How dietitians support people with Prader-Willi Syndrome (PWS)

Key points

- Eating nutritious food is essential for every Australian to achieve the highest possible standard of health and wellbeing.
- Prader-Willi Syndrome (PWS) is a rare genetic disorder which affects a number of systems in the body, including hunger and thirst.
- Accredited Practising Dietitians (APDs) can support people with PWS and their families to develop healthy eating habits and to manage symptoms such as insatiable hunger.
- Discover how an APD has helped Sandra and her son Charlie, who lives with PWS.

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We would like to extend our thanks to the family who shared their experience with us for this piece. While we know every situation is unique, we've shared their story in hope that it can be of support to others in a similar situation.

What is Prader-Willi Syndrome (PWS)?

Prader-Willi Syndrome (PWS) is a rare genetic disorder. It occurs randomly around the time of conception, and results in a change to the 15th chromosome where genetic material is deleted.

It affects a part of the brain called the hypothalamus, which is responsible for regulating a number of systems in the body, including hunger and thirst.

People with PWS have a high fat to lean muscle ratio when it comes to body composition. This means it's easy for them to gain weight in a short period of time, as they have lower energy needs.

Combined with changes to hunger and satiety cues – where people with PWS feel constantly hungry – they are also at greater risk for developing diet-related chronic diseases.

Accredited Practising Dietitians (APDs) are trained nutrition professionals who can help those living with disability tailor their diet to optimise their wellbeing and independence.

Nutrition support for those with PWS begins at birth, where a mix of naso-gastric feeding (a tube which passes through the baby's nose and into the stomach) and breast/bottle feeding is used to help achieve adequate nutrition.

As a child with PWS grows, an APD continues to supports the child and their family to develop healthy eating habits and to manage the onset of symptoms such as insatiable hunger.

Find a dietitian for PWS support

Sandra and Charlie's story

Sandra recently sat down with us to share an insight into how seeking nutrition advice was essential for PWS. She shared some of her concerns as she learnt how best to care for her son, Charlie, who lives with PWS.

"A big part of it is the psychological anguish of having a child with Prader-Willi," said Sandra.

"It's not just the physical, 'what am I feeding my child', it's also the mental anguish…knowing that my child will want more food.

“Constantly wondering what food is good [for Charlie] …If I go to a restaurant, [or] if I’m out in the street and he’s suddenly starving, [or] if I’ve forgotten to pack a lunch.

> *“The dietitian that I am currently engaged with has the answers, responses and actions for these concerns.” - Sandra*

After receiving limited nutrition care when he was an infant, the NDIS has been vital in supporting Charlie to regularly see a dietitian.

Personalised, intensive support from an APD has helped Sandra learn more about nutrition for PWS. This has supported their family’s wellbeing and allowed Charlie to thrive.

“Having a child with Prader-Willi, it’s not just about what food goes in his mouth… there is the right amount of food, there is the proportion size, there is frequency, there is fat saturation [to consider],” said Sandra.

“It’s not just that it needs to be low fat. There’s a certain amount of certain fats and nutrients. There’s a really delicate balance. If that’s thrown out… child will suffer in the sense that they will put on weight. A gross amount of weight very quickly.

“I needed someone who is completely objective, who just gets it… I can do my scrambled brain ramble and they can unpack that information and respond in concise, more sort of technical terms.”

Remote video URL

How your dietitian can help

Dietitians understand that it’s not just about the clinical care. It’s about also understanding your family situation and the broader influence of PWS.

They recognise that some of the needs of a person with PWS are different to the other people in your household, and can help you create meals that are easily adapted for a diverse family dynamic.

An APD works with everyone involved to put together a plan for eating, to find foods that are appropriate for the age of the person with PWS. They also know eating is for life – and provide sustainable options that are manageable for your family.

APDs also work with other health professionals, such as your doctor, occupational therapist and speech pathologist, to support progress towards an individual's goals.

For those seeking a dietitian, Sandra shares these words of advice:

"I'm really up front when I'm looking for someone – I want someone who knows me and my family's needs," said Sandra.

"I didn't try to sugar coat anything. We don't sugar coat anything in our family ... just a little Prader-Willi joke!"

Sandra strongly supports advocating for the right nutrition advice when it comes to seeking support for individuals with disability, like Prader-Willi Syndrome.

"Now that [Charlie's] older, the impact is... it means more, it costs more.

"There's a greater consequence if I get the wrong information. It has to be spot on."

When to see a dietitian

We recommend seeing an Accredited Practising Dietitian (APD) if you or a friend or family member:

- have been diagnosed with Prader-Willis Syndrome (PWS)
- are dealing with any of the symptoms of PWS
- would like personalised advice and support from a professional
- want to know the best dietary approach for you.

Accredited Practising Dietitians (APDs) are university-trained nutrition experts. They can help you with personalised, easy-to-follow and evidence-based advice.

APDs are Australia's most trusted dietetics professionals.

Find a dietitian

Top tips

- APDs are trained nutrition professionals who can support people with disability tailor their diet to optimise their wellbeing and independence.
- Dietitians understand it's not just about clinical care; it's about your broader living situation.
- Dietitians also work with other health professionals to support progress towards your goals.
- You may be able to use your NDIS funding to access dietetic services.