

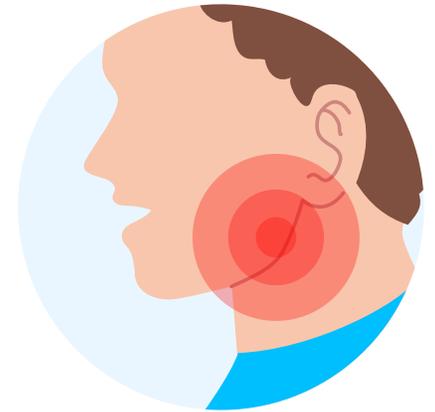
Swallowing in Prader-Willi Syndrome (PWS)

A Family-Friendly Guide

What Is Swallowing?

Swallowing is something our bodies do every day. When we eat or drink, food and liquid should go **down the right tube** into the stomach. Sometimes, things can go **down the wrong tube** into the airway. This is called **aspiration**.

Most people cough when this happens. But many children and adults with **Prader-Willi syndrome (PWS)** may not cough. This is called **silent aspiration**. Even though you cannot see it, it can cause breathing problems or infections.



Why Do People With PWS Have Trouble Swallowing?

Children and adults with PWS may have:

- **Low muscle tone**, which makes swallowing harder.
- **Trouble coordinating** breathing and swallowing at the same time.
- **Delayed swallowing**, meaning food stays in the throat longer.
- **Food left behind** in the throat or esophagus after swallowing.

Doctors have done special X-ray tests called **swallow studies**. These studies show that many babies, children, and adults with PWS have:

- Trouble moving food or liquid to the right place.
- Liquid getting into the airway without coughing.
- Food getting stuck in the throat or esophagus.

This can happen even when the person looks like they are swallowing fine.

Signs of Swallowing Problems

Many times, there are **no clear signs**. But sometimes you may notice:

- Coughing during or after eating.
- Watery eyes or runny nose when eating.
- Food getting stuck.
- Taking a long time to eat.
- Frequent chest colds or lung infections.

If you see these signs, tell your child's doctor.



How Families Can Help

Even though swallowing problems can be hidden, there are things you can do to help keep your child safe.

1. Make Mealtimes Calm and Slow

- Avoid rushing.
- Encourage small bites and slow sips.
- Give time to chew well.

3. Know When to Ask for a Swallow Study

Ask your doctor for a swallow study if your child has:

- Frequent pneumonia or breathing problems.
- Trouble feeding as a baby.
- Gagging or choking.
- Sudden behavior changes with food.

2. Use the Foods and Liquids Recommended by Your Child's Team

Some children may need:

- Thicker liquids.
- Softer foods.
- Help sitting upright while eating.

4. Practice Good Habits

- Keep mealtimes distraction-free.
- Make sure your child sits upright.
- Encourage drinking sips of water during meals if allowed.

Teaching Your Child How to Swallow Pills

Many children with PWS need daily medicines. Learning to swallow pills safely is important and can take time.

Tips for Teaching Pill Swallowing



Start small!

Begin with smaller pills. Practice with water.

Use simple steps.



Sit up tall.



Put the pill on the tongue.



Take a sip of water.



Swallow!



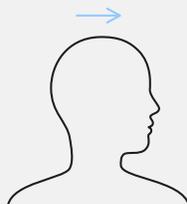
Move up slowly.

Increase the size of the pill slowly.

Try different swallowing methods.



Use a straw.



Tilt the head slightly forward.



Put the pill in Greek yogurt or cottage cheese, only if the medication allows for it

When to Ask for Help

If your child:

- Gags a lot when trying to swallow.
- Has trouble with liquids.
- Seems scared or overwhelmed.

Ask your doctor for support or speech therapy help.



When to Call Your Child's Doctor

Contact your child's healthcare provider if you notice:

- Frequent coughing with meals.
- Not wanting to eat.
- Sudden trouble swallowing.
- Repeated lung infections.

Swallowing problems are common in PWS, and many children need extra help—but with the right support, they can stay safe and healthy.

This document was developed with support from a grant provided by Soleno Therapeutics.

