# Traumatic Brain Injury (TBI)

# Frequently Asked Questions - FAQ#2

## Coping With Post-TBI Emotional Distress

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### *WHAT WAS THE STARTING POINT FOR THIS RESEARCH?*

Before doing any formal research, the RTC gathered together a panel of 50 women to talk about their health. Many of them discussed the emotional problems they had experienced since brain injury and the negative effect it had on their lives. Some of them noted that their emotional problems were seen by their doctors as unrelated to brain injury, although this was contrary to their own experience. This discussion led to our conducting a formal study, including both men and women, to better understand the degree to which people experience emotional problems after TBI. From the RTC sample (see above), 100 people at least one year post TBI were selected. Members of this group participated in a structured clinical interview to document their emotional challenges. The group was varied in composition, but the average study participant had been injured eight years prior, was white, not working and 40 years old. The sample was nearly evenly split between men and women.

In the past few years, this research and training center has interviewed hundreds of individuals about their lives after experiencing traumatic brain injuries. People were eligible to be part of this sample if they viewed themselves as someone who has "experienced a brain injury and has had a disability." A comparison group of individuals without a disability was also interviewed. These samples included men and women from all regions of New York State – from rural areas, the cities and the suburbs. People as young as 18 and as old as 65, of all races, income levels and life experiences participated in this research. In each issue of TBI Consumer Report, we will share some of the insights resulting from these interviews.

### *WHAT DID WE FIND?*

**The most commonly experienced emotional problems after TBI were depression, anxiety and substance abuse/dependency:**

**Depression** is a condition marked by emotional and physical problems. People who are depressed experience a loss of pleasure in things that they usually find enjoyable. They typically feel sad and worthless and have trouble getting through each day. They often complain of altered sleep, appetite and concentration difficulties. In the general population, we would expect that 6 people in any group of 100 will experience a major depression in their lives. In our sample, 10 times this many (60) had experienced

major depression since their TBI. Thus, brain injury triggered a bout of severe depression in the majority of the sample. However, the good news is that more than half of these 60 individuals had gotten over their depression by the time of the interview. Depression seems for many to be open to healing.

**Anxiety** was found about twice more often in our sample of individuals with TBI than in the general population. "Anxiety" refers to a variety of disorders. For example, post traumatic stress is a type of anxiety in which people experience flashbacks in which they relive the event that caused their TBI. Phobias are another common type of anxiety, in which the person experiences great fear centered on a specific situation, such as being in an elevator or car, or flying in a plane. Unlike depression, most people who had anxiety disorders after TBI continued experiencing these problems up to the time of the interview.

**Substance use/abuse** was also frequently found. Findings about this form of emotional challenge will not be discussed here, but instead in a forthcoming issue of TBI Consumer Report.

## *WHAT SHOULD YOU DO IF YOU ARE DEPRESSED OR ANXIOUS?*

If you are experiencing emotional challenges, the first step is to acknowledge you are having a problem. Next you should seek professional help. The earlier you ask for help the better, as waiting often makes things worse. And, depression and anxiety can be helped. You should look for a professional who is both familiar with TBI and who specializes in helping people with emotional problems. To obtain a suitable referral, call the Brain Injury Association in your state, or a local rehabilitation hospital or mental health clinic. Properly trained professionals come from many fields — they may be physicians, psychologists or social workers.

When first meeting with this professional, you need to jointly determine if your depression or anxiety is getting worse, improving or remaining the same. You should describe the emotional difficulties you experienced before (if any) and have been experiencing since TBI, as well as any attempts you have made to 'self-medicate.' This professional will discuss with you the two most common treatment approaches for depression and anxiety — medications and psychotherapy. Either or both of these may be suitable in addressing the difficulties you are having. If you choose to try medications and the person you are seeing is not an expert in prescribing and monitoring such medications, you may at that time be referred to a psychiatrist for selection of an appropriate drug regimen.

**What should you know about medication?** Medications to reduce depression and anxiety are often the first step taken in treating severe emotional disturbances. They are used most often in combination with psychotherapy. With many of these drugs, the initial dosage is low and is increased slowly, during which time your reactions to medications are carefully monitored.

You need to be an active decision maker when selecting a medication that is right for you. Be fully informed about side effects by asking questions: Is this drug associated with weight gain? a change in sexual desire? fatigue? decreased ability to concentrate? Would a nonmedication approach be better for you? Which medications have the fewest side-effects?

**Three 'shoulds' apply to wise use of medications:** First, you should keep in contact with your prescribing physician. Second, you should not increase or decrease the dosage without consulting that doctor. And, third, you should create a system to help you remember to take medications as prescribed. For example, some people ask a parent or spouse to remind them, or they use a pill box holding each day's medications. Others tie their taking medications to a once-a-day event that they know they don't forget to do, such as feeding the cat or eating breakfast. To doubly ensure their remembering, they place their medications next to the cat food or near the cereal bowls, so that these visual cues aid their memory.

**What should you know about psychotherapy?** Psychotherapy ('talk therapy') may be used in combination with mood medications, or it can begin before or after medications are started. It should be continued for a time after you stop taking medications, as a means of insuring that your improved emotional well-being continues. 'Talk therapy' can occur between you and a therapist, or it can be done in groups, with several individuals meeting together with one or two therapists.

Therapy is a place in which you share your fears and worries, mourn the losses you have experienced as part of injury, talk about the 'new you', deal with the reactions of others, plan for a new future and learn healthy strategies for coping with life's challenges. Therapy should focus primarily on here-and-now issues related to your adjustment to injury. Psychotherapy should encourage your attempts to better understand your situation, help you build flexible ways of thinking, encourage you to use compensatory strategies (such as memory aids) and address the behaviors that you and others find unacceptable. A major focus of therapy is to review recent activities to determine what went wrong in specific situations. This paves the way for anticipating problems in similar future situations and helps you plan strategies for preventing further failures.

Who is a good therapist? One who engages in the kind of talk therapy described above. This is a person who you feel really listens to you and does not judge you or your actions. This person can be a trained mental health professional or can be a religious leader, a person in a community agency or members of a self-help group. The essential element in his or her training is being highly knowledgeable about TBI and how it can affect day-to-day life.

## *WHAT ELSE CAN YOU DO TO HELP OVERCOME EMOTIONAL DISTRESS?*

Many people find aerobic exercise to be useful in overcoming or reducing depression. With sustained, fast-paced exercise such as running, walking, swimming or biking, they find themselves less tense and fatigued, and with increased energy and improved self-esteem. As we reported in TBI Consumer Report (Issue No.2), exercisers with TBI who we interviewed experienced less depression and fewer cognitive problems.

Some people find that depression and anxiety are reduced simply by adding structured activities into their daily lives. This may mean they return to school or volunteer their time at a community agency. They might join a self-help group or church activities. They may even increase the number of daily household activities in which they engage. This structure increases the individual's self-esteem and enhances his/her contribution to the family's welfare.

Other people opt for therapeutic approaches such as biofeedback, eye movement therapy, hypnosis, relaxation therapy and desensitization techniques. Other alternative treatments include acupuncture, massage, yoga, Tai Chi and other forms of meditation, as well as overthe-counter herbal medications for mood. These approaches help some individuals but not others.

**A final point . . .** The most important thing you can do is to 'own' your emotional state and define your well-being as your responsibility. Thus, if one path you take to feel better doesn't work, it is up to you to try another approach. Both depression and anxiety after TBI can be helped, especially when you reach out to others in your community to help you find the right path. Your task is to find the way that works best for you.

## *TO FIND OUT MORE:*

*This study was published in August 1998: Hibbard, M., Uysal, S., Kepler, K. et al. (1998). Axis I psychopathology in individuals with TBI: a retrospective study. Journal of Head Trauma Rehabilitation, 13 (4), 24-39.* *TBI Consumer Report is a publication of the Research and Training Center on Community Integration of Individuals with Traumatic Brain Injury and is supported by Grant No. H133B980013, to the Department of Rehabilitation Medicine, the Mount Sinai School of Medicine, New York City, from the National Institute on Disability and Rehabilitation Research, United States Department of Education. The contents of this report do not necessarily represent the views of the Department of Education; readers should not assume endorsement by the federal government.*