

Self-Advocacy: Explaining Brain Injury to Others

Being a self-advocate means you identify barriers to having a better life. Armed with basic information and helpful resources, anyone can become an effective advocate for themselves. One way to practice self-advocacy is educating those around you about your brain injury and the challenges you may experience.

Here are some ways you can communicate with others about your injury:

I need a lot more rest than I did before my injury. This is not because I am lazy. I get physically fatigued along with "brain fatigue," making it harder to think. It is very difficult and tiring for my brain to think, process, and organize.

Even though I look good or "all better" on the outside, my stamina varies. My thinking skills are better some days than others. Pushing too hard may lead to setbacks. Cognition is a fragile function for an individual who has experienced a brain injury.

Brain injury rehabilitation can take a very long time. It continues long after formal rehabilitation has ended. I may not be the same person that I was before my injury. I am not trying to be difficult if I resist social situations. Crowds, confusion and loud sounds can quickly overload my brain. Limiting my exposure is a coping strategy.

If there is more than one person talking, I may seem uninterested in the conversation. I have trouble following multiple lines of conversation. It is exhausting to try and piece the conversation together. My brain can easily get overloaded.

If I tell you that I need to stop when we are talking, I need to stop NOW! I am not trying to avoid the subject I just need time to process the discussion and take a break. I will be able to rejoin the discussion later.

If I am having difficulty in managing how I'm behaving, try to notice the circumstances. "Behavior problems" can be a sign that I am struggling to cope in a specific situation. I may be frustrated, in pain, overtired or overwhelmed.

Patience is the best gift you can give me. It allows me to work at my own pace and work on rebuilding pathways in my brain. Rushing or trying to do too many things at once hinders my cognition/memory.

If I am struggling to find my words, try not to interrupt and allow me the time to find my words and follow my thoughts. This will help me with my language skills.

Know that not remembering does not mean I do not care.

Please do not talk to me like I am a child. I am not stupid, my brain is injured and I am working on getting better. Try to think of me as if my brain were in a cast.

If I seem rigid or inflexible it is because I am working on retraining my brain. It's like learning main roads before you can learn shortcuts. Repeating tasks in the same order is helpful.

If I seem stuck, coach me, ask leading questions suggest other options or ask what you can do to help me figure things out. Talking over me or doing things for me makes me feel incapable.

I may repeat actions, such as checking if the door is locked multiple times or checking to make sure the stove is off. It may be that I am having trouble registering what I am doing in my brain. Repetition helps memory.

If I seem sensitive, it could be emotional fluctuation due to the great effort it takes to do things. Tasks that use to feel automatic now take much longer and require using many strategies. Some tasks are huge accomplishments for me since my injury.

Don't confuse hope for denial. Every day we learn more and more about the brain and ways it can heal. No one can know for certain what my potential is. I need hope to be able to use coping mechanisms, accommodations and strategies to navigate my new life.

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