

Tips for handling dysphagia



MS can cause swallowing difficulties, but there is help out there.

by Matt Alderton



Nereida Delgado Velez experiences both speech and swallowing issues.

Puerto Rican Nereida Delgado Velez prides herself on speaking excellent English. Although she's no longer working due to disability from her multiple sclerosis diagnosis, she once had a prolific career as a civil engineer thanks in large part to her superb communication skills.

“My English has always been really good,” says Velez, 52, of Orlando, Florida. “As a civil engineer, I don’t have the luxury of not speaking the language. When you say, ‘Stop, this is what I’m going to blow up,’ you have to be really clear. I hate the idea of not being understood.”

That’s why it was so difficult when her MS began to affect her speech.

Her healthcare providers realized it before she did. She was attending physical and occupational therapy when her therapists noticed something off about the way she was speaking. Then, one time, she choked on a sip of water. When she recounted what had happened — she found herself keeping the water in her mouth because she couldn’t swallow it — her therapist identified it as dysphagia, a medical term for chronic swallowing difficulties that often manifest as part of neurological conditions like stroke, traumatic brain injury and MS.

Now that she knows what it is, Velez recognizes dysphagia when it’s happening. Like other MS symptoms, such as fatigue and heat intolerance, it gets worse with poor diet and lack of sleep. Sometimes, it affects her speech. Other times, her swallowing.

“I never used to have an accent in English, but I do now,” Velez says. “It feels like my tongue weighs a thousand pounds.”

While the speech troubles are frustrating, the swallowing problems can be frightening. “It’s mostly with drinks. Swallowing doesn’t come naturally anymore. I have to really concentrate,” says Velez, who sometimes even has difficulty swallowing her own saliva. “It’s really scary because all of a sudden you choke, and you can’t breathe.”

There’s no cure for dysphagia. With increased awareness and specialized therapy, however, people with MS who have dysphagia can learn to manage their symptoms.

Swallowing SOS

Among U.S. adults, researchers estimate that 1 in every 25 has dysphagia. Among people with MS, the numbers are even higher: as many as 4 in 10.

Even that is likely a conservative number, suggests speech-language pathologist and MS-certified specialist Rachel Haines, who treats Velez at the Multiple Sclerosis Comprehensive Care Center of Central Florida in Orlando, Florida.

“This is something that’s just not talked about. Even among neurologists. It’s not always on their radar because there are so many other things for them to take care of during a typical 30-minute visit,” says Haines, who cites research suggesting that as few as 1% to 2% of patients are properly referred to a specialist for dysphagia.

Dysphagia’s prevalence in the MS community is due to a number of risk factors, according to medical speech-language pathologist and MS-certified specialist Marissa Barrera, PhD, owner

of New York Neurogenic Speech-Language Pathology and Assistant Dean of Health Science at Yeshiva University in New York City. For instance, the swallowing function may be impaired in people with MS due to lesions in the areas of the brain responsible for the coordination of chewing and swallowing; due to damage to the nerves that control facial and throat muscles; or due to cognitive dysfunction that impairs a person's ability to recognize food and liquid and initiate the swallowing process that for most people happens automatically.

Symptoms can include difficulty chewing food or controlling liquids; difficulty swallowing food, liquid, saliva or medication; feeling as if food is stuck in the throat; coughing or choking while eating; having a "wet" sounding voice during or after meals; drooling; and imprecise or slurred speech.

And it's not just the physical difficulties. "It's also a social and cultural function. There's not a holiday or major life event that doesn't involve some form of food," notes Barrera, who says people with dysphagia may develop such fear and anxiety around eating and mealtimes that they avoid social functions.

A lack of control

Velez describes dysphasia as a tickle in the back of her throat — like the post-nasal drip that accompanies a common cold, except that it comes out of nowhere and chokes her.

Amy Stadnyk of Lexington, Kentucky, describes it as "more of a discomfort." Sometimes, it can take her as many as four swallows to ingest a single spoonful of yogurt. "It comes and goes, but on days where it's harder for me to swallow, I have to really think hard and pay attention when consuming food and drink."



Lauren Franks

Lauren Franks of Dallas, Texas, was diagnosed with MS during the COVID-19 pandemic. About a year ago, she was talking when suddenly her saliva felt "stuck" in her mouth. "I tried to swallow, but I couldn't move my swallowing muscles," she recalls. "They were just kind of

frozen. It was really alarming.”

“It’s a very odd feeling. Your body knows to swallow, but it forgets how to do it,” Franks continues. “It’s scary. You almost feel like you’re drowning because the saliva or liquid or whatever you’re trying to swallow just pools in the back of your throat. For me, it usually only lasts 10 or 15 seconds, but those seconds are terrifying.”

A personalized plan

If you’re experiencing unexplained weight loss, frequent coughing or throat clearing while eating, or recurrent pneumonia, it might be time to see a specialist, says speech pathologist Jessica Copperman of Washington, D.C., who lives with MS.

“A speech pathologist will look at how you’re swallowing, listen to what your complaints are, do some sort of evaluation to figure out where your lesions are and how they might be affecting you, and then give you some personalized strategies to help you manage your symptoms.”

Dietary changes

People who have trouble swallowing dry foods like meat, rice or pasta might have to consume them with sauce or gravy. Others might have to add thickening agents to thin liquids like water, coffee and juice to help them go down the right pipe.

Coping techniques

One of the most important things you can learn is how to respond during a dysphagia episode.

“If I choke, I have to relax,” Velez says. “I put my hands up, I breathe and I just try not to freak out.”

Echoes Franks, “Step one is remembering that it’s temporary and that it will pass, which helps calm my mind a little bit. Step two is putting my tongue on the roof of my mouth and holding my breath. That kickstarts my brain into remembering how to swallow, and after about 10 seconds or so, I’m able to swallow again.”

Matt Alderton is a writer and editor in Chicago.

Learn more about [swallowing difficulties](#).