GLIOBLASTOMA
SUPPORT
NETWORK

REMINDERS FOR CAREGIVERS OF GBM/CRANIOTOMY

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(Craniotomy's are Brain Injury's too) 18 Things Friends and Family Need to Know How to Act around someone with a Brain Injury or Surgery.

1. I need a lot more rest than I used to. I'm not being lazy. I get physical fatigue as well as a "brain fatigue." It is very difficult and tiring for my brain to think, process, and organize. Fatigue makes it even harder to think.

2. My stamina fluctuates, even though I may look good or "all better" on the outside. Cognition is a fragile function for a brain injury survivor. Some days are better than others. Pushing too hard usually leads to setbacks, sometimes to illness.

Brain injury rehabilitation takes a very long time; it is usually measured in years. It continues long after formal rehabilitation has ended. Please resist expecting me to be who I was, even though I look better.

3. I am not being difficult if I resist social situations. Crowds, confusion, and loud sounds quickly overload my brain, it doesn't filter sounds as well as it used to. Limiting my exposure is a coping strategy, not a behavioral problem.

4. If there is more than one person talking, I may seem uninterested in the conversation. That is because I have trouble following all the different "lines" of discussion. It is exhausting to keep trying to piece it all together. I'm not dumb or rude; my brain is getting overloaded!

5. If we are talking and I tell you that I need to stop, I need to stop NOW! And it is not because I'm avoiding the subject, it's just that I need time to process our discussion and "take a break" from all the thinking. Later I will be able to rejoin the conversation and really be present for the subject and for you.

6. Try to notice the circumstances if a behavior problem arise. "Behavior problems" are often an indication of my inability to cope with a specific situation and not a mental health issue. I may be frustrated, in pain, overtired or there may be too much confusion or noise for my brain to filter.

7. Patience is the best gift you can give me. It allows me to work deliberately and at my own pace, allowing me to rebuild pathways in my brain. Rushing and multi-tasking inhibit cognition.

8. Please listen to me with patience. Try not to interrupt. Allow me to find my words and follow my thoughts. It will help me rebuild my language skills.

9. Please have patience with my memory. Know that not remembering does not mean that I don't care.

10. Please don't be condescending or talk to me like I am a child. I'm not stupid, my brain is injured and it doesn't work as well as it used to. Try to think of me as if my brain were in a cast.

11. If I seem "rigid," needing to do tasks the same way all the time; it is because I am retraining my brain. It's like learning main roads before you can learn the shortcuts. Repeating tasks in the same sequence is a rehabilitation strategy.

12. If I seem "stuck," my brain may be stuck in the processing of information. Coaching me, suggesting other options or asking what you can do to help may help me figure it out.

13. Taking over and doing it for me will not be constructive and it will make me feel inadequate. (It may also be an indication that I need to take a break.)

14. You may not be able to help me do something if helping requires me to frequently interrupt what I am doing to give you directives. I work best on my own, one step at a time and at my own pace.

15. If I repeat actions, like checking to see if the doors are locked or the stove is turned off, it may seem like I have OCD — obsessive-compulsive disorder — but I may not. It may be that I am having trouble registering what I am doing in my brain. Repetitions enhance memory. (It can also be a cue that I need to stop and rest.)

16. If I seem sensitive, it could be emotional liability as a result of the injury or it may be a reflection of the extraordinary effort it takes to do things now. Tasks that used to feel now take much longer, require the implementation of numerous strategies and are huge accomplishments for me.

17. We need cheerleaders now, as we start over, just like children do when they are growing up. Please help me and encourage all efforts. Please don't be negative or critical. I am doing the best I can.

18. Don't confuse Hope for Denial. We are learning more and more about the amazing brain and there are remarkable stories about healing in the news every day. No one can know for certain what our potential is.

We need Hope to be able to employ the many, many coping mechanisms, accommodations and strategies needed to navigate our new lives. Everything single thing in our lives is extraordinarily difficult for us now. It would be easy to give up without Hope.