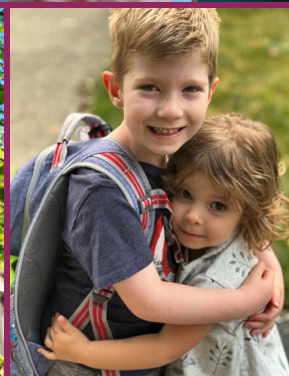
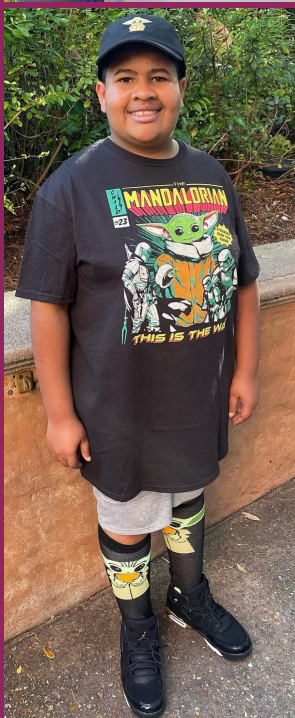


A caregiver's guide to

What to know about Prader-Willi syndrome (PWS) and its defining symptom: hyperphagia

Understand the early signs of hyperphagia and when to talk to your doctor.



Symptoms of PWS start at birth and change over time

In PWS, there are a variety of symptoms that can impact people in different ways. Hyperphagia is a defining feature of PWS, but may be unrecognized at first.



Most people living with PWS will be affected by hyperphagia.



Signs of hyperphagia can start by age 4 or younger, and change with age over time.



Before food-related behaviors become more obvious, hyperphagia may be hard to notice.



Hyperphagia does not always mean being overweight or overeating.

Anxiety about food or constantly asking, talking, or thinking about food can be an early sign of hyperphagia.





Hyperphagia looks different for everyone

Hyperphagia is commonly known as intense hunger and obsession with food, but some signs are more subtle than others.

- **Constantly thinking about food** is an often overlooked sign of hyperphagia that involves frequent questions about food or constantly asking for food
- **A strong desire to eat** can appear normal at first, but people with hyperphagia may take bigger bites than usual and eat very fast. They may try to get food by bargaining or lying
- **Hardly ever feeling full** is a more recognizable sign because it can mean overeating or eating so much that it becomes dangerous
- **Food-related behavior issues** develop over time and can be more easily recognized, like rummaging through the trash for food or stealing food

Routines and rules around food can help manage hyperphagia, but they can also mask it.

While important to maintain, environmental controls may not fully address the effects of hyperphagia.

Keep your doctor in the know

- Doctors can only evaluate hyperphagia based on what they see at appointments, **so it's crucial to share all the details about your loved one**
- **As hyperphagia changes, so can behaviors.** Keep your doctor informed of any new behaviors or patterns you notice at home, no matter how small
- Share how hyperphagia affects you, your loved one with PWS, and your family **to help your doctor get a clearer picture**
- Ask your doctor for **updates, news, and resources** about caring for your loved one with PWS and hyperphagia



[Support4PWS.com](https://www.support4pws.com)

Find stories from the PWS community and helpful perspectives at [Support4PWS.com](https://www.support4pws.com)

