**Pupil Profile:** INSERTNAME

Insert photo

**Diagnosis:** Prader-Willi Syndrome

**Overview of PWS**

PWS is a genetic disorder caused by a segment of genes on chromosome 15

either being deleted or unexpressed. The main characteristics are:

* **low muscle tone**
* **poor motor skills** (symptoms of dyspraxia)
* **excessive sleepiness or easily becoming fatigued**
* **a preoccupation with food and impaired satiety signalling**
* **incomplete puberty and infertility**
* **specific learning disabilities usually coupled with mild intellectual disability (**although some pupils score in the borderline to low average range in cognitive testing, whereas others score in the moderate intellectual disability range)
* **speech delay with ongoing difficulties in expressive speech often occurring** (apraxia)
* **behavioural difficulties linked to anxiety, rigidity in thinking, sensory processing and emotional control** (many similarities to characteristics of ASD - strategies that work well for ASD, usually work well for PWS)
* **impaired social skills** (reading social situations, seeing other perspectives, conversational skills)

**Health and Safety Alerts**

**There is a risk that individuals with PWS may quickly eat a dangerous amount of food if unsupervised access**

**to food is gained. This could result in choking, life-threatening stomach necrosis or rupture.**

Pupils with PWS need to maintain a diet of significantly reduced food intake due to the altered body composition causing reduced energy expenditure. Please **do not allow others to share food with them** and consult with parents about activities involving food. **Food seeking can occur so prevention and monitoring are required.**

**Minor pain, vomiting or a slight temperature may indicate a medical emergency and require evaluation.**

**Poor impulse control in PWS may result in unsafe behaviour, such as leaving the school grounds.**

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| **INSERT NAME’s LEARNING STRENGTHS**  **Visual learning** – make use of visual aids.  **I.T.** – use computers and assistive technology.  **Long term memory** – excellent recall, especially of visual information.  **Reading accuracy. Spelling.**  **Non-narrative writing** when using writing frames / graphic organisers and language banks.  **Friendly** – values relationships, but needs support with social skills and to connect with peers.  **INSERT NAME’s LEARNING WEAKNESSES**  **Auditory processing** – allow an additional 3 to 5 seconds for processing verbal information, use clear, literal language and check understanding.  **Poor short term memory -** lots of repetition to transfer learning from short term to long term.  **Poor auditory memory –** avoidlengthy instructions.  **Poor working memory** – break down tasks, use organisational aids, provide notes to highlight etc.  **Reading comprehension.**  **Creative writing** – better when using personal experience and idea webs / supports.  **Difficulty with abstract concepts** – use concrete examples, systematic steps, hands-on maths aids.  **Poor motor skills** **& stamina** – adapt P.E. (exercise vital to build strength) and some handwriting / typing tasks.  **Expressive speech** – extra time for class speaking, slowly model correct pronunciation of new words, support peer discussion (auditory processing & working memory also affecting conversational skills.) | **BEHAVIOUR MANAGEMENT TIPS FOR INSERT NAME**  **Group work can prove difficult** – provide cues and guidance to encourage appropriate peer interactions.  **Easily fatigued and distracted** – provide activity level changes and breaks, consider positioning in class, homework appropriateness.  **High anxiety levels** – allow achievement in small steps, ensure tasks are not too hard, clear expectations, routines and predictability are reassuring – avoid sudden changes.  **Difficulty with switching task or topic** (obsessive thinking and/or anxiety means they can become ‘stuck’ on a topic or task) – use visual cues / countdowns/ schedules, shorten tasks, use preferential activity incentives, set question or time limits for talking, answer questions specifically, avoiding ambiguity and grey areas, bring topic to a resolution.  **Tenuous emotional control** – anxiety levels become raised with confusion, frustration, unexpected changes or sensory issues. Minimise disappointments. Watch for triggers and signs to prevent ‘meltdown’. INSERT NAME’s triggers are .............. INSERT NAME’s signs are ........................ Acknowledge feelings, encourage use of coping strategies, allow processing or calm down time. Reflect afterwards.  **Non-compliance** (origin in anxiety & thoughts becoming ‘stuck’, or rigidity: once an idea exists it’s difficult to change) – allow time to change thoughts, empathise, give choices, ignore escalation, avoid confrontation, create consistency.  **Skin picking / repetitive behaviours –** use distraction and redirection, keep engaged / busy, avoid giving attention to it. |