**Law Enforcement Matters**

**Regarding People with Prader-Willi Syndrome**

Prader-Willi syndrome(PWS) is a complex, multi-stage genetic disorder that impacts the thinking, understanding, satiety, sensation and behaviour of affected children and adults. Most commonly it is identified by an uncontrollable drive to eat and the inability to perceive fulIness or satisfaction with the amount of food or beverages consumed. In people with PWS the hypothalamus of the brain, which regulates hormones, does not work as efficiently as it should.

*There may be times when law enforcement agencies become invovled in their life, usally due to disruptive or violent behaviour, either at home or in public.This guideline is to assit law enforcement personnel in their knowledge of PWS.*

People with PWS can display the following behaviours as a direct result of how the brain works in PWS, not because they are wilful or have criminal tendencies.

1. *Stealing food or other consumables and/or money (as a way to access consumables)*

People with PWS demonstrate an insatiable drive for food, beverages and cigarettes, if they are smokers. They constantly seek more of anything that is a consumable. This can include, fresh, scrap, frozen and rancid food, which may result in food poisoning, diarrhoea or stomach upset.

It is the responsibility of their caregivers to provide a “safe” environment that prevents access to food, beverages, money or cigarettes, that are not planned for the person but this is not always achieved.

Once food, money or a saleable item is taken, it may be very difficult to remove it from the person with PWS. Proving they have stolen something may be equally difficult to prove and accusing them of the theft will usually result in denial.

Calm, matter-of-fact discussion about the situation is encouraged. Raised voices, threats or accusations will usually cause the person with PWS to become defensive, anxious, argumentative and possibly aggressive.

1. *Verbal or physical behavioural outbursts*

If a person with PWS perceives an injustice to himself/herself, does not understand what is being repeatedly asked or told to him/her, or feels he/she is not being given a choice, behaviour may escalate to a point of temper outburst or tantrum. People with PWS have poor reasoning skills, they are not good at solving problems nor are they competent in comprehension or expression of thoughts, words, or feelings.

Physical damage can be caused by a person with PWS who is experiencing a temper tantrum or when they are attempting to access food, which they are being denied.

They are anxiously trying to satisfy the constant drive to consume. If an outburst escalates to a point of extreme distress, then the person is best left to work their way through the outburst, while their safety and the safety of those around them, takes precedence. At such a point the person with PWS is usually deemed to have diminished mental responsibility and cannot be reasoned with or consoled.

Absconding from a situation is common and at such times people with PWS can be at risk of accidental or deliberate harm. They may be running away from “being in trouble”, “being cornered” or in the pursuit of consumables. Chasing or calling out to a person at this time will only accelerate their anxiety and fleeing, placing them at greater risk of injury or accident.

1. *Confabulating stories and incriminating others*

People with PWS often create stories as a means to achieve something they want or believe to be correct. The stories can become reality to them and 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. This can include believing they have been abused, loved, invited, partnered, are in danger or are meant to be somewhere else. It is essential to investigate any stories you believe may be inaccurate, any proposed actions and any accusations made about others, before acting on what a person with PWS reports, especially if it may have serious consequences.

Confabulation may also be an indication of a developing or escalating mental illness, such as psychosis or severe depression. Bizarre thought patterns, hearing voices or experiencing hallucinations, increased or out of character aggression are clear signs that need to be psychiatrically assessed.

1. *Making regular contact with emergency services*

As well as being prone to increased anxiety, people with PWS are easily excited and can overreact. Being upset with a parent or carer or friend, may cause them to dial emergency services – police, ambulance, for no serious reason. If they have had a pleasant experience that includes consumables, as a result of an emergency service intervention, (for example, are given a cup of coffee and biscuits) this may be interpreted as a reward that encourages repetition of the action. People with PWS often appeal to a higher authority, like police, if they believe they have been wronged in some way or if they think another person is acting in an unlawful way.

1. *Self-harm such as scratching, skin picking, or pulling out hair or nails*

These actions are often the result of increased anxiety, agitation or boredom and can result in the appearance of open sores and scars on any part of the body. People with PWS may look as though they have been physically abused or are infectious and diseased. They can bruise and bleed more easily, causing a small injury to appear worse than it actually is. It is important to be aware of this behaviour should a case of abuse or neglect be suspected or under investigation.

Each person with PWS will present differently, with varying levels of cognition and ability.

Due to how they think and react:

* Remain calm and confident when communicating with the person
* Use fewer and simple words without double meanings, in a low gentle voice
* Do not accuse, threaten or make false promises
* Have a trusted, responsible adult, with good knowledge of PWS, present when you speak with them
* Avoid offering them or having any high energy consumables while they are with you
* Physical restraint may cause breathing problems and injury without complaint, as people with PWS have a high pain threshold and often, poor circulatory and respiratory health

Many adults with PWS will have guardians appointed by the court to assist them in their decision making about food, money, medical issues and of course, decisions involving the legal system. If the person with PWS is involved in a crisis, especially involving a hospital or the police, it is vital to contact the guardian to assist both the person and the community helpers to manage the situation as optimally as possible.

For further information about PWS please contact IPWSO or: NAME……………………………………….