

For brothers and sisters

What is Prader-Willi Syndrome (PWS)?

PWS is a rare and complex syndrome, but 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 the needs that go along with it.

PWS happens entirely by accident and no one is to blame – it's completely down to chance. Your brother or sister's body will look and grow differently to yours, and they may get quite loud and use strong language. 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 (known medically as hypotonia)
- Delay in reaching milestones such as sitting up, crawling and walking
- Emotional and social difficulties
- Insatiable appetite (known medically as hyperphagia)
- Difficulty controlling behaviour and distress
- Difficulty dealing with change
- Difficulty processing instructions and long sentences

You can find out more about the characteristics by reading our leaflet 'What is PWS?'

How does Prader-Willi syndrome affect your brother or sister?



Eating

As you probably already know, living with someone with PWS can have an impact on your family when it comes to food. People with PWS find it very hard to control their eating - their brains don't receive the signal from their stomach to tell them when they've had enough to eat. As a result, they go on feeling hungry for much longer than the rest of us.

It's really dangerous for a person with PWS to eat too much. They'll put on weight very quickly and will find it quite difficult to lose, and this can lead to other health issues. Your brother or sister will need lots of support around food and eating healthily, and they will love encouragement and support from you.

Muscle tone

Your brother or sister's muscles won't be as strong as yours because they have low muscle tone. Their muscles are the same size as yours, but the inside is different. Some things can be more difficult for them, like going for long walks, jumping, cycling or doing exercise and sport. Some people with PWS use wheelchairs, either because they are unable to walk or are not able to walk for long distances and others use aids such as a walking frame.



Emotions

People with PWS can become easily confused, anxious or upset. They find it really difficult to change their thought or action, and they may show confusion, frustration or anger by having an emotional meltdown. It can be a little overwhelming to witness and it's really important to speak to your parents if you feel worried or concerned in any way. The charity SIBS has been set up specifically for siblings of those with a disability - they have support groups and an advisor that you can speak to, as well as lots of information. Find out more by visiting www.sibs.org.uk



School life

Many children with PWS have learning difficulties, so they may need extra support in school, as well as at home. For you, things can get hard in school because of what's happening at home - you may feel tired in class, struggle to get homework done, or find your brother or sister's behaviour in the mornings can have an impact on you. SIBS have some helpful advice on how to manage these situations.

How to cope

It's normal to find it hard from time to time. None of us are perfect and we can't be expected to be in a good mood all of the time, but there are some things which might help you to cope when you're finding it hard.

Food

It's not easy for you, as the sibling of someone with PWS, to monitor your eating all the time, but it'll help not to talk about food or eat tempting foods in front of them. Mealtimes can still be family time, and can be enjoyed. Having a sibling with PWS doesn't mean that you can't enjoy food together – it may just look slightly different to other families.

I think my sibling is taking food they are not allowed to, or stealing from the cupboards. What should I do?

Remember, they find this very difficult to control and they are probably as upset with themselves as you are with them. If you think they may have been taking food, speak to your parents. They will guide you on the best way to deal with it. We have more information about managing diet on our website or you or your parents can call us on 01332 365676. We also have an email address that you can use at any time,



Behaviours of concern

Behaviours of concern can be upsetting, noisy and stressful. Sometimes they can be embarrassing if they happen in public.

Some of the best things you can do when a behaviour happens are:

- Keep calm and if safe and possible, try to distract them
- If not possible, make sure you're in a safe environment, as well as your sibling
- Don't shout back or get angry too
- Don't give in to what your sibling wants

Looking after yourself

It's okay to have your own needs and feelings, and not to feel bad about telling these to anyone, especially your parents! Your own needs are just as important as those of your brother or sister. You might have your own ways of coping, and it's important to know you are not on your own.

It might feel like most of your parents' attention is on your brother or sister, because they need more care, and they may need attention straight away in order to avoid things getting worse. This might be things like keeping your sibling away from food or dealing with upsets, and it's important that you have the opportunity to talk about how this feels for you.

You might feel like you're not getting enough time or attention from your parents, and you should not feel bad about that. Try speaking to them and asking for some time with them without your brother or sister. It may be difficult to arrange to get someone else to care for your sibling at these times, but hopefully there will be times when you can be alone together and talk about your feelings and spend some quality time. Your parents will definitely want this too.

If you feel that you are finding life hard to cope with, and you do not seem to be able to get through to your parents, you can talk to a trusted group of friends or a teacher. It's worth finding out if your school offers counselling or if there are any peer support groups you can join. SIB charity also have a siblings advisor that you can contact at any time.

Life with your brother or sister with PWS

Not everyone will experience the same things when it comes to having a brother or sister with PWS. We asked siblings the good things and hard things about living with their brother or sister:

The good things

- * Seeing them achieve goals which had not been thought possible
- * Having a balanced diet and eating healthy food
- * Their loving, caring, funny and kind personality
- * Learning to be patient and tolerant
- * Helps to face other challenges in life and makes me less selfish
- * Teaching them to do things
- * Getting a better understanding of, and meeting others with, disabilities
- * Having a laugh and a nice sibling relationship
- * Taking part in special activities



The hard things

- ♦ Having to be very careful with food and sometimes feeling guilty about food
- ♦ Emotional meltdowns
- ♦ Listening to them repeating questions and topics over and over again
- ♦ Always having to wait for the person with PWS
- ♦ Sometimes nice family occasions can get stressful or upsetting
- ♦ Feeling bad or guilty about getting annoyed, frustrated or upset with them
- ♦ Obsessive behaviour
- ♦ Embarrassing behaviour in public
- ♦ Person with PWS butting into conversations

Arguments

All brothers and sisters argue - it would be strange if they didn't. In some cases, it may be just now and then and in others, it can be much more often. But there seems to be a difference when it comes to arguing with your brother or sister with PWS. For one thing, they won't listen to reason—or so it seems!

People with PWS have a great deal of difficulty understanding things that are said to them. They need showing and clear explanations. It's best to talk things through, rather than yelling, and perhaps trying to show them what you mean. Sometimes it might be best to walk away or take a few deep breaths and try to explain in a different way. Remember though, arguments will happen just the same as they do for any other siblings.

You are not on your own - we are here to help and you can call us any time on 01332 365676, or email us at supportteam@pwsa.co.uk

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