



ATTENTION EMERGENCY SERVICES

Understanding Prader-Willi Syndrome (PWS) and how you can support me

PWS is a disability that has many complex medical, behavioural and emotional characteristics. Your role is critical in supporting me and helping to manage my emotions and behaviours so there is minimal harm to myself and others.

PHOTO

I have Prader-Willi Syndrome.

Name _____

I have an intellectual disability with associated learning difficulties.

I need your help to explain clearly what is happening, why you are involved and what is likely to happen next.

If I do not have a support person present, could you contact my nominated support person as I am too upset.

Emergency Contact Details:

Person 1

Name _____

Address _____

Phone _____

Relationship to person _____

Person 2

Name _____

Address _____

Phone _____

Relationship to person _____



Check for any emerging medical or mental health issues.

Often changes in behaviour are the first sign of unresolved pain, illness, or emerging mental health issues. ***“I am unable to accurately monitor my health and wellbeing due to my disability. If my behaviour is extreme and out of the ordinary, please check if I need medical treatment as this may be a sign my mental health is deteriorating.”*** Confabulation or fantasizing may also be present and may be an indication of a developing or escalating mental illness, such as psychosis or severe depression.



Talk to my support person.

Ask my parents or support person/carer about behaviour management and strategies likely to achieve maximum cooperation. ***“Please talk to my support person about what is the best approach to take.”***



Speak calmly and confidently.

A calm discussion about the situation is encouraged. ***“I can think better if those around me talk to me in a calm, confident tone. Raised voices, threats or accusations can cause me to become defensive, anxious, argumentative, and possibly aggressive.”***



Reduce the potential availability of food as this increases stress levels.

“I can think better if the interview/hospital room is away from any canteen or kitchen area as I find it difficult to concentrate on the questions if I am around food areas. Please do not offer extra food or soft drinks as I am on a strict low-calorie diet.” For people with PWS food, or the lack of it, and the associated anxiety may influence how they respond or behave. Food might also be an inducement to say and do things that are unhelpful or may not be correct. The drive to eat is so strong in people with PWS, that food offered to a person with PWS while in custody at a police station or in prison, may become an incentive to “re-offend”.



Offer reassurance.

The person will be frightened by the situation despite outward bravado. ***“When I am in an unfamiliar place such as the police station, I get very anxious and sometimes I can be uncooperative and argumentative. Please talk to my support person about what is the best approach to take.”***



Speak in easy English. Short sentences and words are best.

“I often have difficulty understanding questions and instructions. Just because you have given an instruction or asked a question do not assume I have understood. Please always check that I have understood what you have told me.” People with intellectual disabilities, including people with PWS, may not understand formal warnings or cautions and may implicate themselves. People with PWS have been known to confess to things they did not do, perhaps because of the stress at the time or because they didn't understand what was happening or what was being asked of them.



Confirm the important points.

Confirm the important points with the parents/carer/support worker. ***“Take into consideration that I want to please and often I will tell you what I think you want to hear. This may not be what actually happened.”***



Don't take everything the person says at face value.

“Sometimes I have trouble telling fact from fantasy.” Check the facts with a third person. People with PWS often create stories as a means of achieving something they want or believe to be correct. This is termed confabulation. The stories can become reality to them. Sometimes the verbalisation of, or acting upon these stories, may incriminate or harm themselves or other people. ‘Confabulation’, as seen in people with PWS, is defined as a memory disturbance in which a person confuses imagined thoughts and events with actual memories or reality. There is no intent to deceive, as the person believes it is true or real.