Dysphagia and Myositis: What Every Patient Should Know

Let’s talk about Myositis and your muscles. We know that myositis affects your muscles. When we swallow, we use almost 30 of those skeletal muscles to move food from our mouths into our esophagus.

Most people have never made that connection. They know their disease affects their shoulders, their hips, their grip. Nobody told them that chewing, moving food with the tongue, squeezing it down the throat, and protecting the airway all require skeletal muscles, the exact tissue myositis attacks. So when meals start taking longer, or food feels like it's sticking, or they are coughing more at the table, they explain it away. Smaller bites. Slower meals. Quietly removing favorite foods from mealtime.

What is Dysphagia?

Dysphagia is the medical term for difficulty swallowing. A normal swallow has three phases: the mouth prepares and moves the food, the throat moves to protect the airway and squeezes food downward, and the esophagus carries it to the stomach. Weakness anywhere in that chain disrupts the whole process.

Dysphagia is a recognized, clinically significant complication of polymyositis, dermatomyositis, and especially inclusion body myositis. IBM carries among the highest rates of dysphagia of any subtype. Because symptoms often progress slowly, many people don't notice until the problem is severe.

Why does early detection matter so much?

Unmanaged dysphagia can lead to aspiration pneumonia, unintended weight loss, dehydration, and a real loss of one of life's basic pleasures: sharing a meal with the people you love. When caught early, it is manageable and, in many cases, treatable.

The signs worth taking seriously

Coughing or choking during or after meals.

A wet or gurgly voice after eating.

Food sticking in the throat or chest.

Needing several swallows per bite.

Trouble with pills.

Meals that take far longer than they used to.

Unexplained weight loss.

Repeated bouts of pneumonia.

And one more that surprises people: nothing at all.

Some aspiration is silent. Sensory nerve dysfunction can cause food or liquid to enter the airway without triggering a cough.

That's why I never tell patients to simply wait and see. We know nothing is going to get better on its own.

Track Your Swallowing Score

The Dysphagia Early Detection Initiative was created to help patients understand and identify dysphagia symptoms to improve the ability to advocate for functional care.

The EAT-10 is a validated 10-question self-screening tool for swallowing symptoms. You rate each item from 0 (no problem) to 4 (severe problem) and add up your total. It takes about three minutes, and it's free.

The number that matters is 3. A total score of 3 or higher is the evidence-based threshold for a referral to a speech-language pathologist for a full swallowing evaluation. Not panic. Not a feeding tube. An evaluation.

The faster patients identify symptoms, the quicker they get care, the less time they spend rehabilitating the deficits.

Start today

Download a copy of the EAT-10 handout. Answer the questions to get an idea of what swallowing symptoms you may be experiencing.

And if your score is already 3 or higher, say this at your next appointment: “I am noticing a change in my swallow function. I'd like a referral to a speech-language pathologist for a swallowing evaluation.” That sentence is usually all it takes.

What happens after the referral

An evaluation isn't scary, and it isn't pass-or-fail. An SLP will start with a clinical exam, watching you eat and drink, checking the strength and coordination of your mouth and throat. From there, many myositis patients benefit from an instrumental study such as a fiberoptic endoscopic evaluation of swallowing (FEES) or a modified barium swallow study (MBSS), which provides an inside view of swallowing. A swallowing evaluation provides a road map, explaining where your swallow is strong, where it's struggling, and what needs to happen to fix it. Treatment plans get built on what's actually happening, not on guesses.

One note for caregivers and family members: you're often the first to notice. The slower meals, the quiet food avoidance, the constant throat clearing or cough that's become background noise at the dinner table. If you're seeing it, say something. You may be the reason a problem gets identified early.

Your swallowing is not a small thing. And it's not something you just have to live with.

Author bio: Meaghan Arnold, M.A., CCC-SLP, is a speech-language pathologist and the owner of Speech Swallowing and Neurological Rehabilitation (SSNR) in Tyler, Texas, where she specializes in adult swallowing disorders. She and her team at SSNR create content for the Myositis Support and Understanding Dysphagia Early Detection Initiative.