

# Understanding PWS

## SHOWING UP WITH CARE



What is the purpose of this guide?

Solenio 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 chromosome 15, characterized by a range of physical, cognitive, and behavioral changes that may include, but are not limited to:

- Low muscle tone and feeding difficulties in infancy
- Scoliosis
- Repetitive skin picking
- Reduced sensitivity to pain
- Anxiety, temper tantrums, resistance to change
- Intellectual disability

For individuals living with PWS, hyperphagia is not a matter of increased hunger, it is 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
- May engage in unsafe behaviors to obtain 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 1 in 15,000 births of individuals living with PWS in the United States.

## There Is No One PWS Experience

PWS affects each person in their own way. Individuals living with PWS may experience varying symptoms and use a variety of strategies to manage them.



### MYTH

### FACT

"Everyone with PWS is obese"

Food safety is a constant challenge that families have to face every day. Individuals living with PWS can maintain a healthy weight, but this requires strict food security and environmental controls that can be an ongoing 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 am 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 is 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 (Augmentative and Alternative Communication) 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., “You really should be firmer when he has those meltdowns.”)





# 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 is 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

- Show love through quality time and fun, non-food activities
- Only offer food or drinks in a manner that was approved in advance by parents/caregivers
- Help reduce anxiety and support emotional well-being by keeping them engaged in enjoyable, structured activities





# 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

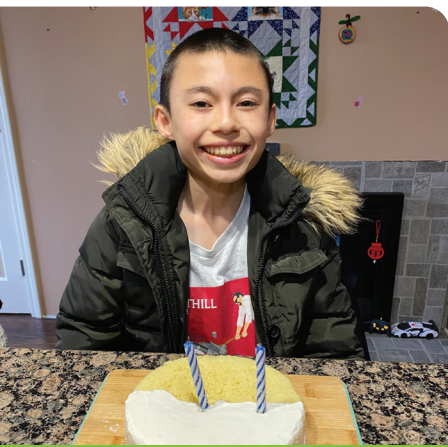
- Give families and individuals with PWS the space to share their stories, whether in person or online. These real-life experiences are powerful tools for education and building empathy

## 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)



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



Global PWS Registry  
[pwsregistry.org](http://pwsregistry.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 Card for Medical Situations



[PWSA USA Resource Cards](#)

## Access & Download This Resource Online



[Understanding PWS: Showing  
Up With Care](#)

## Special Thanks

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### Council Members:

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