

ADULT TRAUMATIC BRAIN INJURY

*for Supporters of Individuals
With Traumatic Brain Injury*

How can I help support an individual who has brain injury-related difficulties?

Family members and loved ones or supporters play a critical and often underappreciated role in recovery after brain injury. Health-care professionals encourage loved ones of the survivor to attend medical appointments to help relay information, track the discussion, and to record instructions for the survivor, with the survivor's permission. Involve the survivor in decision-making when possible. In terms of medical appointments, you can help the person with brain injury track their appointments using an appointment binder, planner, master calendar that everyone can see and contribute to tracking, or online calendar that you can both access (and in the case of mild brain injury, you can serve as a backup reminder system). You can also keep a binder of information obtained from appointments as well as educational resources, all in one central location. You can bring this binder to appointments to help you stay organized.

Especially in the case of moderate to severe brain injury, it will be important to learn how to work with the rehabilitation team, which is frequently a new skill for many. Learn the team members' roles and the parts they play in the rehabilitation of the survivor. You can write their names down in an appointment binder, which can also be helpful for the survivor. You can keep a list of questions for the survivor's providers as well as the answers the providers give. It can be difficult to trust the different team members, but the more questions you ask the more likely it is you will be able to talk openly about your concerns. Also ask what you can do at home or "after treatment hours" to help the treatments generalize. Are there home exercises you can help the survivor to do to ensure the brain and body will get the most benefit from the treatments?

If the survivor has a severe brain injury as determined by a doctor, ask the doctor about whether it would be appropriate to have a guardian (in some states this is known as a "conservator") to delegate decision-making about health care and finances on behalf of the person with TBI. Legal consultation should be sought.

If you have a large family or support network and are interacting with a rehabilitation team during your survivor's treatment, it may be helpful to have one or two immediate family members serve as a representative to family and friends. Information passed from the medical staff can be directed to those individuals, who then relay messages to others and funnel decisions to the medical staff. It may also be helpful for the survivor to visit with 2 to 3 people at a time at most, to avoid overstimulation.

What communication skills can be helpful in interacting with individuals after brain injury?

Consider talking in a distraction-free and non-brightly-lit place. A one-on-one format may work better than "family meeting" format for communication. Because the survivor's speed of thinking may have been adversely affected by the brain injury, speak slowly, as though you are throwing a bunch of commas (like

What Is Cognitive Behavior Therapy?

Behavior Therapy and Cognitive Behavior Therapy are types of treatment that are based firmly on research findings. These approaches aid people in achieving specific changes or goals.

Changes or goals might involve:

- **A way of acting:** like forming a support network to help with tasks;
- **A way of feeling:** like staying positive and remembering you are not alone and that recovery takes time;
- **A way of thinking:** like feeling good about what you are doing, even if your loved one is not able to show appreciation;
- **A way of dealing with physical or medical problems:** like focusing on self-care, such as getting enough sleep;
- **A way of coping:** like educating yourself about brain injury and seeking help to avoid burnout.

Behavior Therapists and Cognitive Behavior Therapists usually focus more on the current situation and its solution, rather than the past. They concentrate on a person's views and beliefs about their life, not on personality traits. Behavior Therapists and Cognitive Behavior Therapists treat individuals, parents, children, couples, and families. Replacing ways of living that do not work well with ways of living that work, and giving people more control over their lives, are common goals of behavior and cognitive behavior therapy.

HOW TO GET HELP: If you are looking for help, either for yourself or someone else, you may be tempted to call someone who advertises in a local publication or on the Internet. You may, or may not, find a competent therapist in this manner. It is wise to check on the credentials of a psychotherapist. It is expected that competent therapists hold advanced academic degrees and training. They should be listed as members of professional organizations, such as the Association for Behavioral and Cognitive Therapies or the American Psychological Association. Of course, they should be licensed to practice in your state. You can find competent specialists who are affiliated with local universities or mental health facilities or who are listed on the websites of professional organizations. You may, of course, visit our website (www.abct.org) and click on "Find a CBT Therapist."

The Association for Behavioral and Cognitive Therapies (ABCT) is an interdisciplinary organization committed to the advancement of a scientific approach to the understanding and amelioration of problems of the human condition. These aims are achieved through the investigation and application of behavioral, cognitive, and other evidence-based principles to assessment, prevention, and treatment.

bullet points) into your sentences. Avoid multipart questions. Pause to check for understanding (survivor can summarize in his/her own key words). Use "key words" that summarize the message. Remind the person that he or she can write down information you are providing in a calendar/notebook during the conversation. The survivor can learn that he or she will attend where his or her eyes are orienting and can use this as a cue to stay "on track" and maintain eye contact as time post-injury progresses. Remember that the brain injury survivor has brain-based difficulties with memory and attention and it is most likely that they are not intentionally tuning you out. Try to assist the brain injury survivor to break complex tasks into a series of simpler tasks. While walking with the person, point out landmarks: these may later serve as reminders of paths to places.

It may be helpful to rely on professionals to explain their rationale for instructions to the survivor so that everyone knows where any restrictions in activities came from. This conversation can be recorded or written with the therapist's and survivor's permission. Written guidelines can also provide cueing in the case of memory problems.

If you were or are significantly involved with the person with brain injury, rehabilitation providers want to gather information from you and to involve you in care. Communicate with providers and attend appointments to the extent possible. This can help prevent miscommunication later.

Consider the impact of communications on the recovery and coping of the person with brain injury. Some families have found it helpful to discuss concerns individually with providers both separately and together from the person with TBI. Consider whether all who want to be involved in the life of the person with brain injury but who disagree can come together for a common good.

How do I prevent burnout as a caregiver?

Learn about how TBI will impact your loved one, because knowing what to expect can lower your stress level. Knowing about TBI and the symptoms it causes for your loved one can also help you understand when symptoms such as irritability are due to TBI. The ABCT fact sheet on TBI for brain injury survivors may be of help.

Ask for help (for example, asking a neighbor to run an errand for you). Do not try to do everything all on your own; you will need a list of support people willing to help you with tasks. You can draw on this list in a time of stress. Be aware that sometimes respite care is available, where another appropriately trained individual can come into the home and assist or provide caregiving for you so that you can take a break. You can find more out about this in the resources section below. You may be able to take time off from work under the Family and Medical Leave Act.

Don't forget to focus on your own self-care, too. Have an outlet for your stress. You need some time to yourself.

Remember that being strong or being a good caregiver doesn't mean taking responsibility for everything around you and completing everything on your own.

Accept offers of help from others. Caregivers who get help (in the form of counseling or talking with a trusted friend or religious or community leader) are less likely to burn out.

Stay positive, taking one day at a time. Even if your loved one is unable to show appreciation, you can choose to feel good about the job that you are doing. Focus on what you can control. Set priorities. Make a list and start with the most important; if you can, let some things go for now. Keep a journal of the progress you have made and milestones. Even if you are unable to restore your loved one to how they were before the injury, you can provide a safe and loving environment for that person.

If your loved one is expected to have difficulties that may be lifelong, recognize that you are probably going through a grieving process. It is completely normal to feel denial, anger, depression, and guilt for not having been able to protect your loved one. It is also completely normal to be unsure where to begin. There is no wrong door to walk through in beginning to seek help. The Internet can help open the door to what resources are available, but you have to walk through it.

Some excellent self-help materials for caregivers are available. Caregiver tips are available at brainline.org. Also check out the Mayo Clinic's guide entitled "Understanding Brain Injury: A Guide for the Family," available at <http://www.mayo.edu/pmts/mc1200-mc1299/mc1298-01.pdf>. Niemeier and Karol's *Overcoming Grief and Loss after Brain Injury* (2010; Oxford) is an excellent resource. Another book some partners of survivors find helpful is *The Stranger in Our Marriage: A Partner's Guide to Navigating Traumatic Brain Injury*, by Dr. Colleen Morgan (2010, Peppertree).

Of benefit for both military veterans and nonveterans alike, there is a free guide called "Taking Care of Yourself While Caring for Others," and other similar booklets, which are available through the Defense and Veterans Brain Injury Center's website at <http://www.dvbic.org/material/taking-care-yourself-while-caring-others>. See the family caregiver curriculum for families of individuals with TBI at <http://www.dvbic.org/family-caregiver-curriculum>. There are also some very helpful tips for preventing caregiver burnout available at <http://caregiver.va.gov>.

What treatment can my loved one receive for brain injury?

There are a variety of treatment and rehabilitation programs that may help your loved one. This will strongly depend on how severe the doctors say the injury is, and on what the survivor's day-to-day functioning is now. Typically, complete cognitive and physical rest, including plenty of sleep, is initially recommended for several days after the injury. After that, people with moderate to severe injuries can participate in rehabilitation during the weeks immediately following the injury, where they receive treatment from a variety of specialists over a shorter period of time. This is usually the most intensive part of treatment. After this program is completed, some people live in transitional living programs, which are nonmedical residential programs that teach skills for community living. Others participate in day treatment programs, where rehabilitation is provided during the day so the person can return home at night. Long-term care and supervised living programs are residential facilities that provide care and rehabilitation to people with TBI who are unable to live independently.

For people with mild brain injury who are more independent but whose symptoms have not resolved, services can be provided through the outpatient setting (a routine medical appointment). Speech pathologists and rehabilitation psychologists or neuropsychologists can sometimes provide cognitive

rehabilitation, a form of treatment that focuses on helping people develop strategies to compensate for changes in memory and thinking. Clinical psychologists (especially rehabilitation psychologists or neuropsychologists) will frequently work with people with brain injuries to help the survivor and their support system understand and adjust to a new medical situation and changes in abilities.

Neuropsychological assessment is a type of evaluation used for treatment planning. This type of assessment is conducted by a neuropsychologist, who has advanced training in the relationship between brain functioning and behavior. Neuropsychologists frequently help individuals with brain injury, their support system, and other health-care providers to understand the severity of the injury, strengths and weaknesses, prognosis (that is, whether one's functioning is expected to return to pre-injury levels or not), applications of the results for daily functioning, and treatment planning for medical care. The assessment provides direction for vocational and educational choices or accommodations, the type and intensity of treatment needed, as well as safety guidance for day to day living.

What are my other resources for getting support?

For those who are affected by brain injury, please remember that you are not alone and that there are so many resources and strategies to understand and compensate for brain injury. Neighbors and members of community or religious organizations you belong to are often good sources of support. If you can enumerate the needs of the survivor and support network, people can offer to fill in the gaps.

You can also talk with the brain injury survivor's primary care doctor, a social worker, or a local area agency about options for respite care, which provides short-term relief to those who are caring for family members.

The Brain Injury Association of America (<http://www.biausa.org>) has state chapters that can provide local referral resources for treatment facilities, respite care, transportation, care coordination, support groups, educational materials, and providers who can help. Also, frequently the regional neuropsychological society has an online roster of neuropsychologists who specialize in assessment and treatment.

If your loved one is a military veteran, you can call VA's caregiver support line at 1-855-260-3274, or visit their webpage at <http://caregiver.va.gov> for further information. A useful fact sheet entitled "Traumatic Brain Injury: A Focus on Family and Caregivers" is available at http://www.polytrauma.va.gov/downloads/VA_TBI_Caregiver_Factsheet.pdf. Caregivers play a critical role in the recovery of individuals with moderate to severe TBI, and the VA supports a family caregiver program which applies to caregivers of individuals with TBI (<http://www.caregiver.va.gov>). This program can provide a stipend, training for caregivers, support via telephone or in-person meetings, in-home skilled nursing, respite care, and a variety of other services for those determined eligible. The Department of Defense and Department of Veterans Affairs use the Defense and Veterans Brain Injury Center (DVBIC) as their clearinghouse for patient and family educational materials about TBI. DVBIC can help people connect with case management, which can help individuals get resources they need for day-to-day living. Their web address is <http://www.dvbic.org>.

Education about brain injury can be empowering and can help reduce the stress that comes with the unknown. Ask as many questions of your survivor's doctors as possible, so you can know what to expect. Read as much as you can on your own, but make sure what you read is appropriately tailored to the severity of your loved one's injury. Your doctor can help steer you toward whether it would be more appropriate to read about mild brain injury or severe brain injury. Some good readings for family members include Brainline (www.brainline.org/landing_pages/categories/caregiving.html) and the Mayo Clinic Guide ("Understanding Brain Injury: A Guide for Caregivers," available at www.mayo.edu/pmts/mc1200-mc1299/mc1298-01.pdf).

Particularly if your loved one sustained a severe brain injury and is expected to have lifelong changes in functioning related to his or her brain injury, it is possible that your loved one may be entitled to social security disability benefits (SSDI or SSI). You can contact the Social Security Administration to find out more about these programs and whether your loved one will qualify for these benefits. Contact the Social Security Administration at www.ssa.gov or (800) 772-1213.

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For more information or to find a therapist: **ASSOCIATION for BEHAVIORAL and COGNITIVE THERAPIES**

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