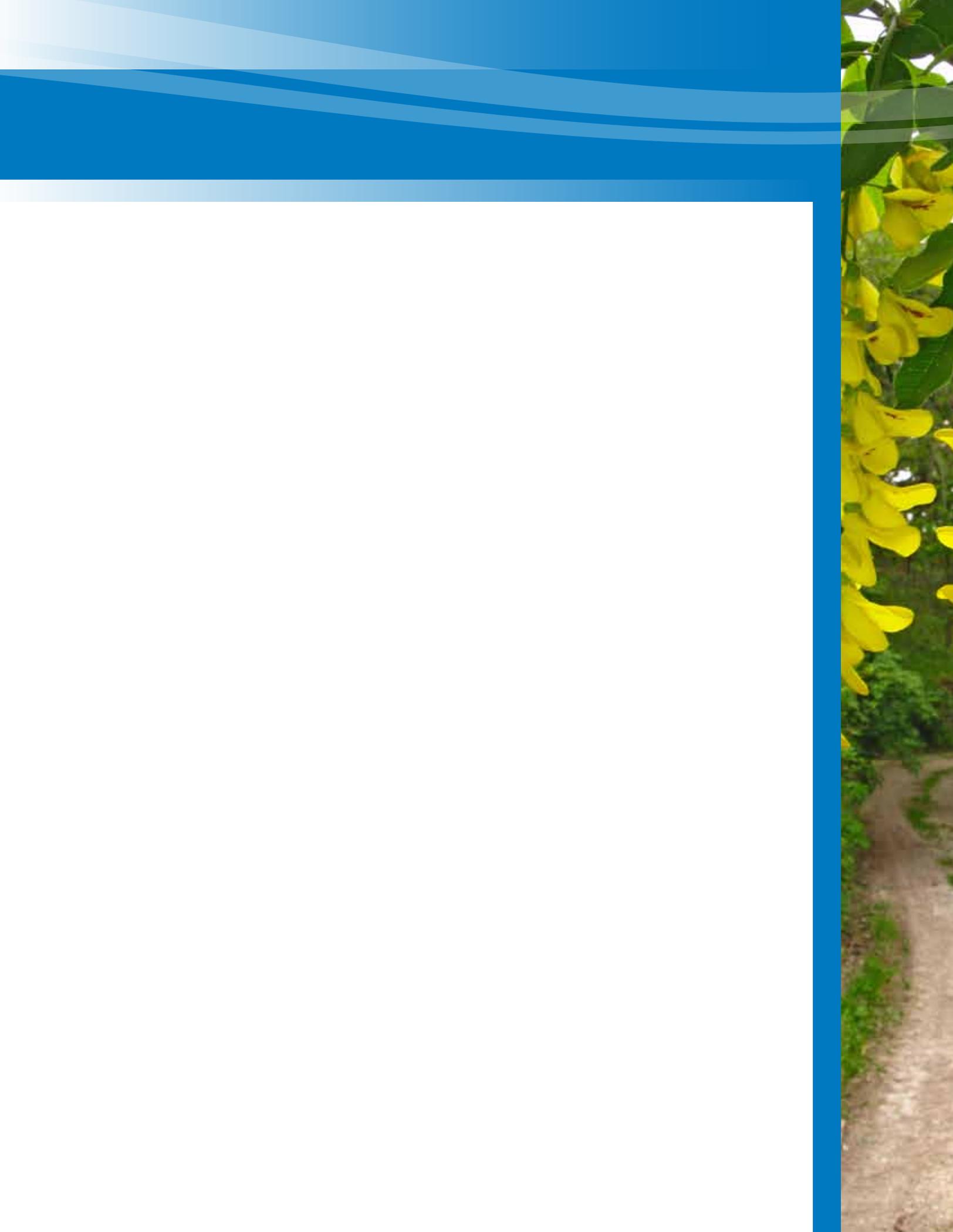


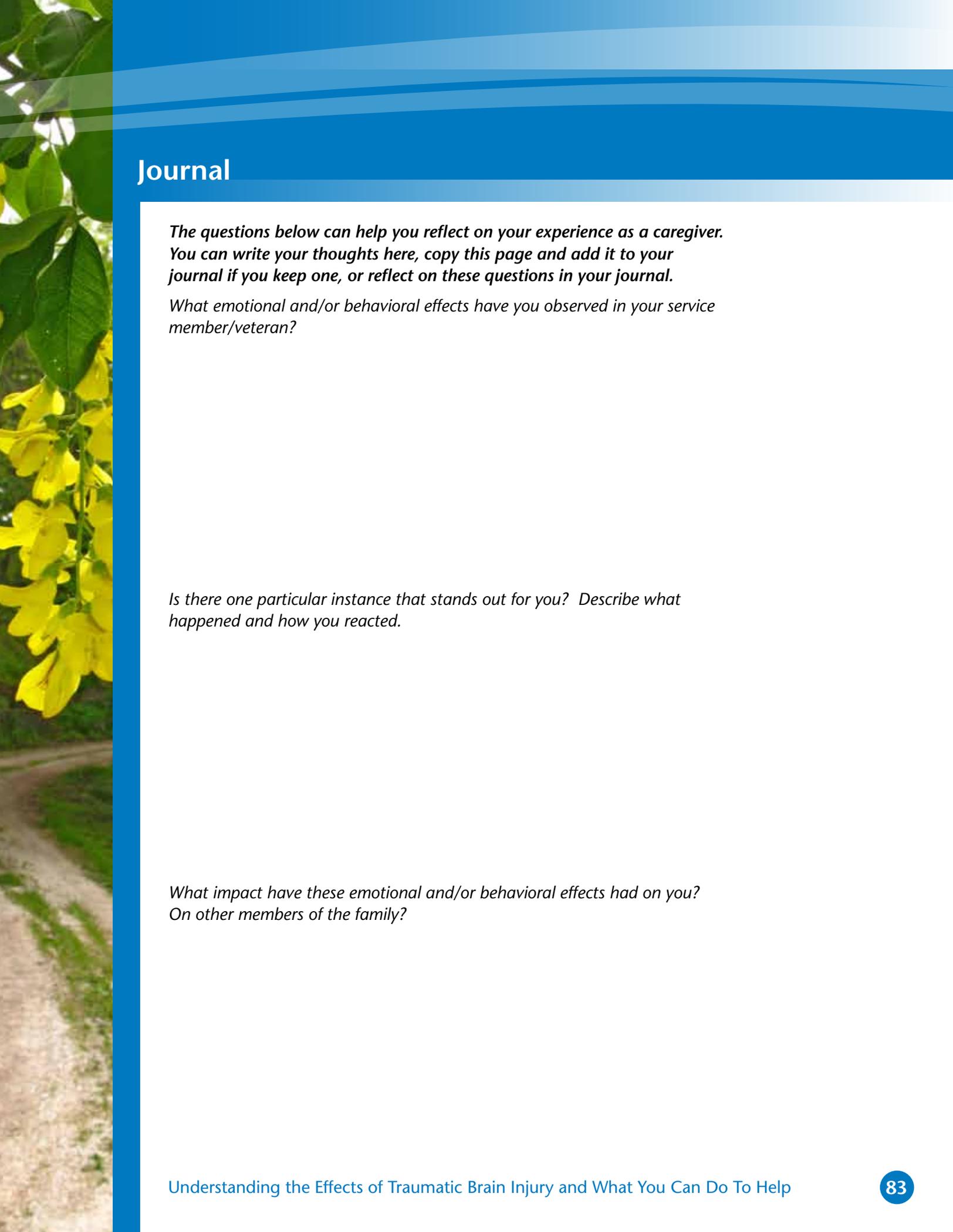
- Denise G.

After reading this module, you may be feeling relieved that your service member/veteran is experiencing only a few effects from his or her TBI. Or you may be feeling overwhelmed by the number and complexity of effects that you are learning to address.

Remember, you are not alone. There are thousands of other military families who are struggling to understand and cope with the same cognitive, physical, behavioral, and emotional changes that you and your service member/veteran are encountering. Healthcare providers are learning more every day about how to effectively treat these consequences of TBI. Your service member/veteran is the beneficiary of new medical knowledge gleaned from other service members’ experiences. In turn, his or her experience will add to the wealth of knowledge about how to treat TBI.

Most effects of TBI fade over time. Keep hope in your heart as you move forward into the future.





Journal

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

What emotional and/or behavioral effects have you observed in your service member/veteran?

Is there one particular instance that stands out for you? Describe what happened and how you reacted.

What impact have these emotional and/or behavioral effects had on you? On other members of the family?

What strategies have you tried to use to help your service member/veteran cope with emotional or behavioral effects? How well have they worked?

What strategies do you plan to try in the future?



Frequently-Asked Questions

1. Why is my service member/veteran with TBI so tired all the time?

People with TBI tire easily for good reasons. First, all thinking takes mental energy.

In a person with a brain injury, thinking activities take two to three times more energy than they do for someone without a brain injury. This is a major reason for fatigue.

After a TBI, a person's natural day/night cycle may be disturbed. Your service member/veteran with TBI may not be able to achieve the necessary deep sleep that allows someone to wake up feeling refreshed. He or she may also wake up many times during the night.

Help your family member to organize the day through the use of a calendar or notebook. This helps him or her avoid mental fatigue. (See Chapter 3 to learn more.) Keep daily activities on a regular schedule. Encourage your service member/veteran to make important decisions in the morning when mental energy is highest.

Finally, set up a sleep routine that includes going to bed and getting up at the same time every day. If fatigue persists, talk to the health care team. Medication can help regulate sleep patterns.

2. Why is my service member/veteran with TBI angry much the time?

During recovery, your family member will learn about how TBI has changed his or her life.

He or she may feel frustrated and angry about these changes. Remain calm. Help your family member to recognize when he or she is becoming angry or frustrated. Encourage him or her to ask for a break or some space to calm down. Praise your family member when he or she uses anger management strategies.

3. Why is my service member/veteran more emotional?

Neurons in the frontal lobe of the brain control the expression of emotion. These are often damaged during a TBI. Your service member/veteran may start laughing or crying, and be unable to stop easily. Likewise he or she may feel emotions, but be unable to express them. These symptoms usually lessen over time as the brain heals.

4. Why does my service member/veteran seem so insensitive and hurtful?

Your family member may seem insensitive and hurtful at times because he or she has less self-control over thoughts and behaviors.

This self-control is located in the frontal lobe of the brain. Damage to the frontal lobe may cause someone to just say things, without thinking about their effect on other people.

People with frontal lobe damage have a hard time understanding another person's point of view. They also have a hard time multi-tasking. For example, it's hard for people with TBI to respond to conversation and monitor what they are saying at the same time.

People with injury to the parietal lobe may have visual-spatial problems. This can make it hard to "read" the nonverbal feedback they are receiving from others.

You can help your family member learn to be more aware of the feelings of others. First, let your service member/veteran know what you are feeling; don't expect him or her to read your expressions. Second, if your service member/veteran blurts out an unkind statement, suggest to him or her: "That's an inside thought, not an outside one." Finally, work with your health care team to help your service member/veteran learn how to conduct simple negotiations.

Remember, it's the injury, not you, that is causing this behavior. If you find that it is having an effect on your self-esteem, please seek help through support groups, counseling, etc.

5. My service member/veteran used to have a lot of "get up and go." Why is he or she so passive now, just sitting around unless I tell him or her what to do?

Both fatigue and damage to the frontal lobe of the brain affect a person's "get up and go." (See Lack of Initiation on page 70.) You can help your family member by setting a regular daily routine. Organize larger tasks into a series of smaller ones. Provide choices for activities from which your family member can choose. This can increase motivation and initiation.



6. I no longer have a spouse; I have another child in the family. How can I restore my marriage?

A spouse's role after his or her partner has a TBI will often change. See Module 3 for suggestions about how to make the caregiving role an easier one.

Help your spouse with TBI become as independent and active as possible. See a marriage counselor if there are sexual problems. Talk to the doctor about medication to address physical problems that get in the way of intimacy.

7. Will our lives ever get back to normal?

The course of recovery after TBI depends on several factors. Your lives may return to "normal" or you may need to learn to adjust to a "new normal." It can take time to adapt to the life changes after TBI. Although many problems will improve in time, some symptoms may persist throughout the person's lifetime. Research has shown that many people who experience TBI do lead a life they find satisfying, even if it is not exactly the life they had prior to the injury.

8. How long is the psychological recovery going to take?

There are two recoveries to consider: the physical and the psychological.

Physical recovery (spontaneous healing of the brain) usually occurs in the first few years after the injury, depending on many factors.

The psychological recovery from TBI—learning to feel good about oneself and one's life--takes time as well. It may take longer than the physical recovery.

There are members of the health care team who will see you both through the recovery process and can guide you.

In addition, some people find that it is helpful to talk with others who are sharing some of the same experiences.



Resources

Injured service members/veterans may be treated at a VA Polytrauma Center, a VA Polytrauma Network Site, or a military hospital:

VA Polytrauma Rehabilitation Centers

- Richmond Polytrauma Rehabilitation Center (McGuire VA Medical Center) – Richmond, VA
- Tampa Polytrauma Rehabilitation Center (James A. Haley VA Medical Center) – Tampa, FL
- Minneapolis Polytrauma Rehabilitation Center (Minneapolis VA Medical Center) – Minneapolis, MN
- Palo Alto Polytrauma Rehabilitation Center (VA Palo Alto Health Care System) – Palo Alto, CA

A complete list of the **VA Polytrauma Network Sites** may be found at www.polytrauma.va.gov.

Military Medical Centers

- Walter Reed Army Medical Center, Washington, DC
- Blanchfield Army Community Hospital, Fort Campbell, KY
- Malcolm Grow Medical Center, Andrews Air Force Base, MD
- National Naval Medical Center, Bethesda, MD
- VAMC – Buffalo, NY
- Womack Army Medical Center, Fort Bragg, NC
- Wright-Patterson Air Force Base Medical Center, OH
- Naval Medical Center, Portsmouth, VA
- Dwight D. Eisenhower Army Medical Center, Fort Gordon, GA
- Keesler Medical Center, Keesler Air Force Base, MS
- Carl R. Darnall Army Medical Center, Fort Hood, TX
- Brooke Army Medical Center, Fort Sam Houston, TX
- Wilford Hall Medical Center, Lackland Air Force Base, TX
- Branch Medical Clinic, Marine Corps Logistics Base, Barstow, CA
- Naval Medical Center, San Diego-Balboa, CA
- David Grant USAF Medical Center, Travis Air Force Base, CA
- Tripler Army Medical Center, Oahu, HI
- William Beaumont Army Medical Center, Fort Bliss, El Paso, TX
- Madigan Army Medical Center, Fort Lewis, Tacoma, WA

Learn more about the effects of TBI:

TBI Model Systems Centers

Visit the Web sites of the TBI Model Systems Centers. The Centers are a network of academic centers across the country dedicated to improving the delivery of services for people with TBI. They are funded from 2007-2012 by the National Institute of Disability and Rehabilitation Research (NIDRR). Many offer useful information for consumers about the effects of TBI.

Alabama

UAB TBI Model System

<http://main.uab.edu/tbi>

Spain Rehabilitation Center - University of Alabama at Birmingham
1717 6th Ave S

Birmingham, Alabama 35233-7330

Project Director: Tom Novack

205-934-3454 or e-mail: tbi@uab.edu

California

Northern California Traumatic Brain Injury Model System of Care

<http://www.tbi-sci.org>

Santa Clara Valley Medical Center

751 South Bascom Avenue

San Jose, California 95128

Project Director: Tamara Bushnik, PhD

408-793-6433 or e-mail: jerry.wright@hhs.sccgov.org

Colorado

The Rocky Mountain Regional Brain Injury System (RMRBIS)

www.craighospital.org/research/Abstracts%5CTBIMS.asp

Craig Hospital

3425 S. Clarkson St.

Englewood, Colorado 80113

Project Director: Gale Whiteneck, PhD

303-789-8204 or e-mail: gale@craig-hospital.org

Illinois

Mid-West Regional Traumatic Brain Injury Center

<http://www.ric.org>

Rehabilitation Institute of Chicago

345 E. Superior St

Chicago, IL 60611

312-238-4087

Michigan

Southeastern Michigan Traumatic Brain Injury System

<http://www.semTBIs.org>

Rehabilitation Institute of Michigan

261 Mack Boulevard Room 520

Detroit, MI 48201

Project Coordinator: Carole Koviak

313-745-9737 or e-mail: ckoviak@dmc.org

Minnesota

Mayo TBI Model System

<http://mayoresearch.mayo.edu/mayo/research/tbims/index.cfm>

200 1st Street SW

Rochester, Minnesota 55905

Project Director: James Malec, PhD

507-255-3116 or e-mail: malec.james@mayo.edu

New Jersey

New Jersey TBI Model System

<http://www.njrehab.org/tbims>

JFK-Johnson Rehab Institute

65 James Street

Edison, New Jersey 08820-3947

Project Director: Keith Cicerone, PhD

732-906-2645 or e-mail: kcicerone@solarishs.org

Northern New Jersey Traumatic Brain Injury System (NNJTBIS)

<http://www.kesslerfoundation.org/research/lab/modelsys.php?lab=nnjtbis>

Kessler Medical Rehabilitation Research and Education Corporation (KMRREC)

1199 Pleasant Valley Way

West Orange, NJ 07052

Project Director: Elie P. Elovic, MD

973-243-2015 or e-mail: tbi@kmrrec.org

New York

New York TBI Model System

<http://www.mssm.edu/tbicentral/>

Mount Sinai School of Medicine

Department of Rehabilitation Medicine, Box 1240

1425 Madison Avenue

New York, New York 10029

Project Director: Wayne Gordon, PhD

212-659-9372 or e-mail: wayne.gordon@mssm.edu

North Carolina

Carolinas TBI Rehabilitation and Research System (CTBIRRS)

http://www.carolinas.org/services/rehab/CIR/brain_system.cfm

Charlotte Institute of Rehabilitation

1100 Blythe Boulevard

Charlotte, NC 28203

Project Director: Flora Hammond, MD

704-355-4330 or e-mail: flora.hammond@carolinashealthcare.org

Ohio

Ohio Valley TBI Model System

<http://www.ohiovalley.org/about/tbimodel.html>

Ohio State University

855 Grandview Ave

Columbus, Ohio 43215

Project Director: John Corrigan, PhD

614-293-3830 or e-mail: corrigan.1@osu.edu

Pennsylvania

MossRehab TBI Model System of Care

<http://www.mossrehab.com/content/view/8909/170>

1200 West Tabor Road

Philadelphia, PA 19141

Project Director: Tessa Hart, PhD

215-456-6544 or e-mail: thart@einstein.edu

Resources

Texas

North Texas TBI Model System (NT-TBIMS)

<http://www.utsouthwestern.edu/utsw/home/research/neurology/tbi/index.htm>

University of Texas, Southwestern Medical Center

5323 Harry Hines Blvd.

Dallas, Texas 75390

Project Director: Ramon Diaz-Arrastia, MD

214-648-7613 or e-mail: ramon.diaz-arrastia@UTSouthwestern.edu

Texas Traumatic Brain Injury Model System of TIRR

<http://www.memorialhermann.org/locations/tirr/forhealthprofessionals/content.aspx?id=1162>

The Institute for Rehabilitation and Research (TIRR)

1333 Moursund Avenue

Houston, TX 77030

Project Director: Mark Sherer, PhD

713-799-7007 or e-mail: Mark.Sherer@memorialhermann.org

Virginia

Virginia Commonwealth University TBIMS

<http://www.tbi.pmr.vcu.edu>

Medical College of Virginia

1200 East Broad St., Rm. 3-102

Box 980542

Richmond, VA 23298-0542

Project Director: Jeffrey Kreutzer, PhD

804-838-9055 or e-mail: jskreutz@hsc.vuc.edu

Washington

Univ of Washington TBIMS

<http://depts.washington.edu/uwtbi>

University of Washington

Rehabilitation Medicine, Box 356490

Seattle, WA 98195

Project Director: Kathleen Bell, MD

206-685-0935 or e-mail: krbell@u.washington.edu

References/Credits

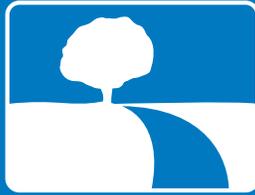
Chapter 1

Prevalence of TBI in OIF/OEF Combat Zones

Cited in a March 2007 letter to the House Appropriations Committee from Rep. Bill Pascrell (D-NJ) and Rep. Todd Platts (R-PA), both Co-Chairs of the Congressional Brain Injury Task Force.







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