



Prader-Willi

SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES



Sibling Support Guide

Featuring Resources for Parents and Siblings of
a Loved One Living with Prader-Willi Syndrome

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For Parents: How Siblings May Feel

“Having a sibling with a disability affects you more than you realize, in ways both big and small. It shapes how you see the world, how you interact with people, and even how you process emotions. And the truth is, most people will never fully understand what it’s like, but that’s why finding a community of people who do or want to is so important. They help you process, support you, and remind you that you’re not alone in this journey.”

~ An adult with a younger sibling with PWS

The worries that come with raising a child with special needs are difficult to put into words. On top of that, parents often carry the added weight of concern for their other children, fearing they may fall short in meeting everyone’s needs. The stress and anxiety can feel overwhelming at times, making balance seem out of reach, but it is possible. With the right support, siblings of children with PWS grow into some of the most compassionate, inclusive, and empathetic individuals, shaped by their unique experiences and deep understanding of others.

The best way to support all your children is to listen to them and understand their needs.

Siblings may feel...

- Resentful if their sibling with special needs receives a lot of attention from their parents.
- Fear and worry: The unknown is scary at any age.
- Isolated from their peers or neglected by their parents.

What you don’t hear about is the life skills your children will learn from their sibling with PWS.

Siblings may...

- Have a greater capacity for empathy and understanding of others' thoughts and feelings.
- Develop a high level of patience.
- Have a greater tolerance for individual differences.
- Become resilient.
- Have high levels of emotional awareness.



When the sibling is older than your child with PWS...

- Help them find ways to cope with emotional adjustments and changes in responsibility, making sure they know they are not responsible for their sibling; they just need to love them.
- Encourage open communication and provide a safe space for expressing feelings. Feelings of frustration or anger are normal in any sibling relationship, there is no reason why this would be any different. PWS just adds another layer. The reasons behind the feelings may differ, but finding a healthy way to express these emotions will help the whole family.
- Teach siblings about PWS and the importance of food security.

For the sibling that is younger than the child with PWS:

- Recognizing that younger siblings have grown up with PWS, and this has shaped their experiences and perceptions from an early age.
- Always answer questions about PWS. If you don't, they may fill their minds with inaccurate and frightening explanations. Answer only the question that was asked and make sure the answer is age-appropriate.
- Encourage activities that facilitate bonding and understanding.
- Foster an inclusive environment, promoting sibling advocacy and compassion.


Additional Resources



Sibling Support Project
[CLICK HERE](#)



Find a SibShop Near You
[CLICK HERE](#)



Sibling Story
[CLICK HERE](#)



Sibling Center
[CLICK HERE](#)



SibNet on Facebook
[CLICK HERE](#)

For Parents:

10 Tips to Help Siblings Thrive

1. Let Them Feel All the Feels

It is normal for siblings to feel love, frustration, jealousy, and everything in between. Let them know their feelings matter, and there is no 'wrong' way to feel.

2. Make Time Just for Them

Even small moments such as grabbing a snack together or watching a favorite show can remind them they are just as important as their sibling.

3. Explain PWS in a Way They Understand

A young child might just need to know, 'Your sibling's brain does not tell them when they are full.' As they get older, they will need more details, but keep it simple.

4. Keep Communication Open

Let them vent. Let them ask questions. Let them be honest, even if what they say is hard to hear. They need to know it is safe to talk to you.

5. Encourage Their Interests

They are more than just 'the sibling.' Help them find hobbies, activities, and friendships that are just theirs.

6. Help Them Connect with Other Sibs

Sometimes, it helps to talk to another kid who gets it. Sib shops, online groups, or even just a cousin who understands can make a big difference.

7. Explain That 'Fair' Does Not Always Mean 'Equal'

One child may need extra supervision or special food rules. That is okay. It is not about keeping things the same. It is about giving each child what they need. Different is okay!

8. Prepare Them for Tricky Situations

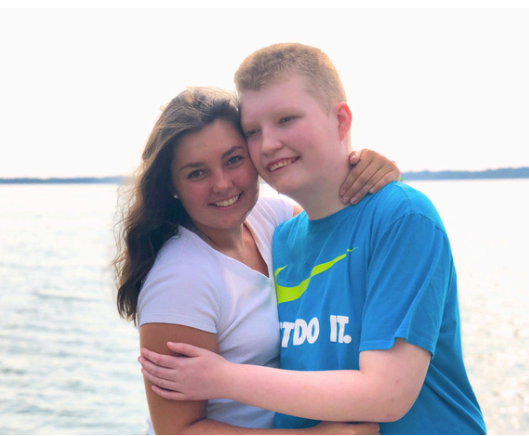
Role-play how they can respond when friends ask questions about PWS or when they feel overwhelmed at home. Give them words so they do not feel stuck.

9. Remind Them They Are Not a Caregiver

They might feel pressure to 'watch out' for their sibling. Make sure they know their job is to be a sibling and not a second parent.

10. Let Them Know You See Them

A simple 'I appreciate you' or 'I know it is not always easy' can mean everything. Even better, celebrate the great things about them!



Understanding PWS from a Sibling Perspective

PWS is a rare and complex syndrome, but it is only a small part of your brother or sister. It's something that they have, not who they are.

Because PWS is so rare, people may not know much about it, and it can be difficult for them to understand what your sibling needs to be safe and happy.

PWS happens entirely by accident, and no one is to blame. Your brother or sister's body may look and grow differently than yours, and they may get quite loud. This is just one of the ways that having PWS may affect them – they're also kind, funny, and really good company. When someone with PWS is feeling safe and secure, they are a joy to spend time with.

Where does the name come from?

Dr. Prader, Dr. Willi, and Professor Labhart first discovered PWS in 1956 in Switzerland. The syndrome was named after only two of the doctors, rather than all three.

What are the main characteristics?

- Low muscle tone (hypotonia): Walking and running can make them really tired.
- Delay in reaching milestones such as sitting up, crawling and walking.
- Emotional and social difficulties: Sometimes making friends is hard for them.
- Insatiable appetite (hyperphagia).
- Difficulty controlling behavior and distress.
- Difficulty dealing with change.
- Difficulty processing instructions and long sentences.

You can find more information at www.pwsausa.org.

For Siblings:

How Does Prader-Willi Syndrome Affect Your Brother or Sister?



Eating

You probably already know that food can be a big deal in your house. People with Prader-Willi Syndrome (PWS) don't feel full after eating because their brains don't get the "I'm full" signal. That means they often feel hungry, even after a meal.

This can be dangerous because eating too much can cause health problems. Your sibling will need help making healthy food choices, and your support can make a big difference. They'll really appreciate your encouragement!



Muscle Tone

Your brother or sister might not be as strong as you because they have something called low muscle tone. Their muscles are the same size, but not as strong on the inside.

That means things like walking, running, jumping, or riding a bike might be harder for them. They might take longer to learn certain things, but with practice, and your help, they can do it!



Emotions

People with PWS can sometimes feel confused, anxious, or upset. They may have a hard time switching activities or changing their thoughts. This can lead to big emotions or meltdowns.

It can feel overwhelming to see this happen. If you're ever worried, don't keep it to yourself, talk to your parents or another adult you trust.



School Life

Your sibling might need extra help at school because of learning difficulties. And sometimes, what's happening at home can make school harder for you too.

You might feel tired, distracted, or find it hard to get homework done. That's totally understandable. Talk to a teacher or school counselor, it's okay to feel frustrated, and you don't have to handle everything alone.



Food at Home

It's tough when you have to be careful about food at home. Try not to talk about food too much or eat tempting snacks in front of your sibling.

Mealtimes can still be fun and full of family time, they might just look a little different from other families. You can still enjoy food together!

What If My Sibling Is Taking Food They Shouldn't?

If you think your brother or sister is sneaking food, talk to your parents. People with PWS have a really hard time controlling this, and they might feel bad about it too. Your parents can help figure out what to do.



Behaviors That Are Hard to Handle

Sometimes your sibling might act out or have a meltdown. It can be loud, stressful, or even embarrassing, especially in public.

Here are a few tips that might help:

- Stay calm. If it's safe, try to distract them.
- If not, make sure you're both in a safe place.
- Don't yell or argue.
- Don't give in just to stop the behavior.



Taking Care of You

You matter too. Your needs and feelings are important, even when your sibling needs a lot of attention. Talk to your parents. Ask for special one-on-one time. Tell them how you're feeling. They love you and want to be there for you, too.

You're not alone—and it's okay to ask for support.



Advice from a Sibling

“My younger brother Gavin was diagnosed with PWS back in 2005 shortly after birth.

Everyday, Gavin is able to find joy in the smallest things and it’s often time the smallest acts that make his day. It’s something that I think we lose touch with as we get older and get caught up in the little complexities of our busy lives. But, if you spend an afternoon with Gavin, you’ll forget all about that ‘big stress’ in life and be amazed by just how much fun you have doing simple activities.

The two most important pieces of advice I’d recommend to other siblings of PWS is first, to try to spread as much awareness as possible, and second, find what your sibling is really excited about and try to learn more about it. As of now, PWS is still not well known and that needs to change if we want to make a bigger impact. So, that starts with us spreading the word about what PWS is! I also recommend learning more about what they’re interested in because it means the world to them to share their interests and it’s a great way to bond with them!”

- Joe G., brother to Gavin (living with PWS), Massachusetts

If you have other questions or need additional support, contact PWSA | USA’s Family Support Team. We are available 24 hours a day, 365 days a year!

 **(941) 312-0400**

 **info@pwsausa.org**

 **www.pwsausa.org**


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Featuring PWS Moms:

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