

A GUIDE TO TALKING WITH YOUR CHILD ABOUT THE PWS DIAGNOSIS

Parents often grapple with when and how to share their child's PWS diagnosis. As children grow, they may notice differences between themselves and their peers. This raises important questions for parents: Will understanding their diagnosis empower their child or could it negatively affect their self-esteem and overall well-being?

A survey of over 50 parents of children with PWS ages five years and older confirms there is no single 'right' way to talk about PWS. While each family's experience is unique, many parents feel a sense of responsibility to be honest with their child about the diagnosis and want to help their child understand the symptoms of PWS, especially hyperphagia.

¹ Moy et al: <https://onlinelibrary.wiley.com/doi/10.1002/ajmg.a.63794>

TIPS FOR SHARING THE DIAGNOSIS

- 1 Consider Timing**
Choose an age-appropriate moment to share this information, possibly when your child begins noticing differences or asking questions.
- 2 Use Simple, Clear Language**
Explain the diagnosis in a way your child can understand based on their cognitive & developmental level.
- 3 Introduce Information Gradually**
Share information in smaller bits over time instead of all at once.
- 4 Be on the lookout for negative responses to THE disclosure**
Provide support, reassurance and seek professional assistance for your child if needed.
- 5 Highlight Strengths & Abilities**
Focus on what they are good at & what they are learning to do.
- 6 Encourage Communication**
Let them ask questions and express feelings without judgment.
- 7 Provide Reassurance**
Emphasize that they are loved & supported. Remind your child that the diagnosis does not define them.
- 8 Normalize Differences**
Emphasize that everyone is unique and has strengths and challenges.
- 9 Connect with Support Networks**
Encourage relationships with others who have similar challenges.