

The Prader-Willi Syndrome Association UK (PWSA UK)

Care Provider Charter

(Aligned to CQC or other regulator for health and social care Inspection Domains: Safe, Effective, Caring, *Responsive*, *Well-led*)

UK care regulations and standards have evolved significantly over the past 40 years. During this time, providers supporting individuals with Prader-Willi Syndrome (PWS) have had to adapt continually to remain compliant. However, regulatory inspections may not always fully recognise the complexity of supporting individuals or groups of adults with a rare and lifelong condition such as PWS, nor how this complexity can impact regulatory compliance.

As a community, our understanding of PWS has never been stronger. Nevertheless, PWSA UK believes further progress is essential. Care and support must continue to improve as knowledge advances and as the UK PWS population grows and ages.

In December 2025, PWSA UK finalised the Charter of Minimum Standards for Care Providers Supporting Individuals with PWS. The Charter has been informed by sector insight and reflects operational realities across UK services. It has been designed to be practical, credible and directly relevant to all providers supporting people with PWS, regardless of previous involvement in its development.

PWSA will maintain a list of providers who sign and commit to this charter. This list will be publicly available and distributed upon request, to enable family members and professionals to make informed choices about PWS care providers.

Participation and commitment to the charter is voluntary. PWSA UK will review the charter annually to ensure it remains current, relevant and fit for purpose.

Background and Rationale

The UK residential care provider market has supported adults with PWS for several decades. PWSA UK is currently aware of almost 70 services, both dedicated and non-dedicated, supporting adults with PWS across the UK. Since its establishment in 1982, PWSA UK has worked closely with providers and recognises the critical role they play in improving quality of life, health outcomes and life expectancy for people with PWS.

This charter sets out the minimum standards that providers commit to in order to deliver safe, effective, compassionate and person-centred care. By signing the charter, providers confirm their commitment to upholding these standards and promoting the dignity, wellbeing and quality of life of individuals with PWS. Parents, families and commissioners may consider charter signatory status as part of placement and commissioning decisions.

Charter Standards

1. Specialised Knowledge and Training

(CQC: Effective / Safe / Well-led)

Care providers will evidence that they:

- Deliver PWS-specific training at least annually, covering hyperphagia, behavioural presentation, and associated medical risks.
- Maintain awareness of emerging research and best practice in PWS care.
- Ensure all staff can recognise and respond appropriately to PWS-related medical emergencies, including gastrointestinal and respiratory risks.

2. Individualised Support Planning

(CQC: Responsive / Caring / Effective)

Care providers will evidence that they:

- Develop and implement personalised support plans addressing physical, emotional, nutritional, behavioural and social needs.
- Actively involve individuals, families and relevant professionals in care planning.
- Review and update support plans, including behavioural support plans, at least annually or more frequently as needs change.

3. Nutritional Management and Food Security

(CQC: Safe / Effective / Responsive)

Care providers will evidence that they:

- Implement robust food security systems to prevent overconsumption while promoting balanced nutrition aligned to individual capacity and health needs.
- Reinforce consistent food security practices through induction, daily supervision and ongoing staff training.
- Work collaboratively with dietitians or other professionals where available.
- Provide clear education and written guidance for staff, individuals and families on maintaining safe food environments, including during home visits and holidays.

4. Behavioural Support

(CQC: Safe / Caring / Effective)

Care providers will evidence that they:

- Use positive, proactive behavioural approaches to support anxiety, rigidity and compulsive behaviours, ideally with input from qualified behavioural practitioners.
- Provide access, where available, to mental health professionals with experience of PWS.
- Maintain behavioural support plans that prioritise de-escalation, consistency and reinforcement of positive behaviour.
- Keep accurate behavioural records and use these to inform practice and outcomes.
- Ensure timely access to specialist behavioural support within the service wherever possible.

5. Health Monitoring

(CQC: Safe / Effective)

Care providers will evidence that they:

- Monitor common PWS-related health risks, including obesity, sleep apnoea, scoliosis and endocrine conditions.
- Distinguish between health needs managed in-house and those requiring NHS or specialist input.
- Arrange regular health reviews with GPs or specialists familiar with PWS.
- Ensure prompt access to medical care when required.

6. Emotional and Social Wellbeing

(CQC: Caring / Responsive)

Care providers will evidence that they:

- Promote emotionally supportive environments that encourage positive relationships and social engagement.
- Enable participation in meaningful activities that support confidence, independence and personal development.
- Facilitate appropriate community involvement aligned to individual interests and abilities.

7. Advocacy and Rights

(CQC: Caring / Well-led / Responsive)

Care providers will evidence that they:

- Respect individual dignity, privacy and autonomy.
- Actively promote and advocate for access to education, employment and meaningful opportunities.
- Support individuals to understand their rights and participate in decision-making wherever possible.
- Engage independent advocacy services where appropriate and available.

8. Family and Community Partnership

(CQC: Responsive / Well-led / Caring)

Care providers will evidence that they:

- Maintain open, honest and consistent communication with families and carers.
- Provide families with education, resources and emotional support relating to PWS.
- Work collaboratively with local services and voluntary sector partners to enhance outcomes.

9. Safeguarding

(CQC: Safe / Well-led)

Care providers will evidence that they:

- Implement clear and robust safeguarding policies.
- Train staff to recognise, respond to and report safeguarding concerns.
- Complete appropriate pre-employment checks for all staff.

10. Commitment to Continuous Improvement

(CQC: Well-led / Effective)

Care providers will evidence that they:

- Use feedback from individuals, families and professionals to improve services.
- Participate in audits, reviews and quality assurance activity related to PWS care.
- Promote a culture of learning, accountability and transparency.
- Ensure information gathered by senior leadership — including from individuals with PWS, families, commissioners and PWSA UK — is shared promptly with frontline staff to support consistency of practice.

Declaration and Signatory Commitment

By signing this charter, the organisation confirms its commitment to meeting and upholding the **PWSA UK Charter of Minimum Standards for Care Providers Supporting Individuals with PWS.**

The organisation recognises that supporting individuals with PWS requires specialist knowledge, consistent practice, and a person-centred approach that prioritises safety, dignity, wellbeing and quality of life. The organisation further commits to working in partnership with individuals, families, commissioners and PWSA UK to support continuous improvement in the quality of care provided.

The organisation acknowledges that this charter complements, but does not replace, statutory and regulatory responsibilities and standards set by relevant UK regulatory bodies.

Signatory Details

Organisation Name:

Name of Authorised Signatory:

Job Title:

Signature:

Date:

Review and Transparency

The organisation understands that PWSA UK will review this charter annually. Signatory status will be published by PWSA UK, to promote transparency and shared learning across the PWS provider community.

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