12 Things Every Stroke Survivor Wished You Knew

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Have you heard about stroke survivor Jill Bolte Taylor?

She's a neuroanatomist/brain scientist/brain researcher (pretty much an expert on all things BRAIN) who got to study *her own stroke as it happened*. And it provided her with powerful insight that she devoted her career to sharing.

So if you haven't watched her TedTalk yet, watch it here – it's inspirational. And if you haven't read her book yet, *My Stroke of Insight*, find it here – it's even better.

In that book, Dr. Taylor lists 40 things that she needed during her recovery – and we found them powerful lessons that *everyone* should know; caregivers, friends, family, and general public alike.

The first 8 topics on this last came from her. After this article was published, it quickly became one of our most popular. So we have updated it with the rest!

1. Be as patient with me the twentieth time you teach me something as you were the first.

Stroke recovery means relearning everything for the first time again. If a child cannot repeat the alphabet from memory after the first try, you wouldn't grow impatient. You'd be understanding because it's his/her first time. The same things applies to stroke recovery.

Stroke survivors are relearning everything *as if it's the first time*. So be patient, compassionate, and caring.

2. I am not stupid, I am wounded. Please respect me.

Stroke does not affect someone's intelligence. A survivor may take longer to find the right words, but they're the same smart person inside.

Every stroke survivor is worthy of respect – period.

3. Protect my energy. No talk radio, TV, or nervous visitors.

This is one of the reasons why mindfulness is so important during stroke recovery. During stroke recovery, the brain needs stimulation in order to heal itself. But it needs specific stimulation – and not too much! For example, the stimulation of doing hand exercises is good. It helps the brain rewire itself and improve hand function.

But the stimulation of background noise only drains on the limited energy that a healing brain has. So limit as many distractions as you can.

4. Make eye contact with me. I am in here – come find me. Encourage me.

If someone avoided eye contact with you, it would be upsetting, annoying, and hurtful, right? Right. And *everyone* feels that way. So make a point of giving everyone the eye contact they deserve.

5. Do not assess my cognitive ability by how fast I can think.

After stroke, the brain is busy rewiring itself through neuroplasticity. During this process, the healthy areas of the brain begin to pick up the slack for the damaged areas – and this take time. In the meantime, the brain is jumbled and it may take a survivor longer than normal to retrieve information. This does not mean they have lost their intelligence. They are simply having trouble pulling up the information.

6. Repeat yourself – assume I know nothing and start from the beginning, over and over.

As the brain heals from injury, it sucks up a lot of mental juice. So when a survivor has a hard time understanding you, don't repeat just the last part. Putting the pieces together is an extra and unnecessary step. Instead, repeat everything and be patient while you do it.

7. Stimulate my brain when I have energy, but know that small amounts may wear me out quickly.

After stroke, it's perfectly normal to sleep A LOT. Survivors may find themselves craving a nap immediately after rehab exercises or even right after getting ready in the morning. Tasks that once came effortlessly now require a tremendous amount of effort (remember, their healing brain is sucking up a lot of juice).

Stimulation is good (like rehab exercises and the activities of daily living), and lots of sleep afterwards is necessary. So if your stroke survivor wants to sleep, let them SLEEP.

8. Please don't raise your voice. I'm not deaf, I'm wounded.

Going back to #6, you know that a survivor may require more time to process your words and search for their own words. So when they ask you to repeat yourself, they just want you to repeat yourself. They do not want you to repeat yourself louder, unless they ask.

Because saying something louder is not going to help them *process* it better. Things like patience, compassion, and slowing down are much more effective ways of boosting communication.

9. My desire to sleep has everything to do with my healing brain; and it has nothing to do with laziness.

Stroke causes damage to the brain that must be healed. Just like a broken leg requires time and energy to heal, so does my brain. So when I desire to sleep instead of doing something, it's not because I'm being lazy. It's because my brain is healing and sucking up a lot of my energy.

10. Please have patience with my memory.

Stroke can affect my short-term and/or long-term memory. It can also affect my cognition. My brain is healing itself, and in the process, things are getting moved around. This makes it harder to retrieve information. So if I don't remember something that you told me a month/day/hour ago, please don't take it personally. Be kind and patient with my recovery.

11. When I'm 'stuck,' try not to take over.

As my brain becomes better and better at processing information, it will not happen in a smooth process. There will be days where I need more patience, explanation, and reason to figures something out. A little coaching or suggesting is helpful. Taking over and doing it for me is not helpful. In order to recover, I need all the practice I can get. Don't take that away from me.

12. I'm not being 'emotional.' I'm recovering.

Stroke can affect the emotion center of the brain and affect my ability to manage my emotions. When this is severe, the condition is known as emotional lability. Whether my emotional swings are mild or severe, please be patient with me.

Things that used to come 'naturally' with minimal effort now require serious time and effort. This can cause anger or frustration just like many difficult tasks can. If I grow upset, frustrated, or depressed, please try to understand how a healing brain may respond to the situation at hand.

Offer me all the support you can.