

Understanding Dysphagia: When Swallowing Becomes Difficult

Lesson Transcript

Meet Amanda

Amanda has been the main person caring for her father for the past 11 years. She stepped into this role after he initially suffered from a stroke; he was later also diagnosed with vascular dementia. Amanda noticed that her father had started coughing during meals. At first, she thought it was nothing serious. But over time, the coughing became more frequent. Her father began eating less and seemed more tired.

Amanda and her family didn't know it yet—but these were early signs of dysphagia, a swallowing problem that can have serious health consequences.

Objectives of this lesson

Hello, I'm Dr. Anthony Levinson from McMaster University and I'll be your guide. By the end of this lesson, you'll be able to:

- Explain what dysphagia is and recognize its most common signs.
- Understand its potential consequences of dysphagia.
- Identify who can help manage dysphagia and when to seek support.
- Use practical strategies to help manage it at home, and
- Access resources to support you as a caregiver.

What is dysphagia?

Dysphagia is a medical word that means trouble swallowing. For some, it might be hard to move food, liquid, and/or medication from the mouth down to the stomach. They might "go down the wrong way," toward the lungs, instead of the stomach. This can make someone cough or choke.

Mechanisms of swallowing

Swallowing involves several different parts of the body working in a coordinated way for food to get safely from the mouth to the stomach.

- The mouth is the entry point where food, liquid, and medication are taken in, marking the beginning of the swallowing process.
- Teeth chew and break down solid food into smaller pieces to make it easier to swallow.
- The jaw supports chewing by enabling the opening and closing movements needed to grind food.
- The tongue moves food around the mouth during chewing and then pushes it to the back of the mouth to initiate swallowing.
- The food pipe or pharynx is a passage for food, liquid, and medication to move from your mouth down to your esophagus, and then your stomach.
- The esophagus is the tube that carries food, liquids, or medications from the throat down to the stomach.
- The breathing pipe or larynx is the tube in front of the food pipe that carries air to your lungs. It needs to stay protected, so food, liquid, and medication don't go down the wrong way.

Swallowing studies on X-ray

What you're seeing is a side view of the person's head and neck. To help you follow along, we've added some labels showing important parts we talked about earlier.

Normal swallow

Let's start by watching an X-ray video of a normal swallow. That black liquid you see in the mouth? That's water mixed with barium. Barium allows us to see liquid and foods more clearly on x-ray. Watch how the liquid travels from the mouth, down the food tube of the throat (also called the pharynx), and then enters the esophagus (the tube that leads to the stomach).

As this person swallows, you'll notice something important: the airway, or larynx, closes. This is the body's way of protecting the lungs from foreign material.

Once the swallow is done, you'll see there's nothing left behind in the throat. That's a sign of a strong, effective swallow. The liquid followed the correct path down to the stomach rather than into the lungs.

Disordered swallow (Aspiration)

Now let's look at another X-ray video, but this time, of a disordered swallow. This video shows the same parts of the head and neck, and again the person is swallowing water mixed with barium.

Watch closely: instead of all the liquid entering the esophagus like before, you'll see that some of it enters the breathing tube, or larynx. When any material enters the airway and moves below the level of the vocal folds, it is referred to as aspiration. Aspiration can be serious because foreign material in the lungs can lead to infections like pneumonia.

Disordered swallow (Post-swallow residue)

Here's another example of a disordered swallow. This time, the issue isn't aspiration, but rather, residue. That means some of the liquid is left behind in the throat swallowing. You can see there's already some leftover liquid there from a previous swallow, and now even more is added.

That leftover liquid can feel uncomfortable, and worse, it can later slip into the airway once the airway reopens after swallowing, resulting in aspiration. So even though this swallow looks better than the previous one, residue can still increase a person's risk of pneumonia.

Knowledge check #1

True or False? During a normal swallow, food or liquid should not enter the breathing pipe (or larynx).

Answer: The answer's true. Entry of material into the airway is a sign of disordered swallowing.

Swallowing changes in dementia

Research shows that up to 93% of people with dementia have dysphagia. As dementia worsens, it becomes harder to eat enough food. This can happen for many reasons. For example, people living with dementia may forget how to use utensils, not recognize food, have trouble chewing and swallowing, or simply refuse to eat. While some people can still eat finger foods during moderate stages of dementia, many will eventually need help to eat and drink. In the late stages, they may stop opening their mouths altogether.

Swallowing problems can look different depending on the type of dementia. Below are characteristics associated with the different types.

Alzheimer disease

People with Alzheimer's may begin by having difficulty feeding themselves. Even when food is brought to the mouth, challenges often continue. It may become hard to coordinate the movements needed to chew and prepare food for swallowing. Chewing may slow down, stop unexpectedly, or continue longer than needed. In some cases, individuals may exhibit uncontrolled bite reflexes, characterized by the mouth suddenly clamping down without warning.

Once chewing is done, food may remain in the mouth longer than usual or not be cleared effectively. Some food or liquid might leak from the mouth, and it's common to see leftovers in the mouth after swallowing.

Swallowing itself can also become slower or weaker. The person may need to swallow several times to move food, liquid, or medication down. Weakness in the throat muscles may limit their ability to protect the airway during the swallow, increasing the risk of food or drink entering the lungs.

After meals, a "wet" or gurgly-sounding voice may be heard, which can signal material, or residue, left behind in the throat or airway invasion, known as aspiration. Together, these changes can make eating and drinking more difficult and less safe over time.

Frontotemporal dementia

In frontotemporal dementia, changes in behaviour around eating often affect swallowing. A person may eat too quickly or put too much food in their mouth at once. This can increase risk of choking. There may also be a delay in starting the swallow after the food is done being chewed. This can cause the sensation of food getting stuck after swallowing, which can be uncomfortable and increase swallowing difficulties.

Vascular dementia

In vascular dementia, swallowing issues often stem from changes in thinking, movement, or coordination, similar to frontotemporal dementia. Some people may eat too fast or take large bites without realizing it, which can raise the risk of choking. There may also be trouble coordinating the different steps of swallowing — for example, starting the swallow a bit too late after chewing. This can lead to food feeling like it's "stuck" in the throat or going down the wrong way, which can be uncomfortable and make eating more difficult.

Dementia with Lewy Bodies

In Lewy body dementia, swallowing changes can make eating and drinking more challenging and tiring. One common issue is coughing or choking during meals. Sometimes, food or drink may even come out through the nose, a sign that the swallowing muscles aren't working together properly.

After swallowing, individuals may feel like food is stuck in their throat. This sensation, combined with a weakened cough that doesn't clear the throat effectively, can increase risk of food, liquid, or medication remaining in the airway.

These difficulties often make mealtimes last much longer than usual. Eating can become exhausting, and the person may feel tired or out of breath even partway through the meal.

Other behaviours

To cope with swallowing difficulties, some individuals may refuse or avoid certain foods, liquids, or medications because swallowing them feels difficult or uncomfortable. They might also cut food into smaller bites or take smaller sips of liquid to compensate for these difficulties.

Knowledge check #2

True or false? People with dementia can usually eat independently until the very late stages of the disease.

Answer: It's false. Changes in swallowing may start from very early on in the disease.

Knowledge check #3

True or false? If a person with dementia doesn't cough but seems tired or breathless during meals, they could be having swallowing problems.

Answer: It's true. Fatigue during meals and "silent aspiration" can happen in people with dementia.

Knowledge check #4

True or false? Refusing crunchy foods but eating purées easily may be dysphagia-related.

Answer: The answer's true. Selective avoidance is common when a texture feels unsafe.

Consequences of dysphagia

Consequences of dysphagia can be medical or physical, emotional or social, or both. Medical or physical consequences include:

Aspiration: When food, liquid, and/or medication goes down the “wrong pipe” into the airway instead of the stomach. This can cause coughing, choking, or even lead to a bacterial lung infection called aspiration pneumonia.

Post-swallow residue: When food, liquid, and/or medication gets left behind in the throat after swallowing. It doesn’t go all the way down like it should. This leftover residue can later slip into the airway or even make swallowing uncomfortable.

Undernutrition: When someone has trouble swallowing, they might avoid eating or drinking as much as they need. Over time, this can lead to not getting enough nutrients (malnutrition), not drinking enough water (dehydration), and losing muscle strength (also known as sarcopenia). These problems can make a person feel weak, tired, and more at risk for other health issues.

Weight loss: If swallowing is difficult or painful, people might eat less, leading to noticeable and unhealthy weight loss. Losing 10% of body weight within three months is generally seen as a serious concern.

Some of the emotional and social consequences of dysphagia include:

Fear: After choking or having material “go down the wrong way,” people may become afraid to eat or drink, worrying it might happen again.

Frustration: Struggling to eat or drink can feel exhausting, especially when it happens over and over again.

Lack of enjoyment while eating: Eating can be fun or comforting, but with swallowing problems, it can turn into a stressful or unpleasant task.

Anxiety: Constantly worrying about choking or struggling to eat can make people feel nervous and tense during meals.

Depression: Losing the ability to enjoy food or share meals with others can make people feel sad, hopeless, or isolated.

Social isolation: If eating with swallowing difficulties feels unsafe or embarrassing, people might stop joining family or friends for meals, leading to feelings of loneliness.

Pain: Some people with dysphagia feel pain when swallowing, making meals uncomfortable or even scary.

Your dysphagia team

Caring for someone with dysphagia is a team effort. Many healthcare providers work together to help make eating, drinking, and taking medications as safe and comfortable as possible.

Here are some of the people who might be part of your loved one's dysphagia team:

Doctor or Primary Care Provider: They help identify possible medical causes of swallowing difficulties and coordinate referrals to other team members like speech-language pathologists and dietitians. They also review medications and monitor overall health to support safe eating and drinking.

Speech-Language Pathologist (or SLP): They are experts in how we swallow. They help when someone has trouble moving food, liquid, and/or medication around in their mouth and swallowing safely.

Occupational Therapist (or OT): They help when someone is having difficulty getting the food, liquid, and/or medication to their mouth, maybe because of weakness, tremors, or difficulty using utensils.

Dietitian: They help make sure your loved one is still getting enough of the right foods and liquids to stay healthy, even if their diet needs to be changed for safety.

Don't forget, you are part of the team, too! One of the most important members of the care team is you, the family care partner. And of course, your loved one plays a key role too, whenever possible.

Working together as a team means:

- Healthcare providers bring their medical knowledge to help manage swallowing safely and comfortably.
- You bring what you know best, including your loved one's habits, likes and dislikes, history, and what makes them feel at ease.
- Your loved one can share their preferences when they're able, either verbally or through their actions, helping everyone make the best decisions together.

What to ask your doctor

If you or someone you care about is having trouble swallowing, speak to your primary care provider about it. Ask your primary care provider for a referral to an outpatient or community speech-language pathologist or SLP, which is typically covered by provincial health plans. Alternatively, you can access a speech-language pathologist in private practice, though this option requires out-of-pocket payment.

What to expect from a speech-language pathologist

An SLP might perform two main types of examinations: a clinical swallow exam or an instrumental exam.

In a clinical swallow exam (also known as a bedside swallow assessment), the SLP will assess how the muscles and nerves of the head and neck are functioning. It includes food and liquid trials with different diet textures (e.g., thin and thickened liquids, soft and hard foods) to observe how safely and effectively a person swallows.

In an instrumental exam, an SLP will conduct an examination using specialized equipment, typically using either dynamic X-rays or a fiberoptic camera. A video fluoroscopy swallowing study is a dynamic X-ray procedure used to assess swallowing function. The Fiberoptic Endoscopic Evaluation of Swallowing uses a small tube with a camera to view the throat and assess swallowing function. It's not usually recommended for people with more advanced dementia (concerns regarding consent due to possible discomfort from the procedure).

Questions to ask your SLP

Here are a few questions that you might want to ask your speech-language pathologist.

- What's the safest and most appropriate food and liquid texture for my loved one, and can we work together to determine the best modifications to support safe swallowing while optimizing quality of life?
- How can I incorporate culturally preferred foods while still following the recommended texture modifications?
- Do you recommend any specific tools or equipment (for example, thickening agents, blenders, food processors) to help with preparing modified textures at home?

- What mealtime strategies do you suggest to help manage my loved one's dysphagia and ensure they receive adequate nutrition?
- Are there any resources or supports available for caregivers of individuals with dysphagia?

Management strategies

With guidance and approval from your SLP, incorporate foods and liquids your loved one enjoys and can tolerate into mealtimes to help promote intake.

- Finger foods that meet the recommended texture guidelines are especially helpful for promoting independence and supporting oral intake in people with dementia.
- Be mindful of taste changes in your loved ones with dementia, as they may experience changes in taste perception and may prefer stronger, sweeter, or saltier flavours.
- Cut food into smaller, easier-to-chew bites or add a binder (like gravy or applesauce) to reduce the risk of residue being left behind in the throat after swallowing.
- Have your loved one sit as upright as possible (ideally at a 90-degree angle) to promote safer swallowing. Using pillows or foam wedges can help achieve this posture.
- Encourage the use of eyeglasses and hearing aids during meals to enhance the sensory experience.
- Use colourful plates on a white or plain tablecloth to help food stand out and make it easier to see.
- Offer gentle prompts, positive reinforcement, and maintain eye contact to help your loved one stay engaged and feel supported during mealtime.
- Minimize distractions by turning off the TV or removing background noise to help them stay focused on eating and reduce the risk of choking.
- Eat alongside your loved one to create a natural eating environment.

Tips to save time

Caregiving can be time-consuming. Here are some tips that might help save time.

- Choose simple, quick meals that require minimal preparation.
- If your SLP recommends thickened liquids, buy them pre-thickened or prepare larger batches in advance and store them in the fridge for later use.
- Ask your pharmacist about pill crushers if appropriate for the prescribed medication, and request medications in easy-to-open bottles to reduce time and effort during medication administration.

Knowledge check #5

True or false? Sitting fully upright (around 90°) reduces the risk of food entering the breathing pipe (larynx).

Answer: It's true. Proper posture is a key recommendation.

Knowledge check #6

True or false? Diet texture modifications is a do-it-yourself task every caregiver can safely try without guidance.

Answer: It's false. You should consult with and follow a Speech Language Pathologists diet texture recommendations to support safe swallowing practices.

Managing oral medications for individuals with dysphagia

Taking medications can be difficult for someone with dysphagia, so here are a few things to keep in mind.

Avoid using liquids with commercial thickening agents when administering oral medications, as this combination can reduce the medication's effectiveness. Instead, consider mixing medications with applesauce or yogurt, if appropriate.

Before considering crushing medications, speak with your pharmacist to determine whether doing so could alter the medication's effectiveness. Pharmacists may be able to recommend an alternative, such as a similar medication that can be crushed, a smaller dose resulting in a smaller pill size, or a liquid formulation.

Tube feeding

When someone has severe dysphagia, doctors may consider tube feeding, which delivers liquid nutrition directly into the stomach through a small tube.

However, research shows that for many people, especially those with progressive illnesses like advanced dementia, tube feeding doesn't improve quality of life, prevent food from entering the airway (aspiration), or help them live longer. In fact, it can sometimes cause more discomfort than relief for patients.

Instead, families and healthcare teams may choose to focus on comfort feeding by hand, offering small sips or bites if it's safe and enjoyable, or switching to mouth care and hydration for comfort only.

The decision to use a feeding tube is personal and can be difficult. It's important to talk with the healthcare team about what's most respectful of your loved one's wishes and quality of life.

To learn more

If you would like to learn more, the following resources are available in the handout included in the resources area.

The **Virtual Canadian Dysphagia Support Group** is hosted by the Aging Swallow Research Lab at McMaster University. The group is intended for individuals with dysphagia and their caregivers.
(agingswallowlab.healthsci.mcmaster.ca/my-resources/support-group)

The **Ontario Caregiver Organization** supports caregivers by providing one-point access to information, services and resources so they have what they need to be successful. (ontariocaregiver.ca/managing-care/working-caregivers)

The **National Foundation for Swallowing Disorders** is a comprehensive resource for dysphagia education and patient support.
(swallowingdisorderfoundation.com)

Find an SLP will help locate an SLP in your area so you can get started.
(member-membre.sac-oac.ca/search/custom.asp?id=7109)

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