

Talking to People About Your Traumatic Brain Injury (TBI)

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<https://msktc.org/tbi/factsheets>

TBI Factsheet

This factsheet contains tips and information about how to talk to people about your TBI. It also offers possible responses to common questions that people may ask.

Talking About Your Traumatic Brain Injury

After a traumatic brain injury (TBI), people will often ask questions about your injury. Sometimes you may want to talk about it. Sometimes you may not—and **that is okay**. Thinking about these conversations before they happen might help you feel more comfortable. It is up to *you* to decide who to talk to, and when and how to answer questions.

This factsheet will:

1. Identify things to think about before having these conversations.
2. Help you decide when and how to talk about your TBI.
3. Offer example responses to common questions.



Think About: How Do You Feel About Your TBI?

Ask yourself: *How do I feel about my injury?* Take some time to consider your thoughts and feelings about your experience. This can help you decide how to answer questions. It may be helpful to write about your experience, talk to a loved one, or work with a mental health professional. What helps you think about your feelings?

Ask yourself: *What does this injury mean to me?* You may have experienced a traumatic, stressful event. People may have trouble adjusting after their injury. Many people may also find themselves growing as a person throughout their recovery. They may find new meaning in life and discover new things that they find important. People may have a new appreciation for life and “the smaller things” or feel proud of facing their challenges. Is this something you have experienced?

Ask yourself: *If this happened to a friend, what would I ask?* This may help you prepare for questions. It can also help if you understand why someone is asking you a question. If you get upset, you can ask yourself, *Would you ask them the same thing?*

Deciding When to Talk, Who to Talk to, and What to Say

When to talk:

- Is this a good time and place to talk about my injury?
- You don't need to disclose your TBI, even if it comes up in discussion.
- Every situation is different. You get to decide if and when to talk, whether you are applying for a job, meeting old friends, or going on a date.



The Model Systems Knowledge Translation Center works with Traumatic Brain Injury Model System centers to provide free, research-based rehabilitation resources for people living with traumatic brain injury. (See <https://msktc.org/tbi> for more information.)



Who to talk to:

- Do I feel comfortable with them knowing information about me?
- Do I trust this person with my personal information?
- If you are worried about someone sharing your information, ask the other person to agree to keep what you say private before you give out personal information.
- How would I feel if this person shared the story of my injury with other people I do not know?



What to say:

- How much information should I share?
- Could sharing details about my recovery change the way I want people to think of me?
- Could this person use my information in a way that could hurt me or help me?
- Could the information I share affect my status at work or school or in relationships?
- Tell people *only* what they need to know and what *you* feel comfortable telling them.
- Keep your answers short, simple, and to the point.

How to Talk About Your TBI

Other people may ask about your TBI, but they may not know the best way to ask questions or may try and ask you things you are uncomfortable sharing. In these situations, being **assertive** about what you are willing to share can help you to set firm boundaries. The following are some tips about assertive communication:

- Communication should be equally respectful, honest, and direct.
- Pay attention to your nonverbal behavior such as eye contact, posture, tone of voice, and facial expressions. For example, speaking loudly and very close to someone can come across as aggressive, whereas avoiding eye contact and turning away from someone can seem passive. Try and strike a balance between the two for assertive communication.
- Let the other person know if you don't want to talk about your TBI. For example, you may say, "I appreciate your concern, but I'd rather not talk about that now."
- Develop a response that you can use in any situation, such as "I'm sorry, that's private," or "I don't feel comfortable talking about that."
- You can always change the topic to something you feel more comfortable with. It may be helpful to have a "signal" for friends or caregivers so they can help you leave or change the subject if you don't want to talk about a topic. For example, squeezing their hand or giving them a secret word or phrase.
- Think about also talking with a counselor or therapist about the best methods for sharing information.



Examples: Responding to Common Questions

Practice can help you feel prepared to have these conversations, and to do so in an assertive way.

- List questions you find hard to answer and develop responses ahead of time. Then practice answering the questions with people you trust.



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- Also consider attending a support group for people with a brain injury. Many communities have support groups that provide a safe place to discuss your TBI, how to talk about it with others, and how people deal with tough situations. People often find that speaking to support groups is validating and allows them to share their struggles and triumphs with others.

Below are some examples of ways you might respond to common questions. These are examples of short responses that can be useful in many different situations and do not give away too much information:

<p>Q: What happened?</p> <p>A: I was in an accident a while ago.</p> <p>A: I had an injury to my brain.</p>	<p>Q: How are you doing now? How do you feel?</p> <p>A: I'm getting better slowly but surely.</p> <p>A: I am healing in a lot of different ways.</p>
<p>Q: How long will you be (or were you) in the hospital?</p> <p>A: I was (or am) in the hospital until my doctors and therapists release(d) me.</p>	<p>Q: What are your doctors saying about your recovery and when will you be back to your normal self?</p> <p>A: They tell me I'm making progress, and I'm hoping for more.</p> <p>A: Recovery is a process. I'm taking it day by day.</p>
<p>Q: What kinds of operations and treatments have you had?</p> <p>A: I have received many kinds of therapies, including physical therapy, thinking and memory training, help with speech, and other tips for daily living.</p>	<p>Q: You look great. When can you go back to work (or school)?</p> <p>A: We're working on a plan right now. I hope to know soon.</p> <p>Q: Why aren't you going back (to work/school)?</p> <p>A: I'm working on my recovery right now.</p>
<p>Q: How much longer will you need treatment?</p> <p>A: My doctors are helping me recover as quickly as possible.</p> <p>A: Recovery may be a long journey.</p>	<p>Q: When can you start driving again?</p> <p>A: When I'm cleared by my doctor and feel safe.</p>
<p>Q: What are your current symptoms and side effects?</p> <p>A: I tend to get tired easily (or) I must pay attention to things more carefully now.</p> <p>A: My symptoms may change throughout my recovery.</p>	<p>Q: Why do you stay home so much?</p> <p>A: It helps me get the rest I need.</p>
<p>Q: What type of medical care do you need?</p> <p>A: I see my doctors and therapists every now and then.</p>	<p>Q: Why do you seem so tired all the time?</p> <p>A: That is a common symptom of a brain injury.</p>



Other Resources

As you decide what to tell others, the following may help you talk about your TBI:

- Understanding Traumatic Brain Injury (a four-part series; <https://msktc.org/tbi/factsheets/understanding-traumatic-brain-injury>)
 - What Happens During Injury & In Early Stages of Recovery?
 - Brain Injury Impact on Individuals' Functioning
 - The Recovery Process for Traumatic Brain Injury
 - The Impact on Family & How They Can Help
- Separate factsheets about alcohol and TBI, balance problems and TBI, cognitive problems, depression, emotional problems, fatigue, returning to school, relationships after TBI, and memory



These and other factsheets can be found on the MSKTC website at <http://www.msktc.org/tbi/factsheets>.

Authorship

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Disclaimer: This information is not meant to replace the advice of a medical professional. You should consult your health care provider about specific medical concerns or treatment. The contents of this factsheet were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DPKT0009). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this factsheet do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

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