

## Communicating with Stroke Survivors: What Matters Most?

Ann Catlin, OTR, LMT

It is likely that, at some point, someone you know will suffer a stroke: a grandparent, parent, sibling, friend, neighbor or client. Stroke is one leading cause of long-term disability in the United States. I've met literally hundreds of stroke survivors while working as an occupational therapist in rehabilitation programs and my grandfather suffered a stroke when I was a child. Even though I've had all this experience the one thing that stands out as challenging, yet critically important, is communication. How to best communicate with a stroke survivor and what really matters most? The topic of stroke, or cerebral vascular accident, is very complex and people who suffer strokes commonly experience physical, behavioral and communication effects. The focus of this article is communication, so it's important to have a basic understanding of what happens during a stroke that leads to communication impairment.

The term *stroke* refers to a situation that occurs when blood flow is interrupted to the brain cells. There are basically two types of stroke. An ischemic stroke is when an artery becomes blocked by a blood clot depriving cells of oxygen. About 83% of strokes are ischemic. Hemorrhagic stroke is when there is actual bleeding from the arteries into the brain tissue, accounting for about 17% of all strokes. The resulting functional impairment or disability depends on the location of the vascular lesion in the brain. Speech and language is a function primarily of the left hemisphere of the brain so when the stroke occurs in the left hemisphere, communication -- the ability to speak, understand, read, and write-- will possibly be affected. The extent of impairment is determined by the severity of the damage to the brain.

This brings me to the point I really want to make. What does the stroke survivor that experiences communication disorders need from us? What matters most? I know what I've observed, but wanted to see what others had to say about it. I set off to find out. In the process I found a jewel of report called *The Psychosocial Spiritual Experience of Elderly Recovering from Stroke*<sup>2</sup>. The elders recalled that the early period following the stroke was terrifying. Connection with others was important in all stages of recovery and that communication difficulties led to feelings of isolation. They stressed that recovery requires a great deal of physical and psychological effort and that hope and inner strength were important.

Jill Bolte Taylor, Ph.D. was 37 when she suffered a massive stroke. Her book entitled *My Stroke of Insight* shines a light on what she needed most during her recovery. On the topic of communication and connection with others, Jill has this to say:

"I needed people to love me – not for the person I had been, but for who I might now become. I needed those around me to be encouraging. I needed to know I still had value. Focus on my ability, not my disability. I needed people to come close and not be afraid of me. I desperately needed their kindness. I needed to be touched- stroke my arm, hold my hand, or gently wipe my face if I'm drooling. I know it can be very uncomfortable for a healthy person to try to communicate with someone who has had a stroke, but I needed my visitors to bring me their positive energy. Since conversation of obviously out of the question, I appreciated when people came in just for a few minutes,

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took my hands in theirs, and shared softly and slowly how they were doing, what they were thinking, and how they believed in my ability to recover."

What people who survive strokes may need most from us is not found in any kind of therapeutic technique or approach. It's found in our ability to show up and be real in our caring. It's found in the simple gift of touch and heart to heart connection. It's found in acknowledging that the stroke survivor is a person whose life has been altered but the individual inside the body remains the same. It's found in shared hope. I'll leave you with this poignant story called *Poor Thing* by Judith A. Russo who cared for her husband following his stroke.

"Did you hear that Joe had a stroke?" asks Person A. "Oh yes, poor thing!" says Person B. "He was such a good person, and a good worker," says A. "Yes, too bad, isn't it?"

My husband had a stroke in February 2000, which left him with Broca's aphasia. Do you know what Broca's aphasia is? What you need to know is that he is not a "poor thing." And he still is, not *was*, a good person. He is a survivor who is living a richer life now than he was before. He was in the rat race of existence, going round and round with the dizzying effects of a non-stop merry-go-round. Now he has time to smell the lilacs, watch the egret fish for its dinner, and marvel as his granddaughter grows inch by inch. How poor can that be? He is, perhaps, disabled, but the same person he was before the stroke. Most folks become so intimidated with the affliction "stroke" that they forget there is a real person living in that body, a person who thinks, hurts, laughs and cries just like you.

The rhetoric continues, "What do you say to him?" asks Person A. "I don't know," replies Person B. "Well, I won't bother him now, or call or visit. After all, he's probably busy, and I don't know how much he understands anyway." "I agree," says B, "he probably wouldn't know who we are, and we don't want to embarrass him."

By the way, Broca's aphasia is the inability to communicate effectively by speech. What is the therapy for people with aphasia? Talking to the survivor and encouraging them to respond. You might have to wait for two or three awkward moments for them to think about what to say. In the meantime, you may see the egret fish for its catch of the day. You may see the lush brown velvet cat-o'-nine tails waving in the wind, or the rabbits playfully goading each other on the lawn, or the huge turtle crawling along the banks of the pond with a goldfish in its jaws. Come at dusk and perchance you will see the deer as they come to the pond to drink. You will go away richer for the visit because you will have escaped the runaway merry-go-around, if only for a few moments. You will feel rich and will have blessed the heart of the "poor one who was such a good person."

When a stroke happens to a relative, friend or co-worker, please do not put them into an isolation they never asked for. Reach out and touch someone today."

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**Aphasia** is one common communication disorders associated with stroke. Aphasia affects the ability to use or comprehend words. It may cause difficulty:

- Understanding words.
- Finding the word to express a thought.
- Understanding grammatical sentences.
- Reading or writing words or sentences.

The National Aphasia Association offers these tips on communicating with a person who has aphasia:

- Decrease background noise such as television, radio, and other people as much as possible.
- Keep communication simple but adult. Don't talk down to the person with aphasia.
- You don't need to speak louder than normal but do emphasize key words.
- Encourage and use other modes of communication (writing, drawing, yes/no responses, choices, gestures, eye contact, facial expressions) in addition to speech.
- Give them time to talk and let them have a reasonable amount of time to respond. Avoid speaking for the person with aphasia except when necessary and ask permission before doing so.

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Resources:

1. American Stroke Association. [www.strokeassociation.org](http://www.strokeassociation.org)
2. Joanna Briggs Institute, The Psychosocial Spiritual Experience of Elderly Recovering from Stroke. (2009) Best Practice 13(6)
3. Bolte Taylor, Jill, My Stroke of Insight (2006) Viking Publishing, New York, N.Y.
4. Russo, Judith A., Poor Thing (2002) *Excerpted from the Readers Room department of Stroke Connection Magazine, January/February 2002*
5. National Aphasia Association, [www.aphasia.org](http://www.aphasia.org)