Tip Sheet #14

Communicating with the Stroke Survivor

Communication can be very challenging for survivors and caregivers. There are a number of possible reasons why your survivor is having trouble communicating with others. Put an X beside all that apply.

__ Trouble speaking because of the stroke (Broca’s aphasia)
__ Trouble understanding others due to stroke (Wernicke’s aphasia)
__ Trouble with communication overall (Global aphasia)
__ Trouble forming words due to paralysis (Dysarthria)
__ Trouble processing what is being said
__ Can’t keep up with the conversation
__ Impaired thinking, poor memory, or confusion
__ Keeps asking the same question over and over
__ Keeps repeating the same word over and over
__ Can’t read or write because of the stroke
__ Can’t use the phone very well since the stroke
__ Trouble with vision, or can’t see as well
__ Trouble hearing what is being said
__ Frustration over not being able to speak well
__ Embarrassment or poor self-image
__ Withdrawal from all people or always wanting to be left alone
__ Depression or hopelessness
__ Personality changes
__ Anger or bitterness about the stroke
__ Irritable or angry toward others
__ Poor relationships with others, doesn’t get along with others
__ Uses foul language – the words just seem to pop out automatically
__ Emotions don’t match thoughts. For example, cries when happy, or laughs inappropriately
__ Other ___________________________________________
__ Other ___________________________________________
__ Other ___________________________________________

Face it, communication is more complex than you think.
When a survivor speaks, they have to:
- Think about what they want to say
- Put their thoughts into the right words
- Say the words out loud

When a survivor listens, they have to:
- Recognize that someone wants to tell them something
- As the person talks, they need to keep their words in mind
- Make sense out of the person’s words and define them
- Put together the meanings of the words to understand the whole message

Although these skills are automatic and learned from childhood for most people, a stroke can damage areas of the brain that can make these tasks very difficult for stroke survivors.

Problems like aphasia, dysarthria, hearing loss, vision loss, and feelings that the survivor has can all affect communication.

What is Aphasia? Aphasia is when survivors have problems with finding and using words, or with comprehending or understanding words. It can also affect a person’s ability to read, write, or gesture.

Aphasia is NOT a loss of intelligence. Survivors can be fully aware of what is going on, but not be able to speak or comprehend speech.

- Broca’s Aphasia (expressive aphasia):
  - Inability to express/speak the words they are thinking
  - Inability to put words together to speak correct sentences
  - Broca’s aphasia is speech that tends to be choppy
  - Broca’s aphasia causes problems with sentence structure, but understanding sentences is not greatly affected
  - Reading and writing can also be impaired

- Wernicke’s Aphasia (receptive aphasia):
  - Difficulty in understanding spoken or written language
  - Stroke survivors with Wernicke’s aphasia talk fluently, but the content of the speech is does not make sense and is garbled or babbled. Some can’t control what they are saying. Foul language is common too.
• Reading and writing also can be impaired

• **Global Aphasia:**
  • Loss of all language ability
  • Cannot speak or understand speech

*Most often, survivors have a combination of different types of aphasia. They may have a mixture of several types.*

Other problems that **may or may not** occur with aphasia:

• **Dysarthria** – This is where the muscles of the mouth, face, neck and throat may be weakened or paralyzed. The survivor knows what they want to say and the correct words (unless they also have aphasia), but they have trouble forming the words. The side of their face may droop as well.

• **Dysphagia** – This is trouble swallowing. The survivor may have trouble swallowing food, liquids, or even their own saliva. Drooling is common. They may also cough, choke, or aspirate (swallow food or liquid into the airway or windpipe). See **Tip Sheet #17 Getting the survivor to eat** for tips on what to do for swallowing problems. **Seeing a dentist is important too!** Dentures may need to be refitted or tooth decay can cause problems with communication too.

• **Vision problems** – Stroke can cause double vision, or partial blindness on one side or the other. If a person is sitting on the survivor’s blind side, the survivor may not even realize they are there. Vision problems can also prevent the survivor from seeing nonverbal communication (noticing facial expressions, smiles, frowns, etc.). Eyeglasses may need adjustment after stroke. **Talk to the doctor or see an eye doctor for help.** A neuroophthalmologist is a doctor that specializes in vision problems caused by stroke. Ask the survivor’s doctor if you think the survivor needs a referral.
• **Hearing loss** - Whether hearing loss was a problem before or after the stroke, it can still cause problems in communication. **Talk to the doctor or see an audiologist for help.**

• **Sensory and perception problems** – Survivors sometimes have problems noticing things on one side of their body. They might not even recognize their own hand. *This is called “neglect.”* Memory problems can also occur. They might also have trouble learning new things. Be sure that you are on the stroke survivor’s unaffected side when trying to communicate. The survivor might not be able to communicate with you if you are sitting on their paralyzed side.

• **Feelings** – Not being able to communicate can be very upsetting. Many times survivors are able to understand what is going on, but they can’t speak. Other people may assume that they are confused or demented when they are not. **Aphasia or inability to communicate does not mean that the survivor has lost their intelligence.** Depression is very common in stroke survivors with speech problems. See Tip Sheet #9 Dealing with the Stroke Survivor’s Emotions While Providing Care. Helping the survivor with their emotions, whatever they may be, can help them move toward recovery quicker. **Tip Sheet #11 Dealing with Difficult Behaviors** can help too.
**What are some specific things I can do to help the survivor communicate?** Here are some specific communication tips that might work for the survivor. Put an X beside the ones you think might work.

__ Go to speech therapy sessions __ with the survivor to see what they can do. This is also a good chance to ask the therapist questions about how you can help as a caregiver.

__ Attend a stroke support group __ with other aphasic survivors and their caregivers. A list of stroke support groups follows Tip Sheet #8 Where to find resources.

__ Give the survivor a card __ that tells others they have aphasia and to speak more clearly. Such a card could look something like this:

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It is very hard for me to speak, read, or write because I have had a stroke.

I can usually understand what you are saying if you speak clearly.

Thank you for your help and patience.
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__ Call the American Stroke Association Warmline __ for advice from other stroke survivors and caregivers. 1-888-4-STROKE or 1-888-478-7653, www.strokeassociation.org

__ Call the National Aphasia Association: __ 1-800-922-4622 or log onto their website: www.aphasia.org
Call the American Speech-Language-Hearing Association for suggestions or information. 1-800-638-8255, www.asha.org/public/speech/disorders

Ask short questions and make short requests. Yes/no questions are good to start with. They can sometimes nod to answer. Giving a thumbs up or thumbs down might be better than trying to say yes or no.

Add hand gestures or point to things. Make pictures of common things and point to them. (Picture of food if hungry, glass if thirsty...). Again, thumbs up or thumbs down may also be a good way to communicate.

Write down what you are trying to say. Sometimes survivors can read better than they can understand spoken words. Sometimes the opposite is true. They may be able to understand spoken words better than reading. Try an English as Second Language Dictionary with pictures they can point to.

Treat the survivor as a mature, responsible adult. Don’t talk down to them. Don’t shout or speak too loudly. Hearing is not usually the problem.

Never assume the survivor doesn’t know what you are saying. Do not say anything you would not want them to hear or understand completely.

Speak in a natural voice, unless you know they have a hearing loss. Talking loudly will not help, and may make them feel worse. Speaking slowly and clearly may help though.

Verify that the survivor understands what you are saying.

IT IS VERY IMPORTANT TO turn off the TV or radio when trying to talk to the survivor. A lot of background noise is confusing.
Avoid noisy restaurants or large groups with a lot of noise if the survivor gets distracted easily. These settings can be overwhelming for some survivors.

Try to have one person talk at a time. It’s confusing when conversation shifts from one person to the next quickly.

Teach friends and family how to communicate with the survivor before they visit. Explain what the survivor is able to understand. Give them tips on how to best communicate with them. Interpret the survivor’s words for friends and family.

Friends and family tend to avoid talking to the survivor and try to talk to you instead. You might try leaving the room for short periods or avoid eye contact with them to try to get them to focus on the survivor. Pay attention to where they sit. Make sure the survivor can see them when they talk.

Slowly get friends and family to visit. Start with one or two trusted friends or relatives at a time. Work your way up to social situations. For ideas on social activities, see Tip Sheet #16 Keeping the Stroke Survivor Socially Active.

Take care of yourself as a caregiver. Aphasia or difficulty communicating with the survivor can be very stressful or frustrating for the caregiver as well as the survivor. See Tip Sheet #27 Dealing with my own emotions.

When do I need to contact a professional?

- It is never too early to ask for help. Call the doctor or speech therapist for any questions you may have. See Skill-Building Tip Sheet #SB5. Communicating with Health Professionals if needed.

- Ask for assistance as soon as communication problems begin or any change in communication ability is noted.
Contact the National Aphasia Association (1-800-922-4622) or the American Speech-Language-Hearing Association (1-800-638-8255) for more information.

A good book on aphasia is: Coping with Aphasia by John G. Lyon. Check your local library, book store, or www.amazon.com

References:

1. www.aphasia.org
