



This fact sheet explains how a severe TBI affects the injured person, what to expect from a team of doctors and other health care professionals providing care, and how you can support this team and your loved one on his or her road to recovery.

A severe traumatic brain injury (TBI) affects more than just the injured person. It also affects family members and friends who love and are close to the person who is injured. As one of these people, you play a very important role in caring for a loved one with a severe TBI. For many, this role is new and comes with a lot of questions.

What is severe TBI?

TBI occurs when an outside force disrupts the brain's normal function. Falls, car crashes, assaults, and a blow or strike to the head are the most common causes of TBI. Severe TBI always includes a period of unconsciousness (uhn-KON-shuh s-nis). During this time, the person will not be able to stay awake. He or she will not be able to interact with surroundings in a purposeful way, such as reaching for an object. Here are the levels of impaired consciousness often seen in people with a severe TBI are the following:

- A **coma** is a state of complete unconsciousness. People in this state can't be awakened. They can't see because their eyes are closed, and they may not respond to sound, touch, or pain. They can't communicate, follow commands, show emotions, or engage in purposeful behaviors.
- People in a **vegetative state** are still unconscious but may be awake at times. They may start to open their eyes. This is also known as "Unresponsive Wakefulness Syndrome." They may react briefly to sounds, sights, or touch and may even cry, smile, or make facial expressions. But these responses are reflexes and are not under the person's control. As with a coma, people in a vegetative state can't show emotions or engage in purposeful behaviors. People in a vegetative state aren't aware of themselves or their surroundings. They can't communicate or follow commands. The word *vegetative* doesn't mean the person is a "vegetable." It refers to the "vegetative" or automatic functions still being controlled by the brain, such as breathing, heart function, and digestion.
- People in a **minimally conscious state** begin to regain consciousness. They may have some awareness of themselves or their surroundings but not all the time. People in a minimally conscious state may engage in purposeful behaviors from time to time. For example, they may follow a simple command, look at people or objects around them, or keep their eyes focused on people or objects that are moving. They may reach for or try to use a common object, like a hairbrush. They may show appropriate emotional responses or try to communicate through gestures or talking.
- **Emerged from the minimally conscious state** refers to people who can communicate consistently or use at least two objects in a purposeful way. During this stage, they may be able to answer simple questions correctly by saying or gesturing responses like "yes" and "no." They may also be able to follow instructions and perform simple tasks.
- When people regain consciousness, they may enter a **post-traumatic confusional state**. This state of recovery may include a condition known as **post-traumatic amnesia** (am-NEE-zhuh). People in this state are confused and have problems forming new memories. They may not be able to walk or talk, recall memories, or recognize people they know. Typically, people can't remember where they are or what happened. They can't remember day-to-day details or events. They can't perform lengthy tasks. They may sleep a lot during the day but find it hard to sleep at night. They may be restless and/or agitated. People in this state may also do unsafe things, like pull on feeding and breathing tubes or try to get up without help.

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

What happens during the acute hospital stay?

Each TBI is unique. Most people with a TBI need a combination of intensive medical treatments. These may include neurological, surgical, and rehabilitative treatment. In the acute care setting, doctors and other health care professionals first address life-threatening injuries. Next, they address and treat other injuries and medical problems that arise. Finally, doctors make sure the injured person is medically stable. Many other health care providers and specialists may be involved too. This can be overwhelming. The following is an overview of the health care team members who will likely be involved. Aside from providing care, the members of this team are an important source of information and support to family members and friends during this difficult time:

- **General medical team:** This team of doctors, nurses, and nursing assistants provide care daily to people with TBI. This team treats medical conditions and manages medicines.
- **Intensive care specialists:** One or more medical professionals who specialize in trauma care and recovery may be a part of the health care team:
 - **Surgeons** – Depending on the injuries, surgeons may be a part of the team. Examples include trauma surgeons, neurosurgeons, orthopedic surgeons, and plastic surgeons.
 - **Critical care doctors** – These medical doctors treat people who require intensive care. They monitor a person's medical condition closely. They also help diagnose and treat medical problems.
 - **Critical care nurses** – These nurse specialists do frequent (in some cases hourly) rounds. They perform informal bedside neurological exams. They may also help doctors perform procedures. Because they interact frequently with the patient and family, they are often the "first line" of communication, education, and support for families.
 - **Neurologists** – These medical doctors evaluate and treat disorders of the brain. They may perform tests to help determine the extent of a brain injury. They may also perform bedside evaluations to guide diagnosis and monitor neurological recovery.
 - **Pulmonologists or respiratory (RES-per-uh-tohr-ee) therapists** – These specialists diagnose and treat breathing problems. They determine whether a person needs a breathing tube or machine to help them breathe.
 - **Dieticians or nutritional specialists** – These professionals monitor a person's nutritional status and manage their dietary needs. They may also help determine whether a feeding tube is needed to provide nutrition.
- **Pharmacists:** In a hospital setting, these specialists work closely with the doctors to monitor a person's medications. They help with medication dosing and prepare medications. They may also provide education to the medical team and sometimes directly to families. They can explain the purpose of the medications being given and provide information on medication side effects.
- **Physiatrists (fiz-ee-A-trists OR fi-ZAHY-uh-trists):** These doctors help diagnose and treat medical conditions—including pain, muscle, joint, and nerve problems—during the rehabilitation (rehab) process. They also direct and oversee a team of brain injury rehab specialists, including physical therapists, occupational therapists, and/or speech therapists.
- **Rehab therapists:** These specialists provide various types of therapies, for example, physical, occupational, or speech-language. People with TBI may receive these rehab services while they are in the intensive- or acute care unit. These services help prevent muscle loss and keep the range of motion in arms and legs. They can also help with swallowing, feeding, and communication difficulties.
- **Neuropsychologists:** These psychologists evaluate and diagnose changes in behavior, thinking, and emotion caused by TBI. They may perform bedside assessments to help diagnose levels of consciousness. They may educate and support family members of people with TBI.
- **Case managers and social workers:** These providers coordinate the health care plan by handling insurance benefits and other financial matters as well as overseeing discharge planning. They are a valuable resource for families and can provide both emotional support and information about TBI. These providers can also plan for future phases of care.
- **Other professionals:** A psychologist, chaplain, and/or patient representative may be available to provide spiritual and emotional support to people with TBI and their family members.

Throughout the recovery process, people with TBI undergo tests and procedures to assess the location and level of brain damage. This will help with diagnosis, prognosis, and treatment decisions. Such tests and procedures may include the following:

- **Neuroimaging studies:** These tests use computed tomography (tuh-MOG-ruh-fee) (CT scans) or magnetic resonance imaging (MRI). They help identify bleeding and injured parts of the brain. Doctors can also use the results of these tests to help determine if surgery is needed.
- **Electroencephalograms (ih-lek-troh-en-SEF-uh-loh-gram) (EEGs):** These tests measure electrical activity in the brain. Results of EEGs can be used to diagnose seizures. They can also show the location and extent of a brain injury.



- **Neurological monitoring/neuromonitoring:** Devices such as intracranial pressure monitors track the amount of pressure in the brain and help manage brain swelling. These devices require placing a tube in the brain that is attached to wires and a monitoring screen. If needed, the tube device can be used to drain excess fluid and relieve excess pressure in the brain. Neuromonitoring also helps diagnose and treat hydrocephalus (an excess of fluid buildup in the brain) and can help determine if surgical placement of a more permanent pressure valve, called a shunt, is needed.
- **Informal bedside neurological exams and formal behavior assessment scales:** Doctors may use these tests to diagnose a disorder of consciousness caused by a TBI. They can help determine a person's level of impaired consciousness. A typical exam tests basic reflexes; doctors look at how the eyes react to light and they assess a person's response to sound, voice, touch, and pain. Doctors also look for signs of purposeful behaviors, like following a moving object with the eyes. This is called *visual tracking*. Other signs doctors look for are following commands and communicating.

What is known about recovery of consciousness and outcomes after a severe TBI?

Some doctors consider certain severe TBIs to be beyond hope. However, this can't be determined in the first few days after an injury. It may take weeks—or even months—for a doctor to determine how or if a person will recover over time. Many people (but not all with a disorder of consciousness related to a TBI) will eventually regain consciousness. The following are some important facts to keep in mind about recovery from a disorder of consciousness caused by a severe TBI.

- Recovery usually follows a step-by-step path. Most people progress through the stages of coma, vegetative state, minimally conscious state, emerged from minimally conscious state, and post-traumatic confusional state. Then, people often continue to improve slowly over time.
- There is a lot of variation in how people move through these stages and how long each stage lasts. Not everyone goes through every stage. Some people move through the stages quickly or skip stages. Others may get stuck in a stage.
- Recovering from a severe TBI can take a long time. Some people regain consciousness within a few days or weeks and recover quickly. Others progress more slowly and may remain in a state of impaired consciousness for months or years. Every injury is different and follows its own timeline.
- As a general rule, the longer a person remains in a coma or in a state of impaired consciousness, the more likely it is that they will be severely disabled.
- Visual tracking is a sign of improvement. It is often one of the first meaningful behaviors seen when a person moves from a coma or vegetative state to a minimally conscious state.
- The earlier a person improves from a coma or vegetative state to the minimally conscious state, the better the long-term outcome. For example, if a person can follow simple, one-step commands by 2–3 months after the injury, the better the outcome is likely to be. This is true even if the responses are delayed or inconsistent.
- People with disorders of consciousness that last for several months after a severe TBI can still improve. They may benefit from specialized TBI rehab.
- Age also plays a role in recovery outcomes. Among those with a prolonged time of impaired consciousness, younger people are more likely to return to living more independent, productive lives.
- An accurate diagnosis about level of consciousness is essential. It helps predict short- and long-term outcomes. It can help when deciding if specialized rehabilitation is needed. An accurate diagnosis is also helpful for family members and decision makers as they sort through difficult decisions like whether to stop care.

What can I do to help?

You may feel powerless, helpless, and afraid. But you play an essential role in the care of your loved one. You can do many things to move treatment along and support ongoing recovery:

- Be ready to answer questions from the health care team. These could be about your loved one's medicines, allergies, or other medical conditions. The more information you can provide, the better prepared the medical team will be in preventing new problems.
- Your loved one won't be able to make decisions about medical procedures. If you are not the legal decision maker your loved one, then find out who is. Other family members and loved ones can support the legal decision maker during this tough and emotional time. If your loved one has an advance directive, discuss with the medical team his or her wishes about resuscitation.



- It might be helpful for you or someone else to become the legal guardian for your loved one. A guardian is someone the court assigns to manage personal, legal, and financial matters for a person who can't make their own decisions. Having a guardian appointed may help when making decisions about your loved one's medical care. Elder law attorneys are lawyers who can assist with this process. These lawyers can also help with financial planning and other legal matters for people with long-term care needs.
- Learn about changes that may occur in people after a severe TBI. These include cognitive, physical, behavioral, and psychological changes. This will help you know what to expect as your loved one recovers.
- Learn about the skills needed to take care of your loved one. This will help you feel more ready during the treatment and recovery phases.
- Don't forget to take care of yourself. When in crisis mode, family members often put their own needs last. But it is important to take breaks, eat regularly, and get a good night's sleep. Trust the care team to be there while you rest. By taking care of yourself, you can be a better support for your loved one.
- Family and friends are often the first ones to notice changes in their loved one's status. Noticing these changes is very helpful to the medical team. It's important to ask questions, raise concerns, and share your observations.
- Understanding how to interact with your loved one may help his or her recovery. It can also help you to quickly recognize signs that may indicate a change in his or her status.

Here are some suggestions on how to interact with a loved one with a severe TBI:

- Balance periods of rest and stimulation. Don't provide too much stimulation at once. For example, limit the number of visitors to only a few at a time. When people are visiting, turn off the TV and make sure the room is calm and quiet. Always follow the care team's recommendations about how much and what type of stimulation is appropriate for your loved one.
- Even if your loved one can't respond, physical contact is important. Hold his or her hand. If the bedside nursing staff allow it, gently massage your loved one's hands, arms, legs, or feet.
- Stimulate your loved one's senses. Offer different smells, sounds, things to look at, and things to touch. Show pictures of friends and family. Play his or her favorite music. Bring in a favorite blanket, stuffed toy, or piece of clothing.
- Talk to your loved one as if he or she can hear and understand you. Read him or her a book or a newspaper. Recall important, special, or funny life events; or put on his or her favorite TV show.
- Occasionally "test" your loved one's ability to make eye contact or watch people move around the room. Ask him or her to follow simple commands like "squeeze my hand," "raise your arm," or "open your mouth." Ask him or her to answer simple "yes" or "no" questions. It may take several seconds for him or her to respond each time. Let your loved one rest briefly between questions.
- Don't pressure your loved one when he or she doesn't show you the behaviors you're hoping for, or if he or she only shows them some of the time. Your loved one can't control changes in consciousness. As recovery continues, you may see these behaviors more often.
- When your loved one regains consciousness, he or she may be confused, and behavior problems may develop. Tell your loved one often that he or she is in a safe place and that people are there to help. Remind him or her of what happened; where he or she is; and the current day, date, and time. Keep a clock and easy-to-read calendar in clear view.
- Help identify things that trigger any behavior problem in your loved one. Write down what was going on just before the problem occurred.

What should I ask the doctors and other health professionals who are treating my loved one?

- *What is my loved one's level of consciousness, and what information and tests were used to determine the diagnosis and prognosis?*
You or other decision makers may have to make decisions about treatment in the first hours and days after the injury. These decisions may need to be made based on unclear information. This can be scary and overwhelming. You may feel more confident when a disorder-of-consciousness diagnosis is based on both bedside exams and objective tests (e.g., results of an EEG). Doctors may deliver a poor prognosis "with certainty." Ask questions about what this means. Often, more specialized bedside exams, tests, and time are needed. This is especially important when deciding whether to remove your loved one from life support. If a definite poor prognosis is given, ask the health care team to give you the full range of possible outcomes, and ask what data they are basing the prognosis on. You may also want to consult a disability specialist with expertise and experience in TBI rehab. Consider what they say along with information from the health care team. These specialists can offer an expert opinion about your loved one's diagnosis and prognosis. They can also help match your loved one with the right rehab services.



- *Are there any other medical conditions that can be treated to help promote my loved one's recovery?*

Factors other than the main injury may make it tough for your loved one to interact with his or her surroundings. For example, medicines may make him or her sleepy. He or she may be having seizures. There could also be an infection or a build-up of fluid on the brain. Ask the doctors to look for these and other factors that can affect recovery.

- *What are the care options for people with severe TBI?*

When your loved one is medically stable, treatment will focus on preparing him or her for the next level of care. At this point in the recovery process, many people still need specialized, inpatient services including rehab. Specialized rehab services are offered in many settings. These include acute care or inpatient rehab hospitals or subacute rehab facilities. However, many health insurance plans won't pay for these services if your loved one can't actively engage with surroundings. Your loved one could also receive care at a skilled nursing facility, but specialized TBI services are often limited in that type of setting. To decide on the next level of care, doctors will look at your loved one's medical status and diagnosis and at brain injury programs in your area. The search for the right placement and services can be difficult. Social workers and/or case managers can help you explore the available options. Additional information and resources to help find the right placement for your loved one may also be available through your local, state, and national brain injury associations. Whatever the next level of care is, you should look for a program with experience in caring for people with severe TBI. If your loved one is in a vegetative or minimally conscious state, look for facilities with experience in caring for patients with disorders of consciousness. Here, your loved one will get care and be observed for a longer period of time. This can help reach an accurate prognosis and guide long-term care planning. Such settings are also best prepared to monitor progress, prevent complications from developing, and help with a discharge home when appropriate. If your loved one doesn't get placed in a facility with specialized TBI services, you may want to stay in touch with a neurologist, rehab medicine physician, and/or a rehab case manager so someone with TBI expertise remains involved in the care of your loved one.

- *How is my loved one progressing, and what is the care team doing today to manage his or her condition?*

Especially in the early phases of recovery, your loved one's condition may change quickly and often. You may feel as if you are in a constant state of worry about his or her medical stability. This can be extremely stressful for families. It may help to stay informed about your loved one's daily status and the progress that the care team is observing. Ask questions to help you better understand his or her care needs, what is being done to manage his or her condition, and what the next days and weeks might look like based on the care team's observations. Information, education, and regular communication with the care team may reduce your stress level and help you feel actively involved in your loved one's care.

Summary of key points about severe TBI

- Severe TBIs always involve a period of unconsciousness. When this period lasts for an extended amount of time, the term *disorder of consciousness* is used. Disorders of consciousness include coma, vegetative state, and minimally conscious state. Each disorder of consciousness is marked by different levels of awareness and ability to interact with surroundings in a purposeful way.
- Many people with a severe TBI regain consciousness; however, recovery is a long process and it involves several stages.
- People with disorders of consciousness that last several months after a severe TBI can still have meaningful recoveries. They often benefit from rehab in programs that specialize in treating people with severe TBI.
- An accurate diagnosis of level of consciousness is essential. It can help predict short- and long-term outcomes. It can also help in treatment planning and informing important decisions early in recovery.
- Early predictions of long-term recovery are often inaccurate. It may take time to make an accurate prognosis. Such a prognosis is based on your loved one's changing condition, especially as the medical condition improves and care is simplified.
- The health care team should have expertise in managing severe TBI. These professionals are best prepared to handle the many complex issues that may come up during your loved one's recovery.

Where can I learn more about severe TBI and DOCs?

- "Facts about the Vegetative and Minimally Conscious States after Severe Brain Injury": <http://www.msctc.org/tbi/factsheets/Vegetative-And-Minimally-Conscious-States-After-Severe-Brain-Injury>
- "Traumatic Brain Injury and Acute Inpatient Rehabilitation": <http://www.msctc.org/tbi/factsheets/Traumatic-Brain-Injury-And-Acute-Inpatient-Rehabilitation>
- Brain Injury Association of America: 1-800-444-6443, <http://www.biausa.org>
- Brainline.org: <http://www.brainline.org>



References

- Giacino, J. T., Zasler, N. D. M., Katz, D. I., Kelly, J. P., Rosenberg, J. H., & Filley, C. M. (1997). Development of practice guidelines for assessment and management of the vegetative and minimally conscious states. *Journal of Head Trauma Rehabilitation, 12*(4), 79–89.
- Katz, D. I., Polyak, M., Coughlan, D., Nichols, M., & Roche, A. (2009). Natural history of recovery from brain injury after prolonged disorders of consciousness: Outcome of patients admitted to inpatient rehabilitation with 1–4 year follow-up. *Progress in Brain Research, 177*, 73–88.
- Leonardi M., Giovannetti M., Pagani M., Raggi, A., & Sattin D. (2012). Burden and needs of 487 caregivers of patients in vegetative state and in minimally conscious state: Results from a national study. *Brain Injury, 26*(10), 1201–1210.
- Nakase-Richardson, R., Whyte, J., Giacino, J. T., Pavawalla, S., Barnett, S. D., Yablon, S. A., . . . Walker, W. C. (2012). Longitudinal outcome of patients with disordered consciousness in the NIDRR TBI Model Systems Programs. *Journal of Neurotrauma, 29*(1), 59–65.
- Pagani, M., Giovannetti, A. M., Covelli, V., Sattin, D., & Leonardi, M. (2014). Caregiving for patients in vegetative and minimally conscious states: Perceived burden as a mediator in caregivers' expression of needs and symptoms of depression and anxiety. *Journal of Clinical Psychology in Medical Settings, 21*, 214–222.
- Whyte, J., Nakase-Richardson, R., Hammond, F. M., McNamee, S., Giacino, J. T., Kalmr, K., . . . Horn, L. J. (2013). Functional outcomes in traumatic disorders of consciousness: 5-year outcomes from the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems. *Archives of Physical Medicine and Rehabilitation, 94*(10), 1855–1860.

Authorship

Severe Traumatic Brain Injury: What to Expect in the Trauma Center, Hospital, and Beyond was developed by Amy M. Rosenbaum, PhD; Alan Weintraub, MD; Ron Seel, PhD; John Whyte, MD, PhD; and Risa Nakase-Richardson, PhD, in collaboration with the Model Systems Knowledge Translation Center.

Source: Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the Traumatic Brain Injury Model Systems.

Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. The contents of this fact sheet were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DP0082). The contents of this fact sheet do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the federal government.

Copyright © 2017 Model Systems Knowledge Translation Center (MSKTC). May be reproduced and distributed freely with appropriate attribution. Prior permission must be obtained for inclusion in fee-based materials.