

## Tips for Healthier Siblings

Here are some tips to increase your children's resiliency and make their lives safer and healthier, thereby helping them be a greater asset to your family and your child with Prader-Willi syndrome. These ideas are gleaned from research interviews with siblings of those with PWS.

### **Communication**

Talk to your children about their experience. Let them feel heard. Know that it is very difficult to grow up with someone with PWS. Know that your children are struggling, too. You can be a big support for your children. Many times, siblings do not feel comfortable talking to friends and their other social supports about their sibling because those people do not understand. This leaves them without anyone to confide about their life situation dealing with PWS. You can be that someone. All siblings interviewed expressed love and admiration for their parents and the hard job they have.

Make conversation safe. Let your children express negative emotions to you, even if the negative emotions are towards their sibling with PWS or towards you.

Initiate these conversations with your children often.

Sibling Quotes:

“Sometimes it helps to talk to my parents, then I'm not so angry inside and I can just say that and feel a little better.”

“My parents are going through it as well.”

“It is not a thing that friends would want to hear or understand.”

“It helps my parents understand where I am coming from, and it helps me to understand what they are doing and see their perspective”

“Talking to my parents makes them and me more aware of everything.”

“It helps when they can listen or try to fix things.”

“I feel like we don't talk about him very much. I think it helps when we do, then they understand.”

“I try to talk to my parents a lot, but they always get mad at me. They say ‘that's not happening, you don't feel that way’ so sometimes I don't tell them.”

“They think that they are the only ones that go through it. It would be helpful if they were more understanding. It is nice to get feelings off my chest.”

“It helps when I talk to my parents. I feel like I don’t want to be alone and keep it a secret.”

“I wish I could talk to my parents about it.”

“Parents can help me manage my emotions regarding him.”

## **Debriefing**

After a meltdown, a traumatic or a stressful event, it is crucial that you sit down together as a family, without child with PWS, and talk about what has just happened.

Here are some ideas:

- The meeting can be structured with specific questions you systematically review or a more informal discussion, whatever your family needs.
- Timing of the debriefing might work better after the child with PWS has gone to sleep. Maybe as part of the debriefing, unlock the pantry and share a treat together.
- Go around to each member and ask how they are feeling now and how they felt during the meltdown/event (make sure parents share as well).
- Try to laugh about what happened. Humor is a great coping mechanism to help move forward. Your child with Prader-Willi syndrome can be hilarious. As one sibling said, “The hard times are funny after the fact.”
- Discuss what you could have done differently during the event to make it less negative on the family. Have a specific plan for specific instances. For example, give specific instructions on what a sibling is expected to do during a meltdown (e.g., go to your room, lock your door, put in your headphones and listen to music; walk across the street to your friend’s house; go get in the car).
- Discuss what everyone did well and what worked.
- Let the discussion flow and go wherever it goes.
- Try not to judge or invalidate anything said even if it is hurtful or hard to hear. It is okay if sometimes your children don’t like their sibling with PWS. They need to be able to express their honest feelings.

Why debriefing is important:

- Family cohesion increases when everyone is on the same page, especially during stressful events or outbursts.
- A specific plan for these events can reduce the contention between family members trying to handle the situation.
- These debriefing sessions are a great way to release pent up emotions for each member of the family.
- A discussion allows siblings to feel they have a significant role or are a part of the solution.
- Siblings and parents can learn from each other if there is an open and honest environment. Sharing perspectives will only benefit everyone.

Sibling quotes:

“When the PWS sibling does something, then make sure you talk about it.”

“Be willing to listen.”

“Know that our feelings are valid.”

“Talking to them would be the biggest, figure out what is hardest for each child, reliving that stress, realizing if they want to get away (in their room or out of the house) it’s not the parent’s fault but just how it is, if they are out of the house or isolating themselves a lot, it’s not that they don’t like you but the situation. Realize that their behavior isn’t bad. Be understanding.”

“Try to be understanding.”

“Do not get offended because it can be hard for us to tell them that we are struggling or need more attention.”

“They need to be open to listening.”

“Approach the kids for a discussion.”

“Keep in touch with them.”

“I would tell them that we love our siblings, but it is hard for us to deal with. But we love and respect them (our parents).”

“I would encourage parents to help their other children. Be understanding of the situation and be patient. Patience is the key.”

“Educate them more, teach them, have them involved, talk about things, keep them informed”

## **Meltdowns**

Define how you want the sibling to act when the child with PWS has meltdowns. Some examples to consider include “let us as parents handle the meltdowns completely. You go somewhere safe and listen to music. We will talk about it after.” or, “Here is something specific you can do to help calm your sibling with PWS.” Consider putting locks on your other children’s rooms so they can go somewhere safe when your child with PWS is losing control. This plan will differ with the needs of different children and families.

Sibling Quotes:

“I feel useless if I am not involved in helping her calm down.”

“I feel that is my time to step in and do the best I can to make him feel better.”

“I am usually sent away, but I want to help.”

“The tantrums make me really uncomfortable.”

“The noise makes me overwhelmed; I try to go to my room and close the door so I can’t hear. It makes me angry cause I wish he was normal, but I have to deal with it.”

“The pure stress of the experience definitely has an effect.”

“I hide and run away.”

## **Spend time with your other children**

Your child with PWS requires a lot of attention, but your other kids do, too. In some cases, the siblings can feel guilty asking for attention because they need to be the “easy, low maintenance” child.

Make sure to spend time with each child away from the child with PWS. You can be a great support for your children, and they can be a great support to you as parents. Make sure you build a solid relationship with them where you can all communicate freely.

You could even go on vacations together without the child with PWS. Many siblings said that vacations with the PWS sibling end up “not being worth it” because they cause so much stress. Some siblings had not even been on a vacation because their sibling made it too hard.

Sibling quotes:

“Make sure they have time for each child even if the PWS kid needs more.”

“Make sure you do fun things with them without the PWS kid.”

“Kind of keep in touch with them and make sure you have fun things set aside with them. Go to a movie without the kid with PWS. Leave the chaos that is Prader-Willi at home and do something fun.”

“Give them some attention and the feeling that you understand.”

“I wish my dad was home more.”

“Try to talk to the siblings, make sure they are recognized and that you care. When the sibling does something then make sure you talk about it. Give them attention and the feeling that they understand.”

“Let’s have a couple weeks where we go off and someone babysits him, so we can experience being in a family without a sibling with PWS and eat as much as we want.”

“Make sure they feel they are a priority. From our retreat, it was clear that the siblings felt left out of their families. Their sibling was the focus. Pay attention to the other kids. Make sure the whole family is included. Tell your kids what is going on.”

“Make sure that all the siblings feel loved, that you don’t focus too much on the PWS kid. If the kids are struggling, give them a break and distract the kid with PWS until they are cooled off. Make sure things don’t escalate too much.”

“Just make time for all of the kids. Be at their things and also know they are there. Take time to notice the other siblings.”

“Most of the attention is on the kid. Set some time aside to do stuff with the other kids. Know how they feel and what they are doing.”

“Spend quality time with them, one on one. We don’t get that a lot. Every kid should have the right amount of attention and they should give it to each.”

## **Caretaking responsibilities**

Ask your children to tend. Don’t just assign them to tend without asking. This will show your children that you respect and value them.

Consider having them tend their sibling with PWS less often. Make sure they have time to relax and unwind away from their sibling with PWS. Consider taking the child with PWS out for an adventure at set times so your other children can feel comfortable bringing friends over to your house.

Sibling quotes:

“I can’t do stuff because I have to watch my 20-year-old brother.”

“It’s a lot more responsibility without the reward.”

“When I tend my sibling, I feel like I am helping my parents. It feels good in a way.”

“We are dealing with a lot at home with them, so let us have more time away from home, more time with friends. Have less expectations because of the stress of home life.”

“Don’t make it difficult on us to constantly watch them.”

“Don’t put the child’s care on our shoulders.”

## **Food**

Make sure your other kids have access to food. A lot of kids are going hungry because the parents do not let them get food when they need it or want it. Giving them access gives your children one more thing that they can control in their lives. Almost all siblings admitted to hiding food themselves so they could eat when they were hungry.

Give your children a space to put their food so the PWS sibling cannot get it. This could be in a locked drawer or a safe in their room, or a secure hidden spot.

Sibling quotes:

“I think it would be nice if we had copies of the keys to have secure access to the food.”

## **Yelling**

Try to refrain from yelling at your children with PWS, without PWS and your partner. This creates more stress, chaos and trauma.

Sibling quotes:

“Don’t yell at us.”

“Do your best not to fight with the child with PWS, as hard as that can be. Fighting is probably the worst thing you can do.”

“Don’t get impatient so quickly. Control your rage.”

## **Seek professional help**

Everyone can benefit from seeking professional counseling and therapy. Your kids have an increased risk for emotional, behavioral problems and mental illness.

## **Other ideas**

- Do not have your child with PWS share a room with any of your other kids.
- Give the siblings a safe for their room to put their money and snacks in to protect their belongings from the sibling with PWS,
- Try to keep your home clean and organized. The surveys show that siblings with Post-Traumatic Stress symptoms almost always come from chaotic disorganized homes. Consider getting help with this if possible.