

WHEN IS STEALING NOT A CRIME?

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- A sixteen-year-old girl is arrested for shoplifting food from Circle K at 3:00 am.
- A nine-year-old boy is arrested for hitting a teacher.
- An eleven-year-old girl is arrested for stealing food from her neighbor's freezer.
- A fourteen-year-old young man is arrested when he eats a large meal at a restaurant and then has no money to pay.

What do these children have in common? Any one of them could be my son, Matt. Is my son a criminal? No, he has a tragic disorder called Prader-Willi syndrome (PWS). PWS is the most common genetic cause of life-threatening obesity that has been identified.

Due to a genetic problem, the brain does not work properly in people with Prader-Willi syndrome (PWS). This results in several wrong messages to the brain. The "wrong messages" in turn can create legal problems.:

The message to the brain is always "hunger" and never registers "full"; thus a person with PWS has an insatiable appetite. As one young man with PWS wrote, "I feel like there are a thousand piranhas chewing at my stomach all of the time." Sneaking or stealing food is common, and because of the intense drive to eat, the person with PWS cannot always control themselves. (Anyone who felt like they were starving to death would react in the same way.)

Because food is everywhere in our society, it is impossible for a caregiver to always avoid situations where the child/adult with PWS might have the opportunity to steal to get food. No medication to date has been effective in curbing this appetite. Unfortunately, they also gain weight on much fewer calories than the average person does. Most families have to lock up all food. They will often transfer the stealing of food to stealing of nonfood items.

This does not mean a person with PWS should be allowed to take things, but we do request that you work cooperatively with a parent/caregiver. Our young people with PWS are not in any way "hardened criminals."

Some of our children and adults with PWS are officially "retarded", and others are in the low normal range – yet all have difficulty functioning normally in society. In fact, often a child/adult with PWS who is higher functioning will have more acting out problems. This is partially because they are constantly frustrated with wanting to be "normal" at the same time they are constantly being monitored and being deprived of the thing they want most – food. They are also bright enough to find creative ways to get at food. A child with the syndrome can often learn to pick a lock in seconds! But – the reality is that food can be very life threatening to our young people, so we need your assistance in preventing food foraging.

Although our young people with PWS are typically mild mannered in personality, the same part of their brain that is dysfunctional creates stubbornness, illogical thinking, and fits of anger. They can get inordinately upset for the situation and cannot be calmed through discussions or threats. (Often a short "time out" can defuse the situation.)

Typically, a law enforcement person becomes involved if the person with PWS:

1. Steals food;
2. Strikes out at another person - typically this is a caregiver because they are upset over something the caregiver said or did;
3. Calls 911 due to being upset with the caregiver and accuses the caregiver of abuse;
4. Destroys property during a tantrum;
5. Runs away – it is not uncommon for our young people to try to run away when upset or when trying to get at food sources.
6. Looks like they are abused -- Skin picking and some forms of self-abuse are also common; thus they may often have sores or scars in various stages of healing. Our children with PWS also bruise easily. This can all look like child abuse. This should be taken into consideration when investigating. It is also not unusual for a teen or young adult with PWS to accuse their caregiver of abuse when they are upset.
7. Is sexually abused – As with most children and adults with disabilities, people with PWS are vulnerable to sexual abuse. The potential for bribery with food adds to the risk factors.

A renowned geneticist who did the initial research on the syndrome, Dr. Hans Zellweger wrote **"I...have reached the conclusion that PWS is one of the two most grave ailments I have ever encountered."**

Although the above is all true and may become a problem you encounter, try to remember that our children and adults with Prader-Willi syndrome are also kind, loving individuals who thrive on positive attention. They have a tragic syndrome and need your support and understanding.