

See Me, Not Just Prader-Willi Syndrome

An everyday guide for people supporting individuals with PWS.



Written by people with PWS.

Every person deserves to be treated with kindness and understanding.

Registered Charity number England and Wales: 1155846 Scotland: SC053700

Hello

I have Prader-Willi syndrome (PWS).

This book is for people like you supporting people like me.

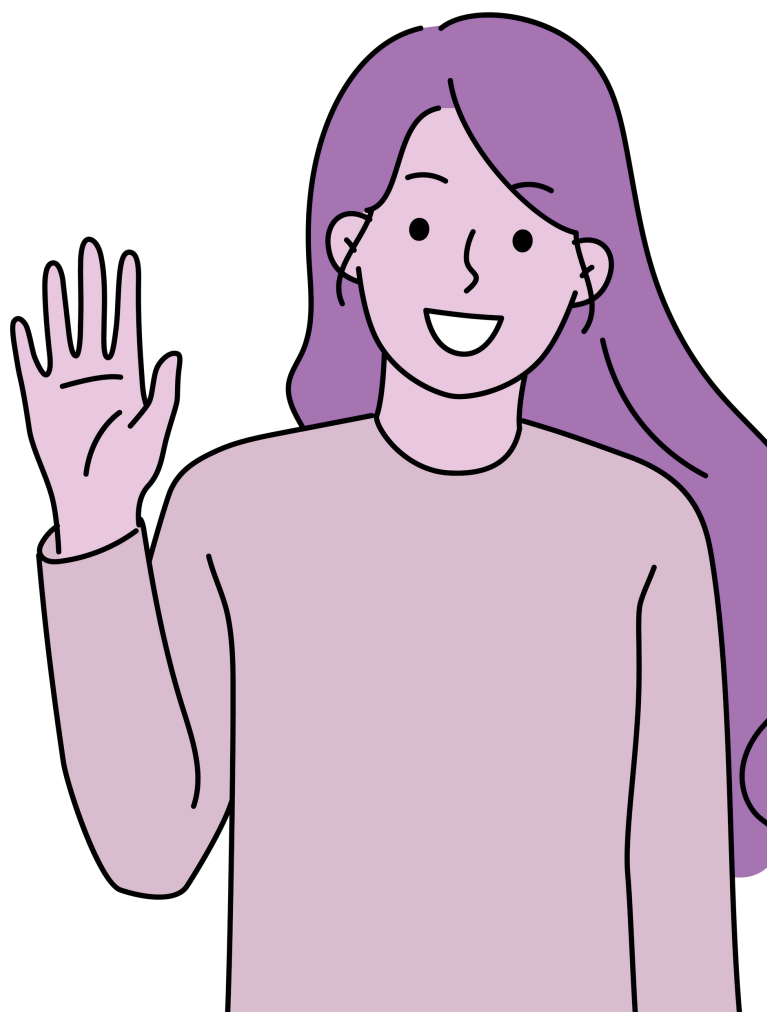
This book will help you:

- Understand me and PWS
- Support me in the way that works best for me
- Help me feel happy, safe, and healthy

As a carer, you are special too.

Let's work together to help me feel my best.

Throughout this book, you will learn the best ways to support me. There are also blank sections we can personalise together.



Visit the Prader-Willi Syndrome Association UK for advice and guidance

**www.pwsa.co.uk
01332 365676
admin@pwsa.co.uk**



I am a Person

There's more to me than PWS.

Just like you, I have:

- Feelings
- Dreams
- Good days and bad days
- Likes and dislikes
- Hobbies and interests
- Ideas and opinions
- Challenges
- Goals



- _____
- _____
- _____

I want people to see ME, not just my PWS.

Understanding PWS is very important, but it's just one part of who I am.

How you support me around food is VERY important

Most people with PWS feel hungry **a lot of the time.**

That's not our fault. You should learn more about this by visiting the website www.pwsa.co.uk

What helps me:

- Have food rules that are the same every day
- Please don't eat in front of me
- Please don't ask me if it's OK to eat in front of me
- Say "no" kindly and clearly, remember, it's not what you say, it's how you say it
- Be imaginative and organise fun things that don't involve food
- _____
- _____
- _____

If I cry, act differently, or try to get food, I'm not behaving badly. I need your help and support.

You need to be aware of my feelings and emotions

Sometimes I feel:

- Angry
- Excited
- _____
- Sad
- Anxious
- _____
- Worried
- _____
- _____

These feelings can come on quickly. I might struggle to explain why.

Changes can be tricky for me, especially if my routine changes suddenly.

What helps me:

- Keep to a routine when you can
- Tell me what is going to happen and when
- Give me space and time to calm down if I feel upset

- Encourage me and say “well done” in a kind way when I do something well

- _____
- _____
- _____

I’m not trying to be rude. My PWS means I sometimes need a little extra help and understanding.



Like many others with PWS, I like routines

Sun

Routines help me stay calm and feel in control.

Mon

What helps me:

Tue

- Daily and weekly plans that include both words and pictures

Wed

- Keep me involved and informed before changes happen if you can

Thur

- Be patient and calm by helping me understand if things must change

Fri

- _____

- _____

Sat

- _____

When I know what's next, I feel better and in more control.



Support Me to Be Independent

I want to do things for myself, even if I need some help.

I like to feel proud of myself.

What helps me:

- Give me safe jobs to do, like cleaning or gardening
- Give me choices I can understand, such as 'Do you want to go to the gym or swimming?' You might need to explain them more than once
- Celebrate when I learn something new
- _____
- _____
- _____



Talk With Me

Please don't talk over me.

Please don't talk about me like I'm not here.

What helps me:

- Use simple, clear words and sentences
- If I'm upset or worried, you might need to repeat yourself, more than once
- Let me speak, even if I need time and repeat myself. Do not finish sentences for me
- Ask me what I think
- _____
- _____
- _____

I want to be part of the conversation.



Looking After My Health

Some people with PWS can have health problems. Here are some examples:

- Weight problems if my food is not managed well
- Sore joints
- Tiredness
- Breathing problems
- Skin picking

You can learn more about health problems in PWS by visiting pwsa.co.uk

What helps me:

- Doing fun exercise every day, like walking, dancing, or swimming
- Going to the doctor with support
- Talking about my health in a safe and kind way
- _____
- _____
- _____

Being healthy helps me to feel good in my body and mind.

Important!

Remember the PWS Warning Signs.

People with Prader-Willi Syndrome may not show usual signs of illness or injury. It's important to look out for:

- **No vomiting reflex**

Most people with PWS cannot vomit, even if very unwell. This can make it harder to spot serious illness.

- **Temperature**

My body does not control temperature like other people's. If I am poorly, I might not get a high temperature. My normal (base) temperature is lower than most people's. I might not feel too hot or too cold, even in very hot or very cold weather. This is because my body finds it hard to adjust to temperature changes.

- **High pain threshold**

Most people with PWS don't feel pain in the usual way. This means injuries, infections, or illnesses might go unnoticed for longer. Pain may also be felt in a different part of the body, this is called referred pain.

- **Bruise easily**

Skin may bruise more quickly or easily than expected, even from small bumps.

- **Rare but serious: stomach problems**

Stomach pain must be taken seriously. Signs might include severe stomach pain, bloating, or feeling very unwell. These could be indications of a medical emergency.

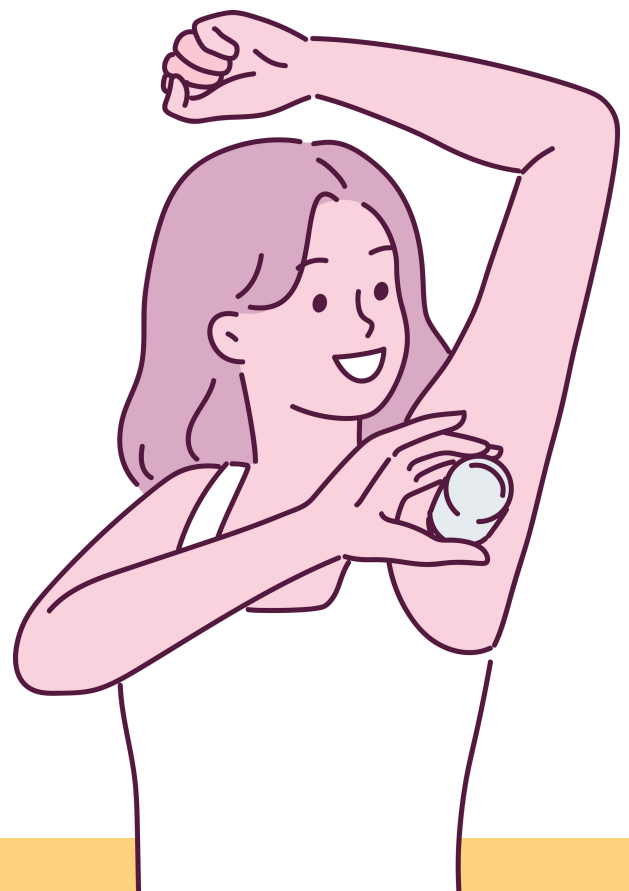


Looking after my personal hygiene

Some people with PWS may need extra help and support with keeping clean and looking after themselves. This can be even more important if they are feeling tired or sad.

What helps me:

- Daily and gentle encouragement and support until things improve
- Reminders and friendly help when I need it
- Step-by-step guides for hygiene tasks
- _____
- _____
- _____



Like You, I Want To Be Happy

Life should be fun, I know we can both agree on that!

What helps me:

- Time with my friends
- Fun hobbies like music, art, sport or gardening
- Helping others and being useful
- Going on safe, well-planned outings
- When I'm doing fun things, it helps take my mind off food
- _____
- _____
- _____

Being happy is very important to me.



Let's Learn Together

You don't need to be a perfect carer.

You just need to be kind, caring, patient and ready to learn about me and PWS.

What helps me:

- Ask me about PWS
- Talk to others who understand PWS
- Learn more about PWS
- Take time for yourself too
- Speak to PWSA UK
- _____
- _____
- _____

We all do better when we care for each other.



Final Words

Having PWS can be hard.

But I can still have a good life with support, care, and respect.

Please:

- Believe in me
- See the real me
- Help me grow in confidence
- _____
- _____
- _____

Let's work together to help me feel my best and proud of myself.



PWSA UK

The Prader-Willi Syndrome Association UK (PWSA UK) are here to help us.

You can find lots of information on their website.

They have Zoom meetings every month for adults with PWS and they also have fun events in the community. You can book these on their website.

They give training to professionals.
They can help with any questions you have.

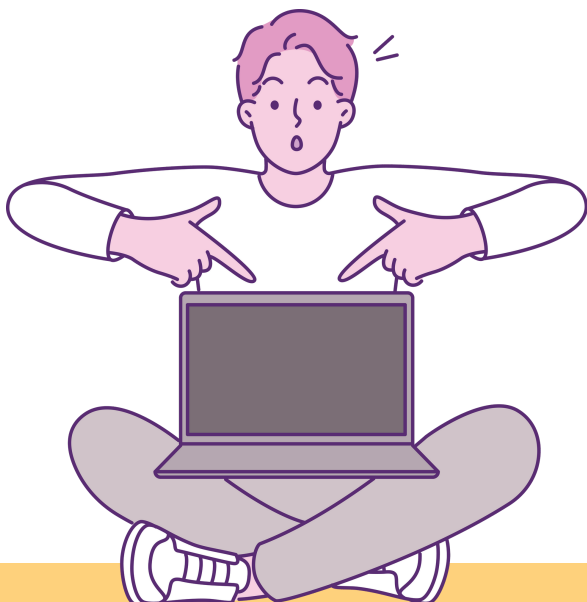
We all want the same thing - to help me live a happy, healthy life.

They are open: Monday - Thursday: 9:00 am - 5:00 pm
 Friday: 9:00 am - 1:00 pm

You can call
them on: 01332 365 676

You can email: admin@pwsa.co.uk or
 supportteam@pwsa.co.uk

The website is: www.pwsa.co.uk



Scan here to go
straight to the
PWSA UK website



Thank you

This booklet was made with help from Eve Metcalf, who has PWS, and the Owl Focus Group.

We want to say a big thank you to everyone who helped.

The Owl Focus Group is made up of 13 adults with PWS. It was started in 2016.

The group speaks up for people with PWS.

They are the voice of the PWS community.



Several members of the Owl Focus Group, pictured at a meeting