

Introduction

Prader-Willi Syndrome is a rare genetic and lifelong disorder characterised by insatiable hunger (Hyperphagia), leading to obesity, along with developmental and behavioural challenges. PWS is diagnosed using both clinical evaluations and genetic tests. Traditionally, diagnosis was based on traits like feeding challenges, delayed development, excessive appetite, and obesity. However, early genetic confirmation is preferred as symptoms can change with age and may be like those seen in other neurodevelopmental disorders (Butler et al., 2019).

DNA analysis of chromosome 15 is currently regarded as the go to diagnostic method, with a reported detection rate above 99% (GeneReviews, 2025). PWS is not inherited but occurs due to random genetic changes during the formation of the egg or sperm. However, DNA testing alone does not determine genetic subtypes, thus, requiring additional assessments or chromosome analysis to establish the specific cause of the syndrome (Beygo et al., 2019).

Current diagnostic routes stand out in supporting early detection, which establishes nutritional management, hormone treatments, and developmental help. However, there are still issues that clinicians may miss, specifically in infants whose symptoms can be unclear, leading to delays and fewer outcomes over time. Additionally, the accessibility of improved molecular tests varies across countries, causing unequal access and diagnostic truth. While moving from symptom-based diagnosis to molecular methods has encouraged reliability, problems with accessibility and early identification still occurs (NHS,2017).

Conclusion

PWS is a lifelong condition and is often misunderstood by society, leading to stigma and exclusion from socialising with other children. Because of this children with PWS are rarely seen outside of education settings or afterschool clubs where their condition is managed and routines are in place.

PWS is sometimes misdiagnosed for other additional learning needs, such as Autism or ADHD due to the behaviours of concern and other characteristics displayed by the children, sometimes children with PWS are non-verbal, self injurious., as well as injurious behaviours towards others.

When routine and plans are in place, such as timers and visual timelines, PWS can often be managed, albeit time consuming and patience from experienced staff. No child should be excluded ,and society needs to adjust for children with all additional learning needs. Making the world inclusive and accessible to everyone.

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PRADER-WILLI SYNDROME (PWS)

Strategies

A helpful way to support children with Prader-Willi syndrome (PWS) is through planned environmental and behavioural management that keeps hyperphagia under control and encourages routine. Because of hypothalamic dysfunction, children with PWS have trouble feeling full and may become fixated on seeking food, so it is important to manage their environment for both their physical health and emotional wellbeing and replace growth and other hormone deficiencies (Butler et al., 2019). Positive behavioural management means sticking to regular mealtimes, supervising access to food, and maintaining predictable daily routines—all done together by caregivers, schools, and healthcare professionals.

Structured environments help children with PWS manage anxiety and behaviour, as predictability aids regulation and eases conflict from food constraints (Rice et al., 2016). Strategies include locking food storage, using visual timetables, preparing for routine changes, and setting clear expectations. Positive reinforcement is crucial; punishing actions can aggravate distress and oppositional behaviours. Individualised plans in educational settings support cognitive, emotional, and social needs, and the effects of clinical trials of oxytocin (Kuppens, Donze and Hokken-Koelega, 2016).

The inclusive approach of this strategy contributes to its overall effectiveness. In addition to alleviating obesity risk, structured behavioural management enhances social functioning, academic participation, and family relationships. However, continuing with strict routines may pose difficulties for families, as continuous supervision can be emotionally taxing and may restrict flexibility in daily activities at home. Despite these challenges, research shows that early multidisciplinary intervention—including behavioural psychology, nutritional guidance, and family education— improves long-term outcomes for children with Prader-Willi syndrome (Lionti et al., 2022). As such, structured environmental and behavioural support continues to serve provide safety for children with PWS, with evidence-based methods for addressing the complex needs associated with Prader-Willi syndrome.



Barriers

Hyperphagia, a persistent and abnormal urge to eat stemming from hypothalamic dysfunction, it is a major challenge faced by children with (PWS). This condition usually rises in early childhood, resulting in significant physical, psychological, and social difficulties. Unlike ordinary overeating, children with PWS struggle with impaired indulgence, rarely feeling full and often seeking food continuously (Butler et al., 2019). Such challenges can innocently hinder daily life and general well-being., thus linking to the medical model of disability (Guevera, 2021).

The effects on these children are wide-ranging. Physically, unrestrained eating raises the likelihood of obesity, type 2 diabetes cardiovascular issues, and limited mobility. Studies indicate that difficulties related to obesity remain a leading cause of health problems among people with PWS (Lionti et al., 2022). On a psychological level, ongoing constraints and control around food may lead to anxiety, frustration, and behavioural outbursts. Children might fixate on food, resort to stealing it, or feel emotional confusion if routines change. These behaviours can disrupt learning and friendships, possibly causing social isolation and stigma, which links into the social model of disability (Shape Arts, 2024).

Additionally, hyperphagia imposes demands on families and caregivers, requiring the implementation of strict environmental controls such as secured kitchens and well-organised meal schedules. Although these measures are essential for ensuring safety, they can restrict the child's independence and participation in social contexts. Despite the effectiveness of multidisciplinary approaches, including nutritional management, behavioural interventions (Wieting et al., 2024), and growth hormone therapy in moderating complications, hyperphagia persists as a enduring challenge that requires continuous monitoring. Therefore, hyperphagia has a substantial effect on both the physical health and psychosocial wellbeing of children affected by Prader-Willi Syndrome (PWS).

