



# Understanding PWS

SHOWING UP WITH CARE



What is the purpose of this guide?

Soleno created this guide in partnership with members of the Prader Willi syndrome (PWS) community to help families, caregivers, healthcare professionals, educators, and the public foster understanding of and respectful engagement with individuals living with PWS.

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# One Condition, Many Experiences

## Definition & Overview

Prader-Willi syndrome (PWS) is a rare and complex genetic disorder resulting from a deletion or loss of expression of a gene cluster on the 15th chromosome, characterized by a number of physical, cognitive, and behavioral changes including hyperphagia (insatiable hunger).

For individuals living with PWS, hyperphagia is not a matter of increased hunger, it's a complex, lifelong condition involving preoccupation with food and a lack of normal satiety (feeling of fullness after eating). This experience can deeply impact daily life and emotional well-being.

The intense focus on food may lead individuals living with PWS to:

- Frequently think or talk about food
- Search for food in inappropriate places, such as the trash or storage areas
- Eat raw or nonedible items
- Get up at night to look for food
- Take food or money in an effort to obtain more food
- Hide or store food for later
- Bargain or negotiate for additional food
- Show rigidity for schedules, especially around mealtimes
- Feel upset, anxious, or overwhelmed when access to food is limited



**PWS occurs in males and females equally and in all races.** There are an estimated 10,000 to 20,000 individuals living with PWS in the United States.

## There Is No One PWS Experience

PWS affects each person in their own way. It can lead to a wide range of physical, behavioral, and cognitive challenges. For example, individuals living with PWS may experience varying levels of hyperphagia and use a variety of strategies to manage their symptoms.



## Common Misconceptions

MYTH	FACT
“Everyone with PWS is obese”	Food safety is a constant challenge that families face every day, and it can become life-threatening. Individuals living with PWS can maintain a healthy weight, but this requires strict food security and environmental controls that can be a constant challenge for the individuals and their families
“PWS is just about hunger”	PWS exists on a spectrum and every individual's experience with symptoms, including hyperphagia, is unique
“They'll grow out of it”	PWS is a lifelong genetic disorder that requires ongoing management

# How to Engage Respectfully

## What to Say & What to Avoid

### Inclusive Language

Refer to people with the language they use for themselves. Mirror individual preferences rather than applying a fixed approach. (e.g., **“a person living with PWS”** rather than “a PWS person”)

### Avoid Comparisons

Saying “Oh, I feel like I have PWS too because I’m always hungry” diminishes the reality of the condition.

### Empathy Over Dismissal

Instead of saying, “They look great for PWS,” acknowledge their **strengths beyond appearance**.

### Listening Over Assumptions

Ask questions and listen to experiences and needs for support, rather than assuming.

## Ways to Support Someone with PWS

### Ask Thoughtfully

Instead of saying, “What’s wrong?” say, **“How can I support you?”**

### See the Person

Lead with empathy, not judgment. Be present, offer understanding, and support the individual with PWS and their family with compassion.

### Be Patient

Some individuals living with PWS process information or respond more slowly—give them time.

Some may also use different ways to communicate, such as AAC devices, gesture, or visual supports. Be patient and responsive to their preferred communication method.

## Engaging with Families & Caregivers

### DO

Ask how you can be supportive (e.g., **“What can we do to help?”**)

### DON'T

Offer unsolicited advice or suggest quick fixes (e.g., “Have you tried just giving them a small treat?”)



# Food & Safety Considerations

## Why Food is a Sensitive Topic

- Individuals living with PWS may experience extreme hunger, thoughts about food, and an urge to eat that cannot be satisfied with food, therefore making food availability a constant challenge
- Offering food without asking an individual's family or caregiver is never acceptable (For example, would you offer peanuts to someone with a peanut allergy?)

## Best Practices for Events & Gatherings

- Encourage non-food activities for celebrations (e.g., crafts, games, music)
- Be mindful when speaking about food, or eating around individuals living with PWS. Avoid mindless snacking and always consider their needs
- Every individual living with PWS has unique dietary needs, and families work closely with care teams to manage them.
- There may be an increased risk of choking, so it's important to follow food safety practices to support overall safety and well-being

### SAY

"We'd love for you to come! Is there anything we should plan for food?"

"I will let you know the party schedule, and the specific times we plan to serve food and birthday treats."

### INSTEAD OF

"We're having pizza and cake, hope that's okay."

"We'll have pizza and dessert out throughout the entire party."



# How to Address Misconceptions & Strengthen Awareness

Take time to learn about PWS. Ask questions, seek guidance from the family and explore training or community events. The more you understand, the better you can support and encourage inclusion. It is essential to keep food completely out of sight and inaccessible to individuals with PWS in any setting.

## For Schools & Educators

- Teach students that asking respectful questions is okay, rather than making assumptions
- Avoid using food as a teaching tool — this includes activities like counting apples or oranges and do not use edible items as rewards or reinforcers



## For Healthcare Providers

- Be open to collaborating with the individual's full care team, including specialists and experts in PWS
- Understand that food should not be offered without a caregiver's input, even in a healthcare setting
- PWS can be challenging and exhausting for families, please be patient and understanding during visits
- Do not assume the absence of hyperphagia in individuals with PWS based on body weight alone — hyperphagia can be present even without obesity



## For Extended Family & Friends

- Do not use food as love, show love in other ways like quality time and non-food activities
- Only offer food or drinks in a manner that has been approved in advance by parents/caregivers



# Community & Social Media Engagement

## Celebrate the Whole Person

- Share stories that highlight the individuality, strengths, and achievements of people with PWS

## Promote Positivity and Education

- Uplift the community with content that informs and encourages understanding

## Create a Safe, Judgment-Free Zone

- Foster an environment where families and individuals can share experiences and joys without fear of criticism or stigma

Refer to page 4 for tips on engaging respectfully

## Encourage Storytelling from the Community

- Give families and individuals with PWS the space to share their stories, whether in person or online. These real-life experiences are powerful tools for education and building empathy

## Be Respectful and Thoughtful

- Use inclusive language, avoid stereotypes and always prioritize dignity in how individuals are represented

## Support Learning and Inclusion

- Encourage others to learn more about PWS through respectful dialogue and by sharing credible, compassionate resources



# Resources & Support

## Where to Find More Information



Prader-Willi Syndrome Association | USA  
[www.pwsausa.org](http://www.pwsausa.org)



Global PWS Registry  
[pwsregistry.org](http://pwsregistry.org)



Foundation for Prader-Willi Research  
[www.fpwr.org](http://www.fpwr.org)



Support for Prader-Willi Syndrome  
[Support4PWS.com](http://Support4PWS.com)

## Printable Quick Guides



PWSA USA Q&A



How you can support someone with PWS



A Parent's guide for supporting siblings

## Emergency Cards for Medical Situations



PWSA USA Resource Cards

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### Council Members:

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