

# Speak for yourself



**If MS affects your ability to express yourself or understand others, help is available.**

by Cynthia L. Kryder



**Melissa Puches was able to clearly say her vows to her husband, Eric, at their wedding**

**last October, thanks to speech therapy.** Photo courtesy of Melissa Puches

Melissa Puches was diagnosed with relapsing-remitting multiple sclerosis in 2001, soon after she graduated from college. With few visible symptoms, she continued to pursue her career in finance with no adverse consequences. It wasn't until 13 years later that she began having trouble regulating her breathing, which affected her ability to speak.

"Attempting to complete even one sentence was hard; by the end I was extremely breathless," Puches explains. "It wasn't as scary as it sounds—it only affected my speech, but it was frustrating. Speaking in any social situation was tough, even just conversing with my husband. I mumbled and it was difficult to raise my voice."

Bridget Gille faces a different issue when she's trying to have a conversation. "I can't always think of the word I want to say," says Gille, who has lived with relapsing-remitting MS since 2006. "The word is right on the tip of my tongue, but I can't get it out. The person I'm talking to has to wait for me to find it. It's very frustrating."

### **Talk about tough**

Communication challenges can be more than frustrating, in fact. The inability to clearly express oneself can affect sense of identity, self-confidence, relationships, parenting and safety.

Studies vary, but most indicate that between 25 and 50 percent of people with MS report speech and/or voice changes over the course of their disease, says Patricia Bednarik, a speech-language pathologist (SLP) and MS-certified specialist (MSCS) at the University of Pittsburgh Medical Center MS Center. In addition, cognitive changes that interfere with communication may occur in 30 to 60 percent of people with MS. "These disorders are believed to arise from the same processes that cause other MS-related deficits, namely inflammation, demyelination, and underlying neuronal injury and loss," says Bednarik.

Medications may worsen or trigger speech, language and cognitive problems, as well. Some medications cause dry mouth (xerostomia), which can make it hard to speak and swallow. Medications also might aggravate weakness, reduce alertness or cause fatigue, all of which can hamper a person's ability to communicate.

Communication difficulties may develop at any point in the disease course. "We would expect these problems to occur more often in people who have greater numbers of lesions in the brain and brainstem, or in people with higher levels of other impairments," says Bednarik.

Being able to produce clear speech that is loud enough for a listener to understand is a complex process that depends on the smooth and coordinated interaction of five systems: respiration, phonation, articulation, resonance and prosody. Any of these systems can be

affected by the MS disease process and interfere with a person's ability to speak loudly and clearly.

## The five speech systems

### [five-speech-systems]

#### **Speech and voice changes to look for**

Like Puches, some people with MS discover they run out of breath or can't speak loudly. Others are unable to speak in a normal pitch. This cluster of symptoms is called **dysphonia**.

A different type of speech problem, called **dysarthria**, is caused by weakness, slowness, changes in muscle tone, or lack of coordination of the tongue, lips, soft palate, throat, vocal cords and diaphragm. Consequently, speech may sound slurred and be hard to understand. Dysarthria and dysphonia can occur together since the same muscles, structures and neural pathways are used for both speech and voice production.

Further speech- and voice-related changes that may arise due to MS include:

- Speech that is too loud or that fluctuates in volume
- Strained or strangled-sounding voice
- Harsh, hoarse or breathy voice
- Unusual stress or emphasis on words
- Nasal speech

#### **Cognitive changes affect communication**

Cognitive changes can cause language disorders that interfere with a person's ability to communicate. Some people with MS find they have trouble concentrating; remembering and paying attention; expressing thoughts and ideas; following directions; or planning, sequencing and carrying out tasks. Others, like Gille, experience word-finding problems. Still others have trouble processing and responding to information they read or hear.

"In many cases, people with MS can understand all of the information around them; they just can't process it fast enough," says Lori Kostich, an SLP and MSCS at Mt. Sinai Rehabilitation Hospital/Mandell Center for MS Treatment and Research in Hartford, Connecticut.

"It's not a comprehension issue. People with MS will get the gist of a conversation but will not process some details. The problem is that the language from their environment goes by so quickly they can't encode or learn the information fast enough."

As a result, they don't receive all the information they need to respond appropriately, so it can be helpful to use strategies such as repetition to ensure that all communication partners have the same understanding of all necessary details, Kostich says.

Communication disorders can be exasperating, especially for a social person like Gille. “I enjoy talking to people,” she says. “But it can be hard to carry on a conversation. I repeat myself a lot because I’m trying to find the words I want to say.”

## Speech and language: What’s the difference?

Speech and language are not the same.

- **Speech** refers to the ability to use the speech mechanism—the tongue, lips, jaw, soft palate, diaphragm and lungs—to produce speech sounds correctly and fluently.
- **Language** refers to a person’s understanding of what words mean and how to use them to get the point across. A person who has trouble understanding others is said to have a **receptive language disorder**. A person who has problems expressing thoughts, ideas and feelings has an **expressive language disorder**.

### Tackling the problem

Bednarik and Kostich agree that there is almost always something that can be done to help a person communicate better. For individuals with speech and voice issues, treatment will vary, depending on which of the five systems necessary to produce spoken language (respiration, phonation, resonance, articulation or prosody) is involved. Specific oral exercises can improve muscle strength, movement and coordination. Neck and shoulder stretching exercises can reduce high muscle tone (or tightness) in the upper extremities and torso. Excess tone in these areas can affect a person’s ability to take in a deep breath and produce a steady stream of air that allows the vocal folds to vibrate in a relaxed way. Inspiratory muscle trainers are devices designed to strengthen a person’s ability to inhale and exhale. Kostich says they are affordable, easy to use at home and are good options for people who can’t come regularly to outpatient therapy. Kostich uses a free smartphone application, called **Bla | bla | bla** (really!), with her clients, which gives feedback about how loudly or quietly a person speaks.

Puches used an inspiratory trainer to improve her breath support and regulate her breathing. She also worked with her therapist to record her speech with a biofeedback device that connects to a computer to provide visual and auditory biofeedback about her pitch, volume and intonation. “The biofeedback made me aware of what my vocal cords were doing and enabled me to make changes to improve my voicing,” she says.

Individuals with language and cognitive issues can learn compensatory strategies in therapy to improve word retrieval, information processing and organization, and then apply those techniques. Gille uses several strategies when she can’t think of the word she wants. She might draw it for her listener, substitute a similar word or describe what she’s talking about.

## **Alternative and augmentative communication**

The need for alternative and augmentative communication (AAC) systems is relatively uncommon for people with MS. However, when a person no longer can use speech alone to communicate functional needs, these systems may be a solution. They range from low-tech options, such as boards with letters or words that a person points to (or gazes at if he or she is unable to point), to higher-tech alternatives such as text-to-talk devices and smart-phone applications that convert typed text into verbal speech. Some AAC devices can be connected to switches that a person operates with eye blinks or slight head or finger movements.

Reimbursement for AAC devices may be available through private insurance, grants or government programs. Medicare, for example, recognizes speech-generating devices as durable medical equipment, which is a covered benefit for Medicare beneficiaries.

## **Don't stay silent**

Kostich emphasizes that education is the key to resolving speech and language issues. "I do a lot of explaining to my patients, because if they understand what is happening—or where the breakdown is in their ability to communicate—then they have a concrete goal to work toward."

Puches had a clear goal in mind—to be understood at her wedding in October 2015—and she achieved it. "I was able to complete my vows without any shortness of breath, and I was able to socialize with my guests and enjoy the evening. It was worth every week for eight months of hard work with my therapists. The help I received is the key in my never-ending battle with MS."

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For a referral to a speech-language pathologist, ask your physician or call an MS Navigator at 1-800-344-4867.