

## PWS Lying, Stealing and Confabulation

One of the lesser known but often troubling symptoms of Prader-Willi syndrome is the potential for some individuals to lie, confabulate or make up stories for no apparent gain, and/or steal both food and non-food items.



PWS specialists Janice L. Forster, M.D. and Linda M. Gourash, M.D. of the Pittsburgh Partnership who are frequent presenters at PWCF's annual conferences, reported in their *Primer for Psychiatrists* (2005) that persons with PWS may lie in attempt to get out of trouble and lie to manipulate others, especially for food. PWS notwithstanding, almost *everyone* would rather not be "caught" in a lie and has probably lied at *some* time in their life to avoid detection or punishment. But because *most persons with PWS have a strong need to be right, they may continue to lie despite any and all evidence*. It is often simply not possible to persuade the individual with PWS to own up to their fib and to continue to engage in finding the truth will likely lead to a power struggle and result in some unwanted behavior.

Drs. Forster and Gourash report that some people with PWS are "creative fabricators, capable of confabulating allegations of abuse, claims of romantic entanglements, and calling 911 with false reports with astounding believability." Drs. Gourash and Forster note that some people possess "massive denial about personal limitations and responsibility for one's actions sometimes borders on the delusional." Stories and confabulations can range from harmless self-important bragging to much more serious confabulated stories of neglect or abuse or "fabricated circumstances in order to obtain admission to [a] hospital" where they may obtain food or unnecessary medical attention. Some people have "medication seeking behaviors that are not related to drug abuse" and "can also be very resistant to changes in medication regimen."

Some people with PWS may lie about feeling pain in order to avoid work or exercise. At the same time injuries can be missed because of abnormal pain awareness. This information is critical for care providers to know so that they look to outside sources to corroborate claims of injury or illness or confirm that no injury exists.

For many parents and care providers, lying and confabulating, especially for "no real reason" and the inability to take responsibility for one's actions can be particularly upsetting. While on the one hand attempts to address the fib, lie, or whopper of a story are often met with escalations of unwanted behaviors, parents and care providers often have great reluctance to simply "let the person with PWS get away with the lie or extreme exaggeration."

Understanding that lying and story-telling are often just another symptom of PWS can help reduce the negative emotional reaction they can provoke in parents and care providers. One suggested response to a blatant lie in which the purpose is to avoid punishment is for the parent or care provider to maintain a calm demeanor while stating it is understood that the individual does not want to be in trouble. It is *not* recommended to point out all of the "evidence" that proves the individual is lying; many people with PWS will try to "protect" themselves by continuing to lie, often irrationally, and become increasingly more upset with every new piece of evidence you present to them. If the lie is about food, it is suggested to simply state that you understand they ate the food. It can be helpful to express regret that the food was left out and made available for them to take, and reassure them that you will do a better job in the future to secure the food.

If the lie is more of a confabulation or story with no apparent gain except that of attention, one suggested response is to maintain a calm demeanor while you share how impressed you are with their wonderful and creative imagination or story-telling abilities. Again, it is not recommended to point out all of the evidence that disproves their story.

Confabulations or stories about abuse or neglect can be extremely challenging because teachers and other specified care providers are required by law to report these to their local police department or child protective services office.

People with PWS may steal both food and non-food items. Stealing non-food items can be related to the obsessive collecting or hoarding symptoms of PWS and the frequent lack of impulse control.

It is recommended that parents and care providers proactively inform your local police department that your child or adult has PWS and that one of the symptoms is lying, confabulating, and stealing. You may wish to provide this article to your local police department, your child's IEP team, Regional Center case coordinator, residential provider, day program provider, and/or employer. If you find yourself in the unfortunate circumstance of having to defend yourself against allegations of unfounded abuse, ask PWCF and/or the national PWSA (USA) for support and assistance.