



**Pittsburgh  
Partnership**

*Specialists in Prader-Willi Syndrome*

www.PittsburghPartnership.com  
E mail: PWS@pittsburghpartnership.com

Linda M. Gourash, MD

Janice L. Forster, MD

## Food Stealing in Prader-Willi Syndrome

Food stealing is a delicate situation. First, it must be viewed as a failure of the care plan for the person. It is not a failure of the person. If we give a person an opportunity to steal food and he does steal food, then the plan is wrong, not the person. We should assume that he will steal food, given an opportunity. If we give a person an opportunity to steal food and he does not steal food, we have still put him under stress that he does not need. Trying to teach a person not to steal food is fruitless because even if we are successful we are creating unnecessary stress.



The exception to this may be some of the children who are growing up with a different type of management. They have been taught "your food" and "my food" from the time that they are very small. These children who have had FOOD SECURITY\* from in a very early age do appear to be able to tolerate some food opportunities and ignore them. This is because they are confident in what they are going to receive and that it will be enough. On the other hand, anyone with PWS who has a history of food stealing, already had a positive reinforcement of stealing food (and enjoying it). Once he or she has been positively and strongly reinforced for stealing food it does not appear that we can un-teach this behavior.



There is no need for a consequence for food stealing behavior unless the individual knows that you know about the food stealing, that is, he has been caught in the act. Otherwise it is advisable to act as if you have noticed nothing. The individual is not confronted with the evidence and there is no consequence. BUT, behind the scenes, the family or the treatment team must review procedures and make adjustments so that the opportunity does not recur.

If the individual knows that you have discovered food stealing which has already occurred then there is a *token* consequence that is very minor, already known and completed quickly. In one program, we removed one small item (the starch) at the next meal. This happened for only one meal no matter how much food had been stolen and consumed. The purpose of this is helps make clear that food stealing is not acceptable but more importantly helps

Please see our handouts on FOOD SECURITY Principles: No Doubt/ No Hope /No Disappointment.  
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prevent a panic reaction when an individual is caught stealing food. These can be dangerous situations and there is less likely to be an uncontrolled outburst if everyone knows what to expect. This also prevents caregiving staff from “freelancing” with punitive consequences. It is important to the dignity of the person with PWS to “hold them responsible” without really giving them responsibility for controlling this impulse.

Food stealing at school should always be reported to the child’s parents. They can decide whether a consequence is appropriate based on these guidelines.

*At the time that the individual is caught, make as little issue about the theft as possible and focus on helping him to stay or become calm. He has been startled and disappointed (by his failure) at the same time. He may have a great deal of difficulty staying in control of himself. He can be asked if he would like to give back the food; if he does, he is praised and there is no consequence. Allow him to hold onto the food if he refuses to give it up. Reassure him that you will not take it away, however, if he starts to stuff large amounts into his mouth, there is a risk of choking and you will have to judge the safest course to take regardless of what you have promised him.*

We never say anything about a consequence during the emotional distress about the food stealing. But there will be less distress and anxiety about the food stealing when the consequences already known as part of the “house rules” or the individual care plan or IEP. Therefore, when all is calm, we inform him very gently of the preplanned consequence and we can even show some sympathy for the loss. Then we encourage him that we know they will do better with more help. *Then we give them the necessary help.* This includes increasing supervision, reviewing procedures with staff and *whatever it takes to protect the person with PWS from opportunities to steal food.*

Sometimes we are so happy that they are able to travel and navigate independently we forget that it is actually not appropriate for anyone who has a history of food stealing outside the home to be unsupervised outside the home. There are some folks who will steal food in the home but will not steal food outside the home. Those individuals may be able to travel to and from work without supervision.

What we say to the person with Prader-Willi syndrome about the food incident is different from what we should say within the family or to caregiving staff. These latter conversations must take place privately. It must be understood that food stealing will happen. A good team will use the occasion to identify the opportunities for food stealing and eliminate them with a plan for more supervision or better locking. These conversations should not be held in front of the person with Prader-Willi syndrome. He should not be allowed to blame the syndrome or to blame someone else for his food stealing but, at the same time, we are very gentle in holding him responsible.