

Prader-Willi syndrome (PWS) is a rare genetic disorder caused by the loss of function of specific genes on chromosome 15.¹ It is characterized by a constant feeling of hunger, which can lead to chronic overeating and obesity. Other symptoms can include poor muscle tone, poor growth and physical development, delayed motor development, and sleep disorders. Best managed by a team approach, various specialists can help manage symptoms of this complex disorder, reduce the risk of developing complications and improve the quality of life for those living with the condition.²

Formed in 1975, the Prader-Willi Syndrome Association | USA (PWSA | USA) unites parents, professionals, and concerned citizens to improve the lives of those with Prader-Willi syndrome. PWSA | USA supports the PWS community through shared experiences, research, education, advocacy, and assistance. As the only national PWS support organization, it has chapters in most states to help individuals with the syndrome and their families at every step.³

TREND Community is a community-powered digital analytics company that turns the conversations of rare and chronic disease communities into actionable insights, using our proprietary analytics engine, Krystie™.

DATA SOURCES

PWS Connect (Discord)		
DOCUMENTS:	AUTHORS:	TIME RANGE:
2,034	157	April 2024–Sept 2026

The dataset is drawn from conversations within PWS Connect, a private Discord community launched in April 2024. The community is made up primarily of caregivers of children and individuals living with PWS. At the time of this analysis, PWS Connect included 157 members and 2,034 posts and comments. In addition, 63 posts and comments were related to anxiety.

A portion of the Discord conversations were guided by topic-specific prompts exploring specific aspects of the PWS journey, which could influence topic prevalence.

How Caregivers Manage Anxiety

Caregivers discussed the strategies they use to help their loved ones manage anxiety and regulate strong emotions.

Approaches included: talking through situations, giving individuals time and space to calm down, preparing for upcoming events or changes, and using tools such as breathing exercises.

Many caregivers emphasized that finding what works often requires an individualized approach and learning when to step in versus when to give their loved one space to regulate.

“When anxiety or strong emotions take over, we give her space to settle down first, then talk through what happened once she’s calm.”

Anxiety Around Change and the Unknown

Caregivers frequently described uncertainty and changes in routine as triggers for anxiety in their loved ones. Transitions related to school, holidays, planned events, and changes in daily schedules were often associated with increased questioning or worry.

Providing advance notice, explaining what to expect, and being open about situations where the outcome is unknown were described as helpful ways to reduce anxiety and make transitions easier to manage.

“When she knows what to expect and how the day will unfold, transitions are much easier for her to manage.”

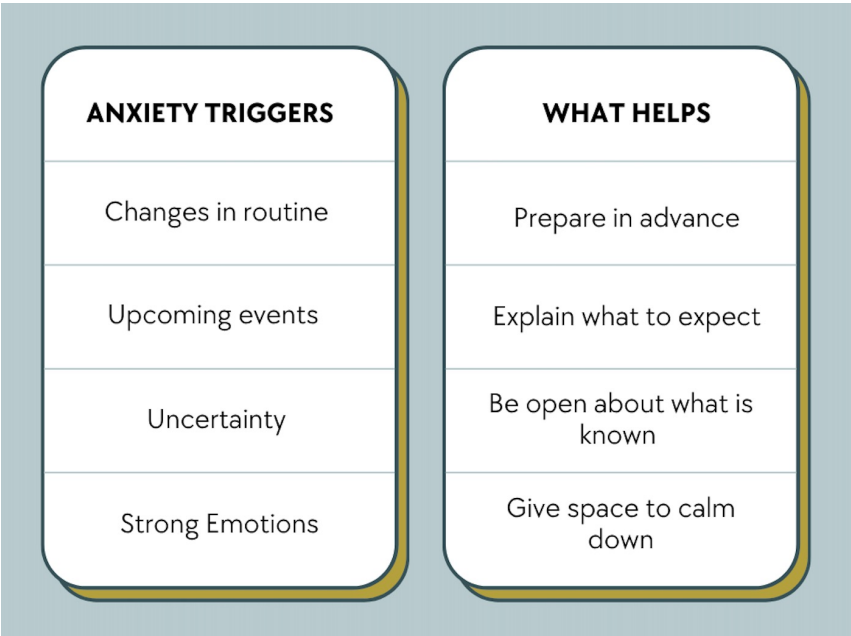


Figure 1. Anxiety Triggers and Management Strategies

¹U.S. Department of Health and Human Services. (n.d.-a). Prader-willl syndrome (PWS). Eunice Kennedy Shriver National Institute of Child Health and Human Development.

² Mayo Clinic: <https://www.mayoclinic.org/diseases-conditions/prader-willl-syndrome/symptoms-causes/svc-20355997>

³Prader-willl syndrome association USA - supporting families. USA. (2024, June 5). <https://www.pwsausa.org/>

What's TRENDing: Anxiety and PWS

How Medication Can Affect Anxiety

Caregivers frequently discussed changes in anxiety alongside medication use and dose adjustments. Experiences varied, with some families reporting improvements in anxiety and emotional regulation, while others described increased anxiety at higher doses or during medication changes.

Medications discussed in relation to anxiety, sleep, or emotional regulation included Vykat, pitolisant, methylphenidate/Concerta, clonidine, hydroxyzine, and melatonin. Caregivers often described closely watching for changes in mood, sleep, behavior, and anxiety after starting a medication or changing a dose and working with their care team to find the right balance for their loved one.

Caregiver Anxiety and The Emotional Challenges of PWS

Caregivers also discuss their own anxiety separately from the anxiety experienced by their loved ones. Common concerns include fear of the future, managing medical appointments and services, making decisions about food and treatment, feeling overwhelmed by responsibilities, and worrying about whether they are making the right choices. Peer support is repeatedly described as an important way of coping and reducing feelings of isolation.



Figure 2. Strategies Caregivers Use to Manage Anxiety

Note: The size of the words are not correlated to how frequently the word appears in the data set.

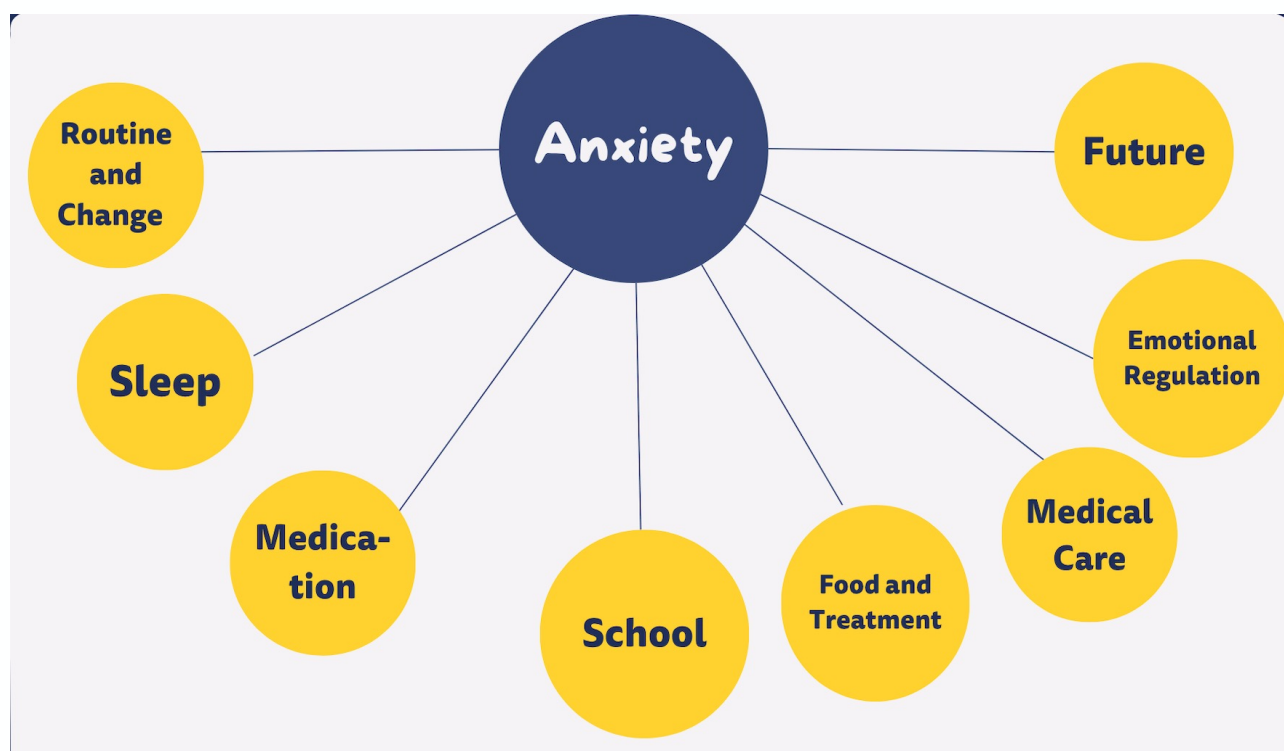


Figure 3. Anxiety Across the PWS Experience

CONCLUSION

Anxiety came up across many parts of the PWS experience, especially around uncertainty, changes in routine, and transitions. Caregivers shared that over time, they learn to recognize what anxiety looks like for their loved one and what helps in the moment. Common approaches included preparing for what to expect, talking things through, and giving space to calm down before revisiting a difficult situation. Anxiety was also discussed alongside medication changes, sleep, and other parts of PWS care, with caregivers paying close attention to how these changes may affect behavior and emotions. Caregivers also spoke about their own anxiety and the value of connecting with other families who understand the challenges of PWS.