

Useful information for law enforcement agencies

The purpose of this document is to enable law enforcement agencies to widen their understanding of Prader-Willi Syndrome, whilst protecting members of the public and themselves.

This includes police officers, bailiffs, HMRC officials, security guards and store detectives. Because of the unique behavioural and emotional characteristics related to this rare syndrome, it is important that you read the following information in order to better understand the situation that you have encountered. It is our aim to provide information to assist you in your role, and provide strategies to help manage situations. Those with the syndrome are vulnerable adults, and should be treated as such, as mentioned in The Policing Vision 2025.

What do you need to know?

PWS is a rare, genetic disorder that causes the brain to function in a way that is not typical of other people. This brain dysfunction can cause problems that may lead to the involvement of law enforcement agencies.

The brain of a person with PWS does not receive a message of being full after eating, regardless of the amount of food eaten. As a result, individuals are left with an intense and overwhelming drive to eat and cannot control themselves around food. It is impossible for a person with PWS to always avoid situations where they may have the opportunity to “steal” or take food, and therefore theft of food can occur. Money or other goods may also be taken with the purpose of buying or bartering for food.

The same part of the brain that regulates appetite (the hypothalamus) also regulates temper and emotional response. As a result, it is quite common for a person with PWS to experience significant meltdowns and behavioural outbursts, both of which are a feature of PWS.

Food theft and behavioural outbursts, whilst actively discouraged by parents and carers, should be treated as a manifestation of the person’s disability rather than a criminal act.

It is important to remember that people with PWS are most often very caring and kind, and with the help of their parents and carers, are positive and helpful members of their community. Occasionally, however, due to their disability they will experience behavioural problems such as we’ve described.

How can you help?

While each person with PWS is unique, the following may help to create a more successful response to a person with PWS who is in need of assistance:

- If the person is with a carer, ask the person with PWS if it is ok for the parent/carer to speak on their behalf.
- If not, insist a carer or parent is present before you speak to them and maintain contact with the parent or carer.
- Utilise vulnerable adult training, and inform carer/individual that you are doing so.
- Those with PWS lack mental capacity around food and are on strict calorie intake for health reasons – avoid high calorie meals while they are in your custody. This

could be seen as a “reward” and an inducement to reoffend in order to gain more food.

- Improper physical restraint is dangerous and can lead to positional asphyxia from diaphragm restriction. The high pain threshold present in those with PWS may mask them being in pain, and may affect how they react to a taser. Those with PWS will also bruise easily and this must be taken into account.
- Many people with PWS will have autistic traits – it is preferable to avoid eye contact, and be aware of sensory overload. Announcing what you are about to do and speaking loudly may escalate behaviours.
- Work with the parents and/or carers to develop positive behavioural solutions to avoid repeat incidents
- Those with PWS may destruct property when upset, abscond for no apparent reason and call 999 if upset with their parents or carer. This may include accusations of abuse or mistreatment, and it is important to investigate this – even if it is obvious it hasn’t occurred.
- Some people with PWS may skin pick or self harm, and it is not unusual to see scars and sores at various stages of healing. It is important to be aware of this when investigating potential abuse involving a person with PWS. This behaviour can be more prominent during times of anxiety, and the individual should be monitored closely to ensure it doesn’t happen whilst in your care.

All people with PWS are individuals. For further information about any person with PWS with whom you are dealing, please contact:

Name:

Role:

Organisation:

Contact Number: