

For Brothers and Sisters

What is Prader-Willi Syndrome?

People with Prader-Willi syndrome (PWS) are special, and so are you. It's good to learn about how it affects your brother or sister, your family and you.

Not many people have PWS, so it is unlikely that anyone you know will have someone in his or her family with the syndrome. So it might be hard for other people to understand the needs of your brother or sister.

Did you know?

There are thousands of syndromes that affect people in many different ways. Some of these you are born with, and others you can develop later in life.

No-one is to blame for your brother or sister having PWS. It is a genetic condition that some babies are born with, and happens by accident.

PWS means that the way in which your brother or sister's body was made is slightly different to yours, which affects some of the ways in which they develop and grow, and some of the things they say and do.

Your brother or sister can't help having PWS, or how it affects them, but they are still individuals in their own right and

have all the same needs to be loved and cared for that you do.

“Siblings” - Another name for “brothers and sisters”

When we talk about brothers and sisters, a word which means both of these is “sibling” or “siblings”. We'll be using this word sometimes in this leaflet.

When your brother or sister was born ...

Your parents might have been told that your brother or sister had PWS soon after they were born. Doctors will have noticed that the baby was very weak and floppy, and didn't cry, and so have done some tests to find out the problem.

But doctors don't always realise that PWS might be the problem, so your parents may not have known your brother or sister had the syndrome until they were older.

Your brother or sister might have spent extra time in hospital after they were born so that they could be looked after by doctors to make sure they were OK to come home.



Where does the name come from?

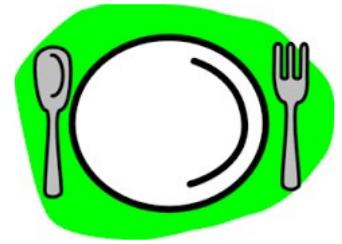
PWS was named after two of the doctors who first put together a list of the symptoms. In 1956. They were called Dr Prader and Dr Willi and they came from Switzerland.



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

Eating

As you probably already know, living with someone with PWS means that you all have to be very careful about food, which can be a cause of upset.



People with PWS find it very hard to control their eating. Their brains do not tell them when they have had enough to eat, so they go on feeling hungry for much longer than most people. Sometimes, because they feel so hungry, they will try and steal food.

It is good to be really helpful with their diet and food as it is very dangerous for a person with PWS to eat too much. They will put on weight very quickly and this can make them very ill.

Muscle tone

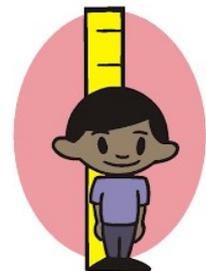


Your brother or sister's muscles will not be as strong as yours because they have weak, or low, muscle tone. This means that some things can be more difficult for them, like going for long walks or doing exercise and sport.

Because of the low muscle tone and the eating problems, it is also very hard for your sibling to keep their weight down, and they need all the help, love and support they can get to keep them healthy.

Growth

Most children with PWS do not grow very well. Now they can get growth hormone treatment with daily injections. This helps them get taller and stronger whilst they are growing up.



Emotions



People with PWS can become easily confused, anxious or upset. They find it very difficult to change direction when they are on a set path of thought or action, and they may show confusion, frustration or anger by having a temper tantrum.

These are very similar to the type of tantrums that toddlers have—but your brother or sister may continue to have these upsets as they grow up.

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

Learning difficulties



Many children with PWS have learning difficulties, so they may need extra help in school, or go to a special school.

For brothers and sisters

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

It's important to try to not be too angry with them. 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, it would be a good idea to speak to other family members to decide on the best way to deal with it.

We have more information about managing diet on our website or you or your parents can phone us about this.

How to cope

It's OK 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

A lot of things revolve around food—turn on the TV, open a magazine, or go in a shop and there is food everywhere. How many times have you seen an advert on TV, smelled cooking as you walk past a take-away, or seen food in a shop and think, "I really fancy eating that"? That's what it's like for people with PWS all the time.

Food can't be avoided, so it's important that your brother or sister grows up with a strong understanding of what they can and cannot have. It is not easy for you, as the sibling of someone with PWS, to control your eating all the time, but it might help not to talk about food or eat tempting foods in front of them.



More about how to cope ...

Temper tantrums

Temper tantrums 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 temper tantrum happens are:

- Keep calm and keep out of the way if you can
- Don't shout back or get angry too
- Don't give in to what your sibling wants



Looking after you

It is important to remember that it is OK 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.



Sometimes 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.

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, talk to a trusted teacher, doctor or youth leader. You can also call Childline 0800 1111 or talk to support staff at PWSA UK 01332 365676

We're all different, so you might have some of your own ways of coping. Write here the things that you think might help you cope. It might be a good idea to ask an adult to help!

Life with your brother or sister with PWS

Here are some things which other brothers and sisters have said are good and some things that are hard about living with a brother or sister with PWS. Not everyone will experience the same things.

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
- ◆ Temper tantrums
- ◆ 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 from time to time—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 actually have a great deal of difficulty in understanding things which 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.



There is a Facebook group specially for brothers and sisters of people with PWS. You can find it at www.facebook.com/groups/pwssiblingsuk/

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The official PWSA UK Facebook page is www.facebook.com/PWSAUK/ where you can keep up to date with all our news and details of family events in your area.

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Find out more about PWS and family events on our website at www.pwsa.co.uk



Thanks ...

Many thanks to Holly Baker-Cliff who helped us put together this leaflet. Holly has a sister with PWS.

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What do you think are the good things about living with your sibling who has PWS?

Write here all the things that are great about living with your brother or sister

What do you find hard about living with your sibling who has PWS?

Write here the things that can be difficult about living with your brother or sister ...

What can our family do to make this better?

Write here some ideas for how you and your family could help you and your sibling