

Understanding Prader-Willi Syndrome (PWS): A Guide for Employers UK Wide

Introduction

Creating an inclusive workplace starts with understanding, structure, and appropriate support.

This leaflet provides practical guidance for employers supporting individuals with Prader-Willi syndrome (PWS) in employment settings across the UK.

With the right adjustments, individuals with PWS can be reliable, consistent, and valued employees.

Strengths in the Workplace

Many individuals with PWS thrive in structured environments. Common strengths include:

- Strong attention to routine, structure, and detail
- Reliability and loyalty
- High task persistence and completion rates
- Preference for repetitive or clearly defined roles
- Good performance with visual structure and predictable systems
- Strong adherence to clear rules and expectations

What is Prader-Willi Syndrome?

Prader-Willi syndrome is a rare, lifelong genetic condition affecting development, behaviour, metabolism, and physical health. It occurs in approximately 1 in 15,000 people.

Key features may include:

- Chronic feelings of hunger (hyperphagia), requiring strict food access management
- Risk of severe obesity without environmental controls
- Mild to moderate learning disability
- Low muscle tone (hypotonia)
- Anxiety, rigidity, and repetitive behaviours
- Social and emotional immaturity

Reasonable Adjustments in the Workplace

Under UK law, employers must make reasonable adjustments where a disability has a substantial and long-term impact on daily functioning.

Legal Framework (UK-wide)

England, Scotland & Wales

Employers must comply with the Equality Act 2010.

This requires:

- Protection from disability discrimination
- A duty to make reasonable adjustments
- Equal access to employment, training, and progression

Northern Ireland

Employers must comply with the Disability Discrimination Act 1995.

This provides equivalent protections, including:

- Protection from disability discrimination
- A duty to make reasonable adjustments
- Fair access to employment opportunities

Key Workplace Adjustments for PWS

1. Structured Working Environment

- Provide clear, predictable routines
- Use written, visual, or step-by-step instructions
- Break tasks into manageable steps
- Check understanding regularly
- Avoid sudden or unplanned changes

2. Food Safety and Environmental Control (Critical)

Food security is a central consideration in PWS.

Employers should:

- Maintain a strictly controlled food environment
- Prevent unsupervised access to food, kitchens, vending machines, or shared food areas
- Ensure consistent application of food-related workplace rules
- Plan ahead for meetings or events involving food
- Ensure all staff are aware of agreed food safety measures

3. Behavioural and Emotional Support

- Use calm, consistent, and non-confrontational communication
- Provide advance notice of changes wherever possible
- Allow time to process instructions and transitions
- Be aware that anxiety may present as rigidity or distress
- Offer access to a job coach or workplace mentor if appropriate

4. Physical and Environmental Adjustments

- Allow regular breaks where needed
- Consider fatigue and physical stamina
- Provide predictable shift patterns
- Offer low-stimulation environments where possible

Positive Communication Strategies

- Use consistent language and instructions
- Avoid unexpected changes where possible
- Recognise effort as well as achievement
- Use clear, structured feedback
- Respond to distress calmly and predictably

What Employers Should Avoid

- Assuming capability based on diagnosis alone
- Using food as a reward or incentive
- Making unplanned or unexplained changes
- Ignoring agreed support plans or reasonable adjustments

Support and Further Information

- Pader-Willi Syndrome Association UK | pwsa.co.uk
- Foundation for Pader-Willi Research UK | fpwr.org.uk
- GOV.UK: Guidance on employing disabled people