

Anxiety and PWS

Most people with PWS experience increased anxiety and this is central to many of the behavioural challenges that can occur. Individuals may be extremely stress sensitive and stressful situations will greatly increase their anxiety symptoms. Their level of anxiety may also be raised by sensory processing impairments, deficits in intellectual and executive functioning and a reduced processing speed, which can all make understanding and interpreting their environment more difficult. People with PWS can be 'hyper-reactive' to their environments.

Anxiety can make individuals emotionally volatile. It can lead to obsessive or compulsive thoughts and behaviours, rigidity, stubbornness or loss of control. Understanding the underlying anxiety and stress sensitivity in PWS is crucial to preventing any unwanted behaviours. Escalating anxiety can make it very difficult for a person with PWS to regulate their emotions because this control is thought to be impaired by hormonal differences in the brain in PWS. Therefore, managing the environment in order to reduce stressors and minimise anxiety is essential.

How to control the environment to reduce anxiety

- Avoid **uncertainty** – reassure, use visual supports and schedules
- Avoid **confusion** – explain slowly, clearly and check understanding
- Avoid last minute **changes** – give advance warning
- Avoid **rushing** – allow extra processing and transition time
- Avoid **hyper responses** or **confrontations** – use a calm tone of voice
- Avoid **sensory overload** or **excessive challenge**

Signs of increasing anxiety and management tips

People with PWS have a high preference for routine and predictability and this need may become heightened when they are feeling more anxious. It's important to provide clear and consistent rules and routines, forewarn of changes, allow extra time for activity transition and check understanding about what is happening next and what is expected.

An increase in repetitive questions or movements is a sure sign that anxiety levels are raised. Questions should be answered specifically with clear, literal language. Provide reassurance, but once understanding is checked, limit their questions and redirect thoughts. Have strategies for coping with stress, calming activities and a 'safe zone' in place.

Stubbornness and oppositional responses can be a 'flight or fight' response as a result of anxiety. Sometimes a refusal to comply is a coping device when their reasoning for non-compliance cannot be explained, perhaps even to themselves. Provide preferential choices to allow a sense of control and allow extra processing time. Do not 'give in' to demands, but offer empathy, remain calm, avoid negative reactions and find a solution together.

Remember the 4C's - Be **Calm**, **Consistent** and **Clear** – and avoid **Confrontation**

Reducing food related anxiety

The abnormal appetite and preoccupation with food in PWS can consume thoughts and raise anxiety. A method called 'Food Security', developed by The Pittsburgh Partnership, not only controls weight by preventing unauthorised access to food, but also reduces the associated anxiety and related behaviours. False expectations are not raised and thoughts of food are locked away, freeing the person with PWS to relax and think about other things.

Food Security: **No Doubt** (predictable food routine) + **No Hope** (of obtaining unauthorised foods and unplanned extras) = **No Disappointment** (and decreased anxiety)

N.B. Anxiety can often be reduced or avoided, but when anxiety problems become severe, expert behavioural support or medications may be required. If you have concerns, do not delay seeking professional advice.

