

How can you help?

PWSA UK has a volunteer group of adults with PWS called the Owl Focus Group. The main purpose of the group is to make sure that PWSA UK hears and understands the voices and experiences of people with PWS.

At our 2026 Owl Focus Conference, members of the Owl Focus Group asked people with PWS some questions to find out how they feel about living with PWS.

The answers will help PWSA UK, and the people who support those with PWS, to better understand their experiences and make sure that people with PWS receive the right support.

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.