



WISE OWL FEATHERS

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The Newsletter for Adults with PWS

ISSUE NUMBER 34





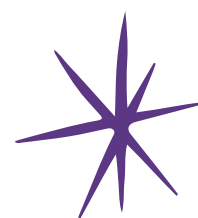
WELCOME

By Ruth, PWS Specialist Adviser

Hello everyone and welcome to this edition of our fab magazine full of stories about you and the things you like to do.

The big story this time is the Conference that the Owl Focus Group (OFG) organised for adults with PWS. You can read all about it over the next few pages and may be able to spot yourself or people you know in the photos.

They gave a presentation introducing themselves to everyone and then went around the room to ask people questions about 'Life with Prader-Willi Syndrome'. You can read all about this later in this magazine.



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MAKING IMPORTANT DECISIONS:

Why you should set up a Power of Attorney

As you probably know, Prader-Willi syndrome affects the way your brain works.

This can make it hard to make decisions when you're stressed, in pain or hungry.

PWS affects part of your brain called the hypothalamus.

In people with PWS, the hypothalamus does not work properly.

This means:

- We might feel more hungry than other people.
- We might not feel full after eating.
- Our bodies can become stressed more easily.

When you are stressed, in pain or hungry, the decision-making part of your brain doesn't work properly.

This can mean we make decisions that put us in danger or we regret later.



Because of this, it's important to have someone who you trust to help you make big decisions about things like your health and money.

Being able to make good decisions is sometimes called 'mental capacity'.



Once you are 18, it is a good idea to set up a 'Power of Attorney'.

An 'Attorney' means someone you trust to help you make decisions when you need it.

PWSA UK can help you set one up.

The 'Attorney' should be someone like your parent or a sibling who knows you really, really well and knows about PWS.

It is the Attorney's job to make sure other people keep you safe and help you live a happy life.

This means can they do things like:

- Help arrange appointments for you.
- Help explain to doctors and others about PWS.
- Make people understand what you like and don't like.
- Help you pay your bills.
- Protect you from people who are putting you in danger.



If you do not make a Power of Attorney, your parents (or your relative or friend) might not be allowed to do these things for you.

This could put you in danger and make your life difficult.

If you don't have a power of attorney, people like doctors, the police or social workers might not listen to your family or friends when making important decisions about you.

- Your parents (or the relative or friend you want to help you) might not be allowed to talk to your doctors, bank or home
- They won't be able to explain PWS to people who look after you
- They won't be able to arrange your health appointments
- They won't be able to arrange your health appointments
- They won't be able to help you manage your money
- They might not find out if someone is putting you in danger or harming you

Power of Attorney can seem complicated but Sarah or Ruth can help you understand it.

Call or message PWSA UK and we can explain how to set one up.

01332 365676 or supportteam@pwsa.co.uk

WISE OWL FEATHERS CONFERENCE



The Owl Focus Group members asked people with PWS some questions to find out how people feel about PWS. The answers will help PWSA to make sure people with PWS are supported well.

1. What helps you feel safe and settled?

Lots of people said they feel safe when they are around their key workers, family and friends.

People also said:

- Being with people you trust and having someone to talk to. Also having support from staff and good routines in place.
- Having a routine and fair rules around food. Some people said having food locked away helped them too.
- Having your own space.
- Pets, weighted blankets, hobbies and calming things.

1a. When you don't feel safe - what do you do that helps you?

- Go to a quiet space and keep busy.



- Talk to someone.
- Take time out.



2. What makes life hard for you right now?

- Mental health and PWS symptoms make life hard.
- Events like Easter and Christmas that include food and sweet treats. Also worrying about food rules being unfair. Some people said “being told they can't have things” and “worrying about portion sizes”.
- People not listening and people not understanding PWS.
- Changes to routines or planned activities and worrying what will happen if things go wrong.
- Loud or busy places.

2a. How do you cope with difficulties?

- Lots of people said “Keeping busy helps you cope”.
- Having some quiet time.
- Talking to someone or asking for help.
- Doing activities or going for a walk / getting some exercise.





3. What would make your life better in the future?

- Opportunities to travel, to work or to do volunteering. Some people wanted to work with animals or in childcare.
- Having my own pets or getting a therapy dog.
- More activities like trips to the cinema, doing Lego, jigsaws etc.
- Seeing more people I know including others with PWS and access to more PWS events, information and support.

4. What do you want staff and families to understand about you?

- Food is a big worry so don't offer food or ask about food.
- Don't ask "why are you upset"?
- Tell us about changes early.
- We need rest after activities.
- PWS is for life, it makes us feel sad and anxious sometimes.
- See us as people, not just PWS.



4a. How do you feel about your PWS?

- Good! We have a superpower – our fantastic memory!
- It's challenging. It can be hard when people stare.

What do you think about the answers people gave? If you weren't at the conference, we would love to hear what you think, too! You can let us know by emailing Ruth.rconsterdine@pwsa.co.uk.

In the afternoon everyone enjoyed taking part in a singing workshop with Jim from 'Misfits Music'. It involved clapping and stamping fast and slow as well as up in the air or on our knees! Some people came out to the front to take part and it was great fun!



Jackie, PWSA UK CEO said:

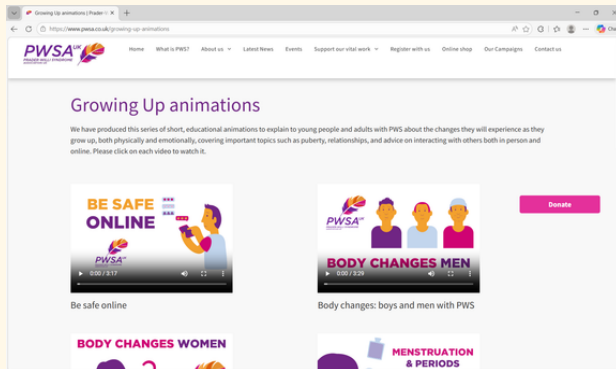
"I was truly delighted to attend the conference, so thoughtfully organised by adults with Prader-Willi syndrome. It was incredibly inspiring to see such empowered individuals coming together to showcase what is possible. The sense of warmth, kindness, and respect was remarkable, and it beautifully illustrated what can be achieved when individuals with PWS are given the opportunity to lead and shine."



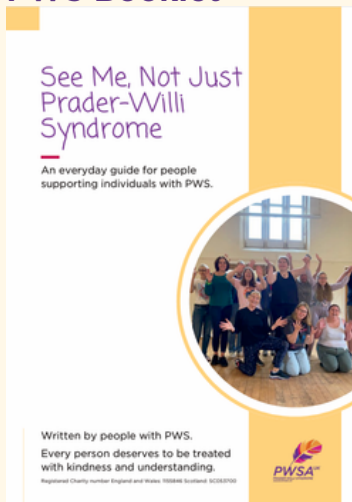
CELEBRATING 10 YEARS OF THE OWL FOCUS GROUP

At the conference we looked back at 10 years of the Owl Focus Group and some of the things they have achieved

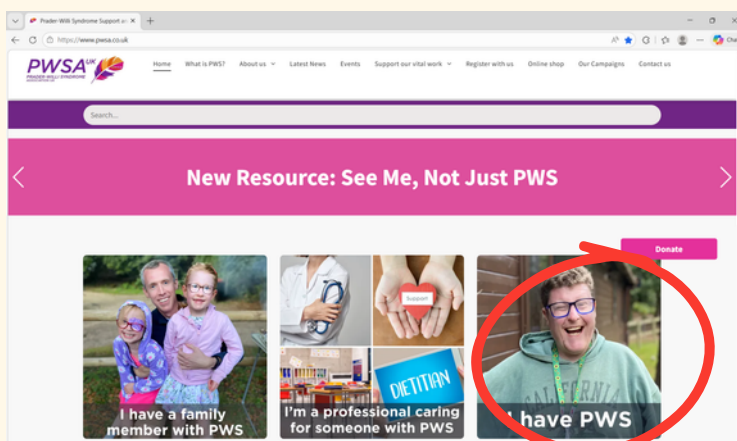
Growing up animations



See Me, Not Just PWS Booklet



Helped PWSA UK to develop a webpage for adults with PWS



Hidden Disabilities Sunflower Lanyard



Left to right: Caleb and Millie – (new members) Adam, (behind Millie) Lizzie, Charles, Ruth from PWSA UK, Kerry, Sam, Aaron and Aniel

We contributed to discussions on:

- Raising awareness of PWS.
- Employment/volunteering opportunities.
- Surveys for adults with PWS.
- Siblings Project.
- Portion Size booklet.

Members of the group have also:

- Spoken at conferences and forums.
- Provided feedback for a National Lottery bid.
- Attended team building days.

Thank you!

WHAT AM I?

Each question is a riddle. The clues describe something in a hidden way. Think about what the clues mean together. Write your answer on the line marked "a." Each riddle has one correct answer.

Q1. You'll find me in Mercury, Earth, Mars, Jupiter, Saturn and Uranus. But never Neptune, or Venus. What am I?



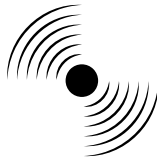
A: _____

Q2. I can be cracked, made, told and played. What am I?



A: _____

Q3. I cannot talk, but I always reply when spoken to. What am I?



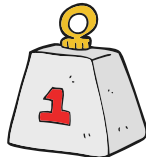
A: _____

Q4. I am easy to lift, but hard to throw. What am I?



A: _____

Q5. Forward, I am heavy; backward, I am not. What am I?



A: _____

Q6. I sometimes run, but I can't walk. What am I?



A: _____

Q7. What can you hold in your right hand, but never in your left hand?



A: _____

Q8. I am an odd number. Take away a letter and I become even. What number am I?



A: _____

Q9. I have a neck, but no head. I have two arms, but no hands. What am I?



A: _____

Winner!

Congratulations to the winner of last issue's quiz, **Joanne Gunn**
A prize is on its way to you!

Send your answers by 7th August 2026 to:
PWSA UK c/o Metcalf Commercial
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3 Deer Park Road, Moulton Park,
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