

# Respiratory (Breathing) Concerns in Prader-Willi Syndrome (PWS)

## *A Guide for Parents and Caregivers*

### Why Breathing Health Matters in PWS

People with Prader-Willi syndrome (PWS) can have breathing problems. These problems may happen during sleep or when someone is sick. Breathing concerns are important because they can become serious if not treated early. Parents and caregivers play a key role in noticing changes and getting help quickly.



People with PWS have a higher chance of having breathing problems. This happens because the part of the brain that helps control breathing does not work the same way, their muscles are often weaker, and their bodies may store more fat. Breathing problems can happen during sleep, when someone is sick, after taking medicine that makes them sleepy, or if they gain too much weight. Experts agree that breathing problems are one of the most serious health risks for people with PWS, especially for children and young adults.

It is very important to notice breathing changes early and keep a close watch. Parents and caregivers play a big role in spotting small changes, like louder snoring, trouble sleeping, being extra tired during the day, or changes in behavior. These may be signs that breathing is not working as well as it should.

### Aspiration and Swallowing Concerns

Swallowing problems and acid reflux can affect breathing in people with PWS.

People with PWS often have low muscle tone and differences in how their brain controls swallowing. This can make it harder to coordinate chewing, swallowing, and breathing at the same time. Because of this, food, liquid, or even saliva can accidentally go into the lungs instead of the stomach. This is called aspiration.

Sometimes this happens without coughing or choking. That is called silent aspiration.

Many people with PWS also have acid reflux (GERD). This means stomach contents can move back up into the throat and sometimes into the airway, especially during sleep.

Because of swallowing problems or reflux, a person with PWS may:

Have a chronic cough

Get frequent chest  
colds

Develop recurrent  
pneumonia

Sound wet or gurgly  
after eating

Wheeze or have noisy  
breathing

Have “mysterious”  
breathing problems  
with no clear cause

Infants and young children with PWS are at higher risk because their muscles are especially weak and their swallowing skills are still developing.

## Common Breathing Concerns in PWS

### Sleep Apnea:

Sleep apnea means breathing stops or becomes very shallow during sleep. In PWS, this can include blocked airways, the brain not sending strong breathing signals, or a mix of both. Signs may include snoring, gasping, restless sleep, or being very tired during the day.



Sleep apnea is a condition where breathing stops or becomes very shallow during sleep. In PWS, this can happen because the airway becomes blocked, the brain does not send strong enough signals to breathe, or a combination of both.

There are different types of sleep apnea:

- **Obstructive Sleep Apnea (OSA)** — The airway becomes blocked or collapses during sleep
- **Central Sleep Apnea (CSA)** — The brain does not send steady breathing signals
- **Mixed Apnea** — A combination of both types

Children with PWS may not wake up as easily when their oxygen levels drop or when carbon dioxide builds up. This can increase risk and make sleep apnea more serious.

### Signs to watch for include:



Loud or frequent snoring



Gasping or pauses in breathing during sleep



Restless sleep



Morning headaches



Being very tired during the day



Worsening behavior or mood changes

If you notice these signs, it is important to speak with your child's healthcare provider.

### Weak Breathing Muscles:

Low muscle tone can make chest muscles weaker, which can reduce breathing strength, especially during sleep or illness.

People with PWS often have low muscle tone. This means their muscles are looser and not as strong. The muscles in the chest that help with breathing can also be weaker. This can make it harder to take deep breaths, especially during sleep or when sick.

Because of weaker breathing muscles, a person with PWS may:

**Breathe too shallowly during sleep**

**Hold in too much carbon dioxide (a waste gas we breathe out)**

**Have trouble coughing hard enough to clear mucus**

**Take longer to get better from colds or other lung infections**

When someone with PWS has a virus or is given medicine that makes them sleepy, their breathing can get worse more quickly than other children. That's why it's important to watch closely and get medical help early if breathing changes.

## Obesity and Breathing:

Extra weight can put pressure on the chest and throat, which can make breathing harder. When this happens, it can:

**Make it harder for the chest to fully expand with each breath**

**Make the throat more likely to close during sleep**

**Cause breathing to become too slow or too shallow**

*(Called obesity hypoventilation)*

**Make sleep apnea worse**

Because of these risks, careful weight management and structured food routines are very important in Prader-Willi syndrome. These supports are not just healthy habits, they are medical needs that help protect breathing and overall health.

## How Breathing Problems Are Checked

### Sleep Studies

A sleep study checks breathing, oxygen levels, and carbon dioxide during sleep. Sleep studies are often recommended for people with PWS, especially if symptoms change or before and after growth hormone therapy.



A sleep study is a special test done overnight to see how someone breathes while they are asleep. It checks:

- How air moves in and out of the lungs
- Oxygen levels in the blood
- How well the chest moves while breathing
- Sometimes carbon dioxide levels (a waste gas we breathe out)

Experts often recommend that children and adults with PWS have a sleep study:

- Any time snoring, breathing pauses, or daytime sleepiness get worse
- Some experts recommend before and after growth hormone therapy

Breathing problems in PWS are not always easy to notice. Even if a child does not complain, changes in sleep, mood, or energy can be signs that breathing needs to be checked. Sleep studies help doctors find problems early and keep children safe.

## Tips for Parents: Improving and Managing Breathing Health

### Watch closely.

Look for loud snoring, gasping, pauses in breathing during sleep, restless sleep, morning headaches, unusual daytime tiredness, or behavior changes. These can be signs of sleep apnea or other breathing problems. Take concerns seriously, even if your child does not complain. Many children with PWS may not clearly say when something feels wrong.

### Support healthy weight management.

In PWS, extra weight and low muscle tone can make breathing harder, especially during sleep. Following a structured meal plan and using food security routines helps protect overall health, including breathing.

### Follow medical guidance.

If breathing problems are found, doctors may recommend CPAP or BiPAP machines to help keep the airway open during sleep. Some children may need to see a lung doctor, sleep specialist, or ear, nose, and throat (ENT) doctor. Oxygen should only be used if a doctor prescribes and carefully monitors it.

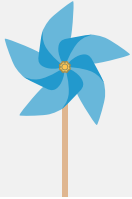
### Act quickly during illness.

If your child has a cough, fever, trouble breathing, is more sleepy than usual, or “just isn’t acting like themselves,” seek medical care early. Always share PWS medical alert information with healthcare providers so they understand the special risks related to PWS.

# Simple Breathing Games to Help Expand the Lungs

## Fun Breathing Activities

Gentle breathing games can help children practice taking deeper breaths and expanding their lungs. These activities should be done when your child is calm and healthy, and should never cause stress or dizziness.



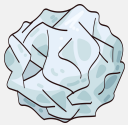
### Blowing Pinwheels:

Have your child blow steadily to keep a pinwheel spinning. This helps practice slow, deep breaths.



### Blowing Bubbles:

Encourage long, slow breaths to make big bubbles. This supports breath control and lung expansion.



### Blowing Crumpled Paper:

Place a small piece of crumpled paper or cotton ball on a table and have your child blow it across the surface.



### Straw Blowing Games:

Blow through a straw to move lightweight objects, helping strengthen breathing muscles.

## Make it Fun and Short

Turn these into short games or playtime activities. Stop if your child becomes tired, frustrated, or short of breath.

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