Hyperphagia

IN PRADER-WILLI SYNDROME

FOUNDATION FOR PRADER-WILLI RESEARCH

What is Hyperphagia?

Hyperphagia (hy-per-FAY-jee-uh) is an intense, persistent drive to eat, often combined with a reduced sense of fullness, or satiety. It is often described as the hallmark symptom of Prader-Willi syndrome.

Hyperphagia can include:

- Frequent thoughts or talk about food
- An intense drive to eat
- Food-seeking behaviors
- Difficulty feeling full after eating
- Anxiety or repeated questions about when meals or snacks will be available

Not everyone with PWS experiences hyperphagia in the same way. Some people may frequently report hunger or seek food. For others, hyperphagia may appear as a strong focus on food, repeated questions about meals, or a need for reassurance about when food will be available.

Hyperphagia is not always easy to identify. It often develops gradually and may show up as persistent thoughts about food, repeated questions about meals, or difficulty feeling full before more obvious food-seeking behaviors appear.

Hyperphagia may also be less noticeable in a food-secure environment, where access to food and meal times are predictable.

Hyperphagia is biologically driven. It cannot be overcome by willpower, self-control, or simply "knowing better."

Nutritional Phases in PWS

People with PWS do not begin life with hyperphagia. Appetite and eating patterns change over time, progressing from feeding difficulties in infancy to increased interest in food and hyperphagia.

Nutritional phases are approximate, and **hyperphagia varies widely in timing, presentation, and intensity.**

PRENATAL AND INFANCY

0 **Before birth**
Reduced fetal movement & lower birth weight.

1a **Birth to 9 months**
Low muscle tone and feeding difficulties are common.

1b **9 months to 2 years**
Feeding improves and appetite is usually still typical.

EARLY CHILDHOOD

2a **2 to 4.5 years**
Weight may increase before appetite noticeably changes.

2b **4.5 to 8 years**
Interest in food increases, though the child may still feel full.

CHILDHOOD - ADULTHOOD

3 **Usually after age 8**
Persistent hunger and difficulty feeling full become more apparent.

4 **In some adults**
Hyperphagia may lessen over time for some adults.

How Hyperphagia Affects Daily Life

Food can take up significant mental space
Hyperphagia affects much more than hunger. For some people with PWS, thoughts about food can take up significant time and attention and may lead to behaviors such as seeking, sneaking, or taking food.

Weight can be harder to manage
PWS can create a difficult mismatch: the drive to eat may be greater while the body's caloric needs are lower. Reduced muscle mass and low muscle tone can also make physical activity more challenging, making weight management even harder.

Uncertainty around food can cause anxiety
Hyperphagia can also create anxiety around food. Knowing when meals and snacks will happen and having consistent expectations around food can help reduce uncertainty and stress.

Food-seeking can become intense
For some people with PWS, hyperphagia may lead to sneaking or taking food, eating discarded or unsafe food, or searching for food at night. These behaviors vary widely and are not experienced by everyone with PWS.

Support can make a difference
Every person with PWS is different. The right combination of support, treatment, and a safe, predictable environment can make a meaningful difference.

Managing Hyperphagia

Managing hyperphagia requires ongoing **environmental, nutrition, and behavioral support.** A food-secure environment with predictable meals and snacks and limited access to food can help protect physical health and reduce anxiety.

Helpful strategies may include:

- Keeping meals and snacks predictable
- Securing food, including locking refrigerators, pantries, and cabinets
- Home alarm systems or tracking monitors
- Following nutrition guidance appropriate for PWS
- Maintaining regular physical activity
- Keeping expectations consistent across home, school, extended family, caregivers, and other settings

Because **people with PWS often have lower caloric needs,** a dietitian familiar with PWS can help develop an individualized nutrition plan that supports healthy growth and weight.

The goal is not to teach someone to simply "control" hunger, but to **create an environment that helps them feel safe.**

No Doubt + No Hope = No Disappointment

A food-security principle developed by Janice Forster, MD, and Linda Gourash, MD

In PWS food security means:

- No doubt about when and what food is coming.
- No hope of getting extra or unplanned food.
- No disappointment because expectations are clear and consistently followed.

Treatment and Research

VYKAT XR
In March 2025, VYKAT XR (diazoxide choline extended-release, formerly known as DCCR) was approved for the treatment of hyperphagia in adults and children ages 4 and older with PWS.

Treatment decisions should be made with a healthcare provider who understands PWS and each person's individual health needs.

FPWR helped pave the way for VYKAT XR
FPWR supported early DCCR research and led PATH for PWS, a natural history study that provided real-world data on hyperphagia. Those data helped demonstrate how people receiving DCCR differed from the natural course of PWS and supported the evidence that ultimately contributed to FDA approval of VYKAT XR.

Research continues
VYKAT XR is an important advancement, but **it does not end the need for hyperphagia research.** Hyperphagia varies widely among people with PWS, and researchers are continuing to study the biological pathways that regulate hunger and satiety and develop additional treatment approaches.

- Learn about VYKAT XR
- Explore PWS treatments in development
- Find a PWS clinical trial

What about growth hormone?
Growth hormone does not directly treat hyperphagia, but its benefits for muscle mass and body composition support overall health in PWS.

Frequently Asked Questions

Does everyone with PWS develop hyperphagia?
Hyperphagia is a hallmark feature of PWS, but its timing, intensity, and presentation vary widely. It may be mild or emerging for some people and much more pronounced for others.

When does hyperphagia start?
It develops gradually. The average onset is around age 8, but it can begin earlier or later.

How do I know if someone has hyperphagia?
It is not always obvious or simply a matter of saying "I'm hungry." It may appear as persistent thoughts about food, repeated questions about meals, difficulty feeling full, or food-seeking behavior.

Can someone with hyperphagia learn to control their food intake?
Hyperphagia is biologically driven and cannot simply be overcome through willpower or "knowing better." Environmental support and food security are important.

Does locking food make hyperphagia worse?
A predictable, food-secure environment can actually reduce uncertainty and anxiety for many people with PWS. The goal is not punishment or restriction, but safety and predictibility.

Can hyperphagia change over time?
Yes. Eating behaviors and food interest can wax and wane, and hyperphagia may be less intense in some adults, although that is not true for everyone.

Frequently Asked Questions

Does growth hormone treat hyperphagia?
No. Growth hormone does not directly treat hyperphagia, but it can improve muscle mass and body composition, which can support overall health and weight management.

Will a healthy diet stop the hunger?
Not necessarily. People with hyperphagia may continue to feel hungry even with a healthy diet and appropriate nutrition support.

Is there a treatment for hyperphagia?
Yes. VYKAT XR is FDA-approved to treat hyperphagia in people with PWS ages 4 and older. Research into additional treatments continues.

Why is more hyperphagia research needed if there is an approved treatment?
VYKAT XR is an important advance, but hyperphagia varies widely. Research continues to improve understanding, measurement, and treatment.

Will we be able to go to restaurants?
Many families with PWS eat at restaurants with a little planning. Choosing the restaurant and meal ahead of time, setting expectations, and avoiding long waits can help. What works will depend on the person and their hyperphagia.

How do families affected by hyperphagia celebrate holidays?
Families can keep holidays fun while maintaining food security by putting food away after meals, keeping it out of sight between meals, setting expectations ahead of time, and building traditions around activities beyond food.

Resources

You do not have to navigate hyperphagia alone.
Explore these resources for practical guidance, treatment information, and ways to stay connected to research.

More information:

- Hyperphagia in Prader-Willi Syndrome - The main FPWR resource for understanding hyperphagia, treatment, research, and related support.
- Nutrition and PWS - Guidance for supporting healthy eating, growth, and weight in PWS.
- Physical Activity in PWS - Research and strategies for supporting movement and physical activity.
- Learn about VYKAT XR - Information about the first FDA-approved treatment for hyperphagia in PWS.

Get involved in research:

- Global PWS Registry - Contribute information that helps researchers better understand PWS.
- Explore PWS treatments in development - See therapies currently being studied for PWS.
- Find a PWS clinical trial - Explore opportunities to participate in current studies.

Sources & References

- Behavioral Features of Prader-Willi Syndrome
- Hyperphagia Questionnaire for Clinical Trials

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