

PWS and Theft

*By: Katherine Crawford, Lisa Graziano, M.A.,
With input from: Elizabeth Roof, Ph.D., Janice Forster, M.D., Evan Farrar*

Megan stole a bag of chips from another student's lunch. Kirk took money out of his father's wallet to buy candy from a vending machine. Walter went into his brother's backpack and took one of his comic books to trade for food on the bus. Eloise went into her mother's room and took some jewelry to sell at school to get money for a candy bar. Isabelle was given recess detention after she took a star eraser from her teacher's desk.

There are many reasons for theft amongst children and adults with PWS. Like all things in the spectrum-world of PWS, not everyone with the syndrome has the same degree of symptoms including the theft of food and non- food items. For those who are impacted by this challenge, this article is for you.

Food-Related Theft

Food-related theft is a well-documented challenge with Prader-Willi syndrome. Parents and care providers who live with a high food drive individual know that theft can be a recurring concern. Within food-related thefts, there are differing levels of complexity.

One-Step: Megan

Acquire Food

The simplest form of food-related theft is one-step food acquisition. Such individuals are at risk of stealing food - from other's lunches, from the school or work cafeteria, or even shoplifting from the gas station down the street. Megan's story is a good example of simple, one-step food acquisition to gain access to food: just taking it.

Two-Step: Kirk

Acquire Money, Buy Food

Two-step food acquisition – stealing money to purchase food – can occur as well. Kirk's story (where he took money out of his father's wallet in order to buy food) is a classic example. When an individual is known to steal money to acquire food, it becomes necessary to lock away purses, wallets, and bedrooms to keep the individual safe.

But money isn't the only thing that gets food.

Two-step: Walter

Barter possessions for Food

Another form of two step food acquisition is bartering - trading an object for food. Walter knew that the boys on the school bus were interested in comics, so he took one out of his brother's collection to barter for food. There can be a delay in the discovery of this kind of behavior, and restitution is difficult because it involves both the brother and another child.

Three-Step: Eloise

Acquire Object, Exchange Object for Money, Buy Food

Next, we move on to three-step food acquisition: stealing an item which can be exchanged for cash which then is used to buy food. Eloise's story highlights the potential emotional repercussions that such thefts can cause; her mother could be deeply hurt by theft of her jewelry. Unfortunately, potential emotional repercussions may not enter into Eloise's thinking. She doesn't intend to hurt her mother; she simply intends to obtain food.

Each of these examples is food-related theft, no matter how many steps we add. Each also involves a breach of boundaries to acquire food.

Managing Food-Related Theft

When managing food-related theft it is important to remember that the underlying *drive* of the theft is outside the control of the person with PWS. The individual with PWS wants to be "good" in your eyes and do the "right" thing, but the drive to obtain food is too strong. It is up to the family, care providers, and the community around them to provide the compassionate supports they need.

Restrict one-step food theft by preventing access to all food sources with a lock (i.e., refrigerator, food pantry, etc.). Human supervision alone is inherently fallible. Lock down sources of money to prevent "two-step theft." Reinforce personal boundaries by locking bedrooms, especially older siblings. For "three-step" acquirers, lock jewelry boxes or keep valuables behind locked doors. In addition to locking access to food wherever possible, provide continuous supervision. When the hope or chance to acquire food is not possible, the person's mind is free to think about other important things.

Sometimes people, especially extended family members, are resistant to the idea of locking up food or keeping food in a restricted area. In this case it may be helpful to describe PWS's hyperphagia food drive like this: think of having a good friend who was just diagnosed with diabetes. Would you have rich desserts or candy bars out on your counter tops or on the table, even though you know they are trying not to eat such foods? Of course not. It wouldn't be the compassionate thing to do. It would just

increase your friend's anxiety, suffering, and daily struggle. More than most of us, when someone with PWS sees food, he wants it, and he can't get the thought of it out of his mind.

When working through food-related theft (whether one-, two-, or three-step) it is best to respond by matter-of-factly acknowledging the taking of the food and quietly reducing calories from the remainder of the day or week to compensate. Take responsibility for your lack of providing adequate food security and secure the food source so that it is no longer accessible. Never punish or shame the individual for stealing food; this is simply a symptom of PWS.

Some may suggest punishment (such as taking away a preferred activity) in response to a food-related theft. Such a person might say, "Megan knows that she can't go out to recess because she stole chips from another student's lunch. How could we reward her with recess after she stole food from another student?" They may even be proud of the individual with PWS for verbalizing their understanding that they have lost recess because they stole food. But the question is not "*does the person understand why they are being punished*" but rather "*will the experience of punishment or threat of punishment prevent the individual with PWS from stealing food in the future?*" In almost all cases the answer is "No, neither punishment nor threat of punishment prevents food stealing behavior." The critical piece to understand is that even if the individual with PWS understands and accepts such punishment *it will not shape future behavior*, which is the intended goal of punishment.

The most effective way to manage food-related theft is to eliminate all opportunities for the individual with PWS to do it!

Non-Food Related Theft

There is a different kind of theft that occurs in some people with PWS, that of stealing non-food items. This behavior can range from the "innocent" taking of items to compulsive stealing. Underlying all non-food stealing are likely higher degrees of egocentricity ("It's all about me") and impulsivity ("I want what I want, and I want it right now").

Not understanding social boundaries ("what's yours is yours and what's mine is mine") may make stealing non-food items more likely. In the case of Isabelle, this would be the case if she took the star eraser from her teacher's desk without understanding that she should ask before taking something that is in or on someone else's property.

Having low impulse control may increase the potential for non-food stealing behavior. An example of this might be the individual who walks through a store, sees an item they really like, and impulsively pockets it. In our case of Isabelle, the fact that she knows the eraser does not belong to her, or that to take it constitutes theft, or even that she's already been in trouble for stealing something in the past does not enter into her impulsively made decision-making process.

There are also people with PWS who appear to have extremely “sticky fingers” and indiscriminately steal objects. These individuals may experience more of a compulsive “need” to steal or “collect.”

Managing Non-Food Related Theft

The management of non-food theft is similar to that of food-related theft. First, teach and reinforce the understanding of boundaries. Make sure that stolen objects are returned to their owners with a written letter of apology whenever possible. Writing the owner’s name on all objects to the extent possible is helpful. Mutually and cooperatively creating rules regarding non-theft behavior is helpful. Writing down or using pictures to symbolize the rules helps make it easier to enforce them. Here’s an example scenario of how to create those rules together.

Aide: “Isabelle, I heard that you love erasers! Which eraser is your favorite?”

Isabelle: “I don’t have a favorite. I like all of them.”

Aide: “Me too! Hey, I was thinking of our class rules the other day. Do you think it would be a good rule to say that other students shouldn’t take your erasers, even if they like them?”

Isabelle: “Yeah!”

Aide: “What should a student do if they take an eraser?”

Isabelle: “Give it back and say sorry.”

Aide: “Brilliant idea! I’ll write that down on the bottom of our Class Rules List! Students should not take erasers from other students. If they break that rule, they should give the eraser back and say sorry.”

You’ll notice that throughout this dialogue the aide is phrasing things in the positive and turning the discussion towards how Isabelle would feel if someone took *her* erasers. This is done to get Isabelle’s buy-in to increase her compliance, not necessarily to reduce her degree of egocentricity or to teach empathy, although these are excellent skills to teach.

It should be remembered that Isabelle’s egocentric desire to have that eraser may still overpower her affection or empathy for her teacher. There is, however, an appropriate recourse built into the rule-making process: Isabelle told the aide what a student should do if they take an eraser and it’s written down in black and white. Isabelle may initially deny and/or perseverate, but if the aide is patient and calmly brings Isabelle’s attention to their written agreement, this will help Isabelle return the eraser. As soon as Isabelle returns the eraser the aide will praise, praise, *praise* her.

What if our hypothetical Isabelle brings home an object from school that does not belong to her, and when questioned she says a friend gave it to her? The circumstances of this scenario should be investigated for accuracy. Or what if another parent calls Isabelle's parents because they believe Isabelle took their child's CD? While Isabelle is adamant that the CD is hers, a search of her collection reveals an identical CD. It could be that Isabelle didn't *intend* to steal anything but actually believed her friend's CD was indeed her own. This example underscores the importance of labeling all of the individual's items to allow parents and care providers the ability to quickly resolve such situations.

What we're looking for isn't exactly a "cure" for impulsive theft but rather management of the environment to eliminate the expression of the symptom. It is possible that the individual with PWS may struggle with impulsive theft throughout their lifetime, so the knowledge and understanding of this symptom by those around them will make a big difference.

Continuous supervision is highly advisable when someone is known to have a history of stealing, and especially in situations where theft could have serious repercussions. It is also advisable to introduce your individual with PWS to your local police department, and provide officers with written information about the syndrome, available from the PWCF office and our website.

Theft can be tricky to manage in persons with PWS. The fundamental keys to reducing both food and non-food theft are environmental management, supervision, and continuous caring support of the individual with PWS.

For more information about Prader-Willi syndrome please contact the Prader-Willi Syndrome Association | USA at (941) 312-0400 or visit www.pwsausa.org.