

# DYSPHAGIA: WHEN MYOSITIS IS HARD TO SWALLOW

This article was compiled from the following presentations and articles: Aziz Shaibani, MD, FACP, from the 2003 Annual Conference; Lisa Orloff, MD, from the 2001 Annual Conference; and previous articles written for *The Outlook for the Inflammatory Myopathies*, TMA's quarterly newsletter.

Most people swallow without even thinking about it. But for those who can't seem to do it without coughing or choking, swallowing can be very frustrating.

Symptoms begin slowly: You may become aware of coughing or choking more often while you're eating, or losing weight without meaning to do so. You may notice a change in your voice after eating, a change in your breathing, a discharge from your nose, a feeling that food is stuck in your throat, heartburn or reflux, or recurring pneumonia. All of these are signs of trouble swallowing, or dysphagia.

How common is dysphagia in myositis patients? One-third of myositis patients develop problems with swallowing. Though swallowing is a reflex, you can control a part of it, says Aziz Shaibani, MD, FACP, Director of the Nerve and Muscle Center of Texas. For instance, it is much easier to swallow foods you like, Dr. Shaibani told the myositis patients in his session in Houston. He outlined the stages of normal swallowing:

- Oral, including oral preparatory (chewing your food) and oral transit (tongue against the roof of your mouth, pushing back)
- Pharyngeal (larynx closes, forcing your food down)

- Esophageal (food is squeezed through your throat to your stomach, your airway reopens)

If you have dysphagia, you have trouble getting through at least one of these stages, explained Dr. Shaibani. You may drool or get food in your nose if you have problems in the oral stage. You may choke if the difficulty is in the pharyngeal stage, or you may vomit if your abnormality is in the esophageal stage. The oral stage is the one you can control, while the other two are involuntary or reflex stages, harder to improve. Members gave real examples from their lives:

"My dysphagia seems to be the result of a flaw in the final stage of swallowing," says Mike, who has IBM. "That is, I can initiate the swallowing process with no problem and get the food started down. But there is a point, right near the opening to the windpipe, where the food tends to stay, and only patience, and small amounts of liquid, will get it to go down further." This happens more toward the end of a meal, he says.

Incomplete swallowing shouldn't be ignored, said Dr. Shaibani. Bits of food may get into the lungs, causing an infection if you can't cough the food out. This infection may lead to aspiration pneumonia, a more serious problem. Treatment of the pneumo-

nia depends on how severe your symptoms are and what other medicines you are taking.

## Treatments and helpful suggestions

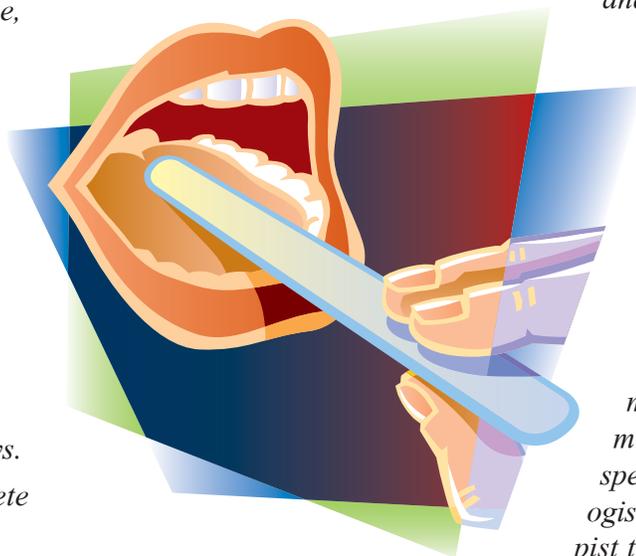
There are some practical steps you can take, along with some medical procedures. Be sure to take in plenty of food and water to avoid more problems, including dehydration, malnutrition and pneumonia, says Dr. Shaibani. Your doctor may recommend a nutritionist to make sure you are taking in enough calories each day. It's important to maintain a good weight for you. Losing weight can be a sign that your body is not getting the nutrients it needs.

"Do not wait until it is difficult to sort it out," says Dr. Shaibani. Go to your doctor, who may question what foods cause you the most trouble, if the problem seems to be

getting worse, and if you notice

the difficulty all the time or just on occasion. He or she may recommend a speech pathologist or therapist to examine your head, neck, mouth and tongue;

test your gag reflex; x-ray your chest to look at your lungs; or order a modified barium swallow. For the barium swallow, or videofluoro-



scopic swallowing study, you swallow a barium solution that coats the inside of your esophagus. This allows the x-ray to see the muscle activity of your esophagus as you go through the swallowing process. Doctors can see where an obstruction is so they'll know how to treat you. Your doctor may decide to do other tests, depending on your own situation.

If dysphagia is the first sign that alerted you to your disease, the medicines you use to treat the myositis itself may be enough to stop your trouble swallowing. There are medicines that can help specifically with dysphagia, including intravenous immunoglobulin (IVIg). Antidepressant medications may help, says Dr. Shaibani, since certain emotional conditions, like anxiety, can trigger dysphagia. Your doctor will choose the medicine that best treats the cause of your dysphagia, keeping in mind the other medicines you may be taking for your myositis.

Actually thinking about swallowing may help, says Dr. Lisa Orloff, a throat surgeon in San Diego. Clear your throat before you swallow, she recommends, so any residue left over from what you just tried to swallow won't leak into your airway. "If you start out with a clear throat," she says, "you're less likely to aspirate."

You can make simple changes yourself to improve your swallowing and avoid more problems:

- Chew your food well and take smaller bites and sips. Eat slowly.
- Hold your breath while you swallow.
- Eat when you are fully alert, not tired, so you'll pay attention to

each bite. Try to stay away from distractions like the television. Don't talk while you eat.

- Eat six smaller meals each day. This can be less tiring than three larger meals.
- Do lip and tongue exercises. Also work on your jaw and face muscles. Different exercises can help you strengthen the muscle or improve your coordination for swallowing.
- Change the consistency of your food to find what works best for you. Also consider how very cold or very hot foods affect your swallowing, then adjust your foods accordingly.
- Limit your dairy foods, which can cause thicker saliva. Choose citrus juices to reduce thickness.
- Find the head position that helps you avoid problems swallowing. Tuck your chin down to change your head angle, which lifts parts of the back of your throat, or tilt it up to use gravity in your favor. One side of your throat may be stronger than the other, says Dr. Orloff, so use it more.
- Sit up straight while you're eating and for an hour or so afterwards to help direct the food toward your stomach.
- Maintain healthy teeth and gums to help prevent aspiration pneumonia.

### When other treatments just don't help

Sometimes the medicines and changes in how you eat don't solve

the problem. There are still options for you.

Several TMA members have tried dilatation, a procedure to expand the width of your esophagus. If the passageway is too narrow, this will help you swallow. Doctors pass a soft device into your throat to stretch it with increasing sizes of dilators.

The cricopharyngeal myotomy is also a procedure used to open your throat. Doctors cut the muscle fibers in your esophagus. These fibers are like rubber bands, so cutting them will widen the opening so your food can pass through more easily.

Some myositis patients have feeding tubes inserted into their stomachs, but this is typically one of the last options a doctor chooses. With the feeding tube, you miss out on the part of the swallowing that causes the trouble in the first place. This helps you take in the proper amount of food so you can avoid further problems.

"It's not what most people think," says Dr. Todd Levine, a Phoenix neurologist who treats a number of myositis patients. "It's not a giant tube going down your throat but a very small button – about the size of your navel – going directly into your stomach." You can use this tube to supplement what you eat regularly, so you don't have to give up eating altogether. This procedure is sometimes called a PEG (Percutaneous Endoscopic Gastrostomy), a common, simple surgery. The tube can be removed once the symptoms of dysphagia are no longer there.

See page 28 for list of terms commonly associated with dysphagia and its treatment.

