

Serious Mental Health Concerns in PWS

A QUICK OVERVIEW



You know their normal.

Pay attention when something changes.

Mental health concerns in Prader-Willi syndrome may first show up as changes in everyday behavior. Look for differences from the person's usual patterns, or their baseline.



Eating

Less interest in food or eating less than usual



Sleep

Sleeping less, waking earlier, or napping more than usual



Behavior

More agitation, aggression, talking more, withdrawal, or less interest in activities



Personal Care

Less interest in showering, brushing teeth, dressing, or usual routines

Rule Out Medical Causes

Behavior changes can also be caused by physical illness.

Ask the healthcare provider to consider possible causes such as:

- Infection
- Medication side effects or reactions
- Sleep problems
- Other illness or physical discomfort

If changes are not explained by a medical issue and continue for more than 1–2 weeks, contact a healthcare provider for a mental health assessment.

Getting Help

Start with primary care or a mental health provider.

Share information about mental health concerns specific to PWS so the care team understands how PWS may affect treatment.

PWSA | USA Peer Consultation: Your child's doctor or therapist can call 941-312-0400 for guidance on PWS mental health concerns.

Starting Medication?

Start low. Go slow.

People with PWS may be especially sensitive to medications.

Before starting or changing a medication:

- Choose 2–3 specific behaviors to track
- Note whether those behaviors improve, worsen, or stay the same
- Ask how quickly the medication is expected to work and when you might expect to see changes

Special Considerations for Prader-Willi Syndrome

Genetic subtype can matter.

People with PWS due to maternal uniparental disomy (UPD) have a particularly high risk for psychiatric symptoms. People with the deletion subtype also have an elevated risk compared with the general population.

Stress and change can have a big impact.

Changes that may seem small, such as a new teacher or caregiver, a sibling moving out, or illness in the family, can trigger significant psychiatric symptoms.

Changes in self-talk are important.

Self-talk or imaginary friends can be common in PWS. A significant increase, or a shift toward frightening, threatening, or distressing content, should be discussed with a healthcare provider.

Going to the ER or hospital? Remember food security.

Hospital staff may not be familiar with the food-related needs of people with PWS. Make sure the care team understands the need for appropriate food access and food security.

What is Psychosis?

Psychosis can change how a person thinks, communicates, or experiences reality.

Watch for:

- New confusion or major changes in sleep, anxiety, or behavior
- Hearing or seeing things others don't, or unusual beliefs
- Speech that becomes confusing or hard to follow

Discuss significant changes from baseline with a healthcare provider.

Learn More

Find more information, tools, and resources about mental health and PWS at: fpwr.org/pwsmentalhealth

