

## 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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