

## How you can help ...

### BE KIND, PATIENT AND UNDERSTANDING

- ✓ Try to understand what makes a person's anxiety or frustration worse. Notice when this is happening and think what could have been done differently to prevent this.
- ✓ Disappointment can be hard to manage for everyone, but this emotion is harder to control in PWS. It's best not to make sudden changes or make promises you are not sure you can keep, e.g. inviting someone to a party and then changing your mind.
- ✓ We have a golden rule that helps keep anxiety low. It's called the 4Cs: **Be Calm, Consistent and Clear – and avoid Confrontation.**
- ✓ If you have a disagreement, be understanding. Show them that you understand their feelings and explain your feelings too. Allow extra thinking time.
- ✓ If a person loses control, trying to talk about it probably won't work. Remember they can't help it. You don't need to 'give in', but don't argue. You may need to walk away and sort things out when they are calm again.
- ✓ Someone who has PWS might always be hungry, but they need to eat less and have strict diets. This part of PWS is cruel and not easy to live with. Be kind and help them by:
  - not eating in front of them if it's something they can't have
  - not talking about yummy treats you have eaten
  - not offering food unless you have checked with a parent, teacher or support person
  - helping them to keep busy and not think about food
  - keeping them safe around food by storing it securely and out of sight (too much food all at once can be dangerous)
  - remembering that if they do take your food, they can't help it.
- ✓ It's harder for people living with PWS to lose weight. It's important to build muscle and to stay healthy. Have some fun doing exercise together.

## How we can help ...

### THE PWSA(NZ) SUPPORTS PEOPLE LIVING WITH PWS, THEIR FAMILIES & CAREGIVERS

#### ADVOCACY

- Providing advocacy services on behalf of people living with PWS and campaigning on relevant issues.

#### EDUCATION

- Accessible information via our website and our range of free publications and resources
- Training workshops offered to schools and residential care providers
- Increasing awareness and understanding of PWS
- Circulating research to medical professionals as needed
- Keeping members informed of the latest news, ideas and research through our newsletters
- Links to the international PWS community.

#### SUPPORT

- Offering information, diagnosis and crisis support to people living with PWS, parents, whānau and caregivers
- Facilitating connection via our parent support network
- Hosting events, family meetings and support weekends.

#### PLEASE CONTACT US

More copies of this pamphlet can be ordered from our website.

**Prader-Willi Syndrome Association (NZ) Incorporated**



0800 4 PWS HELP  
(0800 4 797 4357)  
enquiries@pws.org.nz  
[www.pws.org.nz](http://www.pws.org.nz)

## An introduction to Prader-Willi Syndrome for Peers & Housemates



ADVOCACY | EDUCATION | SUPPORT

**PWS** PRADER-WILLI SYNDROME ASSOCIATION NEW ZEALAND



# What is Prader-Willi Syndrome?

PWS is a rare disorder that happens randomly before birth. It is named after two of the doctors from Switzerland who first described the symptoms.

Not everyone will have all the symptoms of PWS – every person is different. They might be affected more by one symptom than another. Many symptoms are caused by the hypothalamus in the brain not working properly.

This controls:



Dr Prader ▲  
Dr Willi ▼



**Hunger** – Food is usually enjoyed more (like it tastes better) and from 4 to 8 years old, constant feelings of hunger can start. For these reasons, people who have PWS think about food a lot and get anxious about it.



**Weight** – Less energy is used by the body so less food is needed compared to other people. This means that weight increases very easily.



**Growth** – Children today can have growth hormone treatment to normalise their height.



**Muscle development** – Children are born floppy and weak. They must work hard to strengthen their muscles. Hormone treatments can help.



**Puberty** – This happens a little differently in PWS and may take longer. Hormone treatment can help.



**Sleep** – Not having good sleep at night often makes people living with PWS more tired during the day.



**Emotions** – Feelings are difficult to control so they are often felt more strongly. A person may seem extra sensitive or might react more when they are stressed. Most people feel more anxiety (worry) about food and other things.

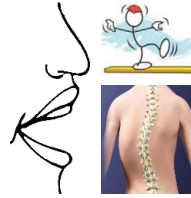


**Body temperature** – This control doesn't work properly. A person may feel more hot or cold and may wear too many or not enough clothes.

# More about PWS ...

This lists some other challenges that people living with PWS may have. It's important to remember that a person will also have lots of strengths, such as being able to remember things from a long time ago, or having good technology and visual skills. They are probably very determined and work hard to overcome challenges.

**PHYSICAL CHALLENGES** – Some people experience problems with balance and coordination (parts of the body not working well together.) A person may feel a bit wobbly and find some sports difficult. Their weaker muscles and coordination might also make it difficult to speak clearly.



**Take the time to listen more carefully.** Some people have scoliosis which is when the backbone grows in a curved shape.

**PROCESSING DELAY** – Following speech can be difficult because sounds can get jumbled up. Focusing is easier without background noise. **A little bit of extra time is needed for listening, so don't say too much at once. Clear information is helpful.** A person may also process senses differently and be more sensitive to things like noise, smell or touch.



**THINKING DIFFERENCES** – Because people living with PWS have high anxiety levels (worry), they can feel more comfortable if they know what is going to



happen or if things stay the same. They might like things to be done in the same way, objects in a particular place, or to repeat a habit. **It is best to tell them in advance if they need to stop what they are doing or before any changes.**

**SOCIAL SKILLS** – People living with PWS are sociable and friendly, but the listening problems can make conversations difficult. They may have lots to tell you - **help them with taking turns to speak and give time for listening.** They may find it hard to recognise emotions in other people but **when you explain how you feel, they will understand.**



These are some of the things that our Adults living with PWS Leadership Group want people to know:

It's hard to say no to food. Please don't offer things we can't have.

We find it hard not to think about food. Help us to not think about it.

It's easier if you keep food out of the way.

PWS affects people differently. We are all unique.

I'm not PWS. I'm me. I don't like to be treated differently.

Check to see how I'm feeling. Find out why I am anxious.

PWS is a syndrome where you can't control yourself sometimes. Don't take our temper too seriously.

Give us an opportunity to talk and think. Have patience with understanding me.

Sometimes we need personal space.

I like clear information, not too much that I forget.

We are not always able to explain ourselves or our thoughts. We are often misunderstood.

It's not my fault – PWS is not going to change.

Be understanding of my energy levels. Sometimes we get tired easily.