

## Appendix 1

# A STROKE SURVIVORS BILL OF RIGHTS

Dr. Jill Bolte Taylor\*

*\*Dr. Jill Bolte Taylor is a trained and published neuroscientist. In December, 1996, while teaching and performing research at Harvard, she experienced a severe hemorrhage in the left hemisphere of her brain. Following her stroke, Dr. Taylor was completely disabled; she could not walk, talk, read, write, or have any recollection of her life. She describes her condition on the day of the stroke as that of being “an infant in a woman’s body.” Dr. Taylor has completely recovered and is back to teaching at the medical school level. She has written the “Stroke Survivor’s Bill of Rights” to help others better understand what she needed in order to recover completely. In addition, Dr. Taylor has written a book titled: My Stroke of Insight: A Brain Scientist’s Personal Journey. Dr. Taylor resides in Bloomington Indiana and teaches at the IU School of Medicine. She can be reached at: 812-335-0459. You can visit Dr. Taylor’s web site and purchase her book at <[www.drjilltaylor.com](http://www.drjilltaylor.com)>.*

## Take Brave Steps for Stroke Survivors and Families

1. I needed you to treat me like I was going to recover completely. It might take two years or five years or a lifetime, but I needed to be treated like I was going to recover completely.
2. I needed you to honor the healing power of sleep. The brain is a brilliant machine that processes trillions of bits of data every moment. The brain uses sleep to shut down incoming stimulation and create order out of the day's events. In the beginning, my brain wanted to sleep a lot. I believe that it was partially because we honored the healing power of sleep that my brain recovered so well.
3. I needed to challenge my brain systems immediately. I understood that connections in my brain had been broken, and it was critically important that I challenged the system before more cells had a chance to die. When awake, I was always given choices—did I want this or that to eat, did I want to do this or that? I was forced to answer questions that made me think, instead of yes/no questions that required nothing from me.
4. I needed you to love me—not for the person I was before, but for who I might become. The woman I had been died that morning. With my left hemisphere no longer functioning, I needed people to love me for who I had become. I might have looked the same and sounded the same, but I was different—and that had to be OK.
5. I needed to define my priorities for what I wanted to get back the most. I lost my ability to speak and understand language, to walk and drive, as well as all my science and math abilities. Because I had very limited energy, I had to focus my time. I realized that I might never be a scientist again, but I had a

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message to communicate about the beauty and resiliency of the brain. I chose to focus my energy on public speaking. Because speaking on the telephone was an obvious energy drain for me, my family protected me by not letting me speak on the phone. That was a lot of help.

6. I needed you to focus on my ability, not my disability. I needed to celebrate everything. If all I was doing was breathing, then we could celebrate that I was alive—and breathe deeper together. If I stumbled, then we could celebrate when I was upright! If I was drooling, we could celebrate my swallowing! It was way too easy to focus on my disabilities because they were vast. I needed you to celebrate my triumphs every day! My successes, no matter how small, inspired me.
7. I needed to allow myself to receive support, love, and help. It would be at least two years before we really knew how extensive my recovery would be. I needed to get out of my own way. I needed to stop beating on myself for being less. I needed time to let my brain heal. I needed you to cut me some slack and not be so heavy all the time! I was not less, I was different, and it's OK to be different.
8. I needed to divide every task into smaller and simpler stages or steps of action. Instead of rolling over, I might rock. Instead of standing up, I might sit and rock. Just because you could not see that I was trying, it did not mean that I was not trying. Sometimes when I was tired, I just needed to sleep, and I needed you to just accept that.
9. I needed you to assume that I knew nothing. I had, after all, lost my mind. Pieces of information did not fit together anymore in my brain; for instance, I

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might not know what a fork was. I might not know what a shoe was—much less that my socks went on first and why. As my caregiver, you were my teacher. It helped when you talked to me, repeated yourself and didn't act like I was stupid if I didn't get it the first 20 times! Raising your voice did not help you communicate with me. I was not deaf, I was wounded.

10. I needed you to come close and not be afraid of me. I needed you to touch me, stroke my arm, my hair, and wipe my face if I was drooling—to be kind to me. What you said was not as important as how you said it. What you did was not as important as how you did it. It helped when you came close and enunciated clearly. If you brought your best self forward, my spirit would greet you—only when I trusted you as a caring giver would we heal my brain together.