



Traumatic Brain Injury: A Focus on Family and Caregivers

Traumatic Brain Injury (TBI) affects far more than just the Veteran or Servicemember. Family, friends, and loved ones all experience the anxiety, fear, and uncertainty associated with this condition. One minute the individual is fine, the next minute s/he is involved in an overwhelming medical emergency. If you are in one or more of these categories, you may find yourself suddenly trying to make sense of a very complicated situation while having to make critical decisions that affect you and your family. While nothing could fully prepare you for this circumstance, there are resources available to help you navigate the inevitable questions and concerns.

As a Caregiver, What Can I Expect?

While your initial concern was about whether or not your family member would survive, with time you may begin to worry about other issues, like: will I be able to meet my care-giving responsibilities? To what extent has our life together changed? You may experience unrealistic expectations regarding your loved one's recovery, even though some degree of change following a TBI is inevitable. Frustration is a typical emotional reaction experienced sometime throughout the rehabilitation process, whether it is dealing with paperwork, recovery setbacks, or identifying resources. In addition, you may experience stress as a result of feeling overwhelmed and/or being unable to cope with your current demands. There may also be periods during the process when you feel down or depressed. Some signs of depression include: overwhelming feelings of sadness or guilt, loss of pleasure and/or interest, crying spells, sleep and appetite disturbances, and suicidal thoughts. Given what you are going through, having these feelings occasionally is normal but they should pass with time. If you begin to experience several of these symptoms and they persist beyond a few weeks, it is time to take action and speak with a trained professional.

The Importance of Family Involvement

VA's Polytrauma System of Care strongly advocates family involvement throughout the rehabilitation process. VA strives to ensure that patients and their families receive all the necessary support services to enhance the rehabilitation process, while minimizing the inherent stress associated with recovery from a TBI. It's not just about accommodating family members—it's about integrating you into your loved one's recovery process.

VA offers multiple levels of clinical and logistical support to ensure a smooth transition and continuous care for patients and their families. VA assigns a dedicated case manager to each patient and family at a Polytrauma Rehabilitation Center. The ratio of case managers to patients is 1:6, so that they can provide individualized, hands-on care for their patients.



Recovery & Rehabilitation

It is difficult to predict a person's ultimate level of recovery, because each TBI is unique. And each patient responds differently to rehabilitation. Some patients have lengthy stays in an acute, inpatient program while others receive their care through outpatient services. Some patients treated in the polytrauma programs are able to return to active duty, pursue school, or return to work, while others will continue to need more intense supportive services and care.

What Questions Should I Ask?

Understandably, you may be overwhelmed at times and not know what to ask or where to begin. By writing down questions before your appointments, you can be sure to cover everything you need to know. Consider the following questions when talking to doctors, technicians, and other support team members:

- ▶ What course of recovery and treatment can we expect?
- ▶ What timeframe is associated with this recovery and treatment schedule?
- ▶ What is our next step in VA's Polytrauma System of Care?
- ▶ How can I get in touch with others who are experiencing a similar situation?
- ▶ Why is my loved one getting this particular medicine?
- ▶ Why is the dose changing?
- ▶ Why does my loved one need this procedure or test?
- ▶ Can you point me to other written materials about this drug/surgery/etc?

What is My Role as a Caregiver?

You are your loved one's advocate—and it is important to be very comfortable with that responsibility. To do so effectively, ask questions and get informed. If your doctor is using terms that confuse you or you are not familiar with, let them know. Say to the doctor, "did I hear this right?" or "I need you to explain that to me in less technical language." Also, be sure to communicate your end goals with your treatment team. They will be able to help break those long-term goals into shorter-term goals that are aligned to your treatment plan, and which are more manageable for you.

Lastly, after an appointment, it can be easy to forget what information your doctor and treatment team may have shared with you because you were, understandably, engaged more in the discussion than in writing down that information. For important appointments, ask a friend or family member to join you and take notes.

It's Important to Take Care of Yourself, Too!

As you learn to deal with your own reactions while at the hospital and upon your return home, here are several suggestions for managing your complicated thoughts and feelings.

Anxiety

- ▶ Allow yourself 15 or 20 minutes during the day when you do nothing but worry about whatever concerns you. When your “worry” time is up, refocus yourself on the tasks at hand.
- ▶ Keep a journal. Write down your thoughts, feelings, and concerns.

Unrealistic Expectations

- ▶ Develop a “one day at a time” attitude.
- ▶ Celebrate the good days; learn from and re-group after the tough ones.

Frustration

- ▶ It is okay to take a break for a couple of hours or even a day. Ask another family member or friend to take over for you.
- ▶ Do not try to resolve important issues when you are frustrated; give yourself time to calm down before talking to someone.
- ▶ Try to identify the particular source of your frustration and then devise a plan to fix it. Ask your care providers for help.
- ▶ Create a progress journal. Pick one day a week and write down what your loved one did during that day, especially any progress made. Repeat this action the next week on the same day (e.g., every Wednesday). After one month, review the “Wednesday” activities to give yourself a proper assessment of progress made.

Stress

- ▶ Learn to pace yourself. Try to delegate and divide responsibilities amongst family members and friends.
- ▶ Keep a “To Do” list handy and pull it out whenever anyone offers to help. Provide them with a specific chore/job that will help ease your burden (e.g., prepare a meal, drop off clothes at the drycleaners, arrange for carpool).
- ▶ Allow your loved one to be cared for by the treatment staff. They are professionals and it is their job to help. This also provides you time to rest and regain energy.
- ▶ Identify one person other than yourself to serve as a chief communicator. Inform them of your loved one’s situation, and then let that designated person share all information (and future updates) with your family members, friends, neighbors, and colleagues. Repeating the information over and over again can be physically and emotionally exhausting for you. Having someone else do much of the communicating to others allows you to focus more attention on your loved one.
- ▶ To be an effective caregiver, you must try to remain healthy, both physically and emotionally.

Depression

- ▶ Oftentimes, talking the situation over with a trained professional will help you process your thoughts and feelings.
- ▶ Maintain close family relationships.
- ▶ The rehab team is there to help you in any way they can.

Quick Tip Summary:

- ▶ Express your feelings (write in a journal, talk to others in similar situations)
- ▶ Maintain close family relationships
- ▶ Limit your “worry” time
- ▶ Keep a “To Do” list handy and give specific chores/jobs to those who offer to help
- ▶ Appoint a chief communicator to share information and updates with your family, friends, and neighbors
- ▶ Ask questions, get answers
- ▶ Make “one day at a time” your motto
- ▶ Create a progress journal
- ▶ Know the signs of depression and seek help from the rehab psychologist
- ▶ Try to eat properly
- ▶ Avoid excessive use of alcohol or over-the-counter medications

Support is Out There

VA offers multiple levels of logistical and clinical support for patients and their families.

Logistical Support:

Families may face significant financial sacrifice as they stay with their loved one through the rehabilitation process. Generous donations from VA Voluntary Services, Fisher House Foundation, Operation Helping Hand, local businesses, and others frequently provide free housing and free or discounted meals. The polytrauma/TBI point of contact or your loved one’s case manager will be able to help you identify and access these resources.

Clinical Support:

Prior to discharge from a Polytrauma Rehabilitation Center, family members may be scheduled to stay with the patient in a family training apartment. This allows family members to experience what the return home may be like for their loved one, while rehabilitation staff and nurses are available to answer questions, address unexpected problems, and provide the emotional support a family may need as they prepare for this new phase of rehabilitation.

Emotional Support:

VA recognizes the emotional stress that family members face while dealing with the realities of their loved one’s life after a polytrauma injury. Our facilities offer family support, education sessions, and family counseling services to help families cope with adjustment issues following injury.

Please contact your local VA and ask for the polytrauma/TBI point of contact. For more information visit www.polytrauma.va.gov or www.caregiver.va.gov