

Initial Checklist Assessment

- Conducted by a nurse, social worker, or other professional.
- Assesses twelve areas (domains)
- Scores need A=High B=Moderate C=Low /none
- To move to full assessment one of these must apply:
 - Two or more As
 - Five or more Bs
 - One A and four Bs

How PWS may affect CHC domains

- Breathing: sleep apnoea, daytime fatigue, choking, poor respiratory effects.
- Nutrition: Hyperphagia (constant need for food security), risk of life-threatening overeating, inability to self-regulate, need for low calorie monitored diet.
- Skin: Skin picking, risk of infections, need for monitoring and treatment.
- Behaviour: meltdowns, aggression, self-harm, food seeking, supervision and redirection required, hoarding, violence
- Cognition: Learning disability, lack of risk awareness, rigidity of thought
- Psychological and emotional needs: anxiety around food and routines, obsessive behaviours, emotional dysregulation, frequency, and intensity of outburst.
- Communication: Limited verbal skills, difficulty expressing needs, difficulty processing information.
- Mobility: Poor muscle tone, fatigue, need for walking aids, risk of falls, scoliosis
- Continence: constipation, toileting support, accidents, supervision for hygiene.
- Drug therapies and medication: GH treatment, laxatives, psychiatric/behavioural medication, supervision with meds, testosterone/estrogen
- Altered states of consciousness: seizures, fainting, collapses, extreme fatigue.
- Other significant care needs: constant supervision around food and safety, vulnerable adult, frequent hospital clinic appointments family carer strain.

ICB Decision

- The Integrated Care Board (ICB) makes the final decision, usually within 28 days.
- If refused, you have the right to appeal.

If you are refused CHC

- The ICB must give written reason.
- You can appeal – this may take time.
- Look for social care funding.

Tips for Parents

- Keep a diary of care needs and behaviours.
- Record all appointments, who you speak to and when.
- Ask to be fully involved in assessments.
- Be clear, it is about need not just diagnosis.
- Get support from PWSA UK.

For support, please contact PWSA UK on 01332 365676 or email supportteam@pwsa.co.uk