

Lesser known but often troubling symptoms of Prader-Willi syndrome include the tendency for some individuals to lie or confabulate completely untrue stories. It is hoped that knowing these behaviors can be symptomatic of PWS will help parents and care providers feel less personally hurt if or when they occur and respond with less emotional negativity.



Almost *everyone* has lied at some time in their life to avoid detection or punishment. And who among us hasn't exaggerated a story or two to add a little excitement or drama to a tale. But for many parents and care providers, the PWS symptoms of lying and confabulated storytelling are quite distressing. Like many symptoms of PWS, these symptoms vary in presence and intensity from person to person.

PWS specialists Janice Forster, M.D. and Linda Gourash, M.D. of *The Pittsburgh Partnership Specialists for PWS* report that persons with PWS may lie in attempt to get out of trouble and lie to manipulate others, especially for food (*Primer for Psychiatrists 2005*). One of the differences between lies or fabrications told by individuals with and without PWS is that individuals with PWS often hold to their deception despite any and all evidence to the contrary, without regard to proof, logic or reasoning and attempts to discredit or even talk about the fib, lie, or whopper of a story are often met with escalated upset.

Drs. Forster and Gourash further report that some individuals with PWS are "creative fabricators, capable of confabulating allegations of abuse, claims of romantic entanglements, and calling 911 with false reports with astounding believability." They note that for some individuals, "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 more serious contrived stories of neglect or abuse. Individuals with PWS have "fabricated circumstances in order to obtain admission to [a] hospital" where they obtain food or unnecessary medical attention, or have "medication-seeking behaviors that are not related to drug abuse."

How do we as parents and care providers respond to or manage these behaviors? Of course it's important to specifically teach from a very early age the concepts of truth, honesty, lying, and dishonesty, as well as the potential consequences of these behaviors, namely that honesty increases trust and makes relationships better, while dishonesty eliminates trust and hurts relationships. Unfortunately, individuals with PWS who experience this symptom do possess a clear understanding of truth vs. deception and continue to lie or confabulate *even if they are honest and truthful individuals at all other times*. For these individuals, lying and confabulating are simply symptomatic of their PWS diagnosis and neurochemistry.

It's understandable that parents and care providers don't want to "allow" the individual to "get away with" their lie or confabulation, especially when there are siblings or other members in the household who *are* held accountable for their dishonest behavior. Pursuing the truth or admission of the guilt about a blatant lie or confabulated story, however, often leads to a power struggle that culminates in some unwanted maladaptive behavior and can disrupt the entire household even further. If only enduring the resultant unwanted behavior long enough would teach the individual that "honesty is the best policy!" Unfortunately, this is rarely the case. These symptoms are typically resistant to change for probably a variety of reasons, one of which includes the fact that most persons with PWS have a strong need to be perceived as "right", "good" and "competent" that typically outweighs any feelings of guilt or shame.

Suggested Parental or Care Provider Responses

Maintain a calm demeanor while addressing or responding to the deception or confabulation. If your initial attempts to clarify the truth are unsuccessful, disengage. Don't continue to pursue an admission of guilt.

Use humor. As with managing many PWS symptoms, use humor or silliness to reduce defensiveness. When we believe our son is lying or confabulating we call it a "Fibber McGee" as in, "I think you're telling a Fibber McGee." While we *never* expect to hear, "You're right, I was lying" we do attempt to communicate in a non-reactive manner that we are aware of the deception.

If a lie is to avoid blame or culpability, share your understanding that you know the individual does not want to be in trouble. Focus on future-oriented problem-solving as in, "I know you don't want to be in trouble. Let's talk about what to do next time."

If a lie is about unauthorized food acquisition, express regret that food was left out or somehow accessible and assure the individual that for their health and safety food will be secured better in the future.

If feigning injury or illness to avoid work or exercise is suspected, assess all possibilities for genuine injury or illness. This can be tricky because injury and illness can easily be missed due to PWS's high pain tolerance and temperature dysregulation. If no injury or illness exists, use empathy, praise, and non-food incentives to motivate. As a general rule it is helpful to schedule non-preferred physical activity or tasks immediately *before* scheduled meals or snacks.

If a story appears to be confabulated, listen and then not-too-enthusiastically thank the individual for sharing their story. Or, enthusiastically and with great sincerity express how impressed you are with their creativity, imagination, or story-telling ability.

Confabulations about abuse or neglect are extremely challenging, both emotionally and practically. It's hard *not* to take it personally when a loved one falsely accuses a parent, family member, or caring staff person of abuse or neglect. False accusations of abuse or neglect occur in the most loving PWS families and homes, often for no apparent reason. Teachers, residential providers, health care providers, and certain other professionals are required by law to report allegations of abuse or neglect to their local police department and to the child or adult protective agency *even if they don't believe the accusation*. Becoming involved with a police or social service investigation can be *extremely* frightening and stressful on everyone involved. If your loved one exhibits lying or confabulating symptoms, it may be helpful to proactively inform your Regional Center service coordinator, school IEP team, residential provider, day program provider, and even your local police department that your child or adult has PWS and the symptoms of lying, confabulating, and/or stealing are symptoms he or she exhibits. Provide them a copy of this article and other pertinent PWS documents. While mandated professionals are required to report allegations of abuse, if they are prewarned that these symptoms are symptoms of your loved one's diagnosis, it *could* help avoid a report or help a report be written in such a way that an investigation is more easily and quickly closed. If you find yourself in the unfortunate circumstance of having to defend yourself against a false allegation of abuse contact PWSA | USA and the Prader-Willi California Foundation PWCF for support and assistance.

As with many symptoms of PWS, not everyone will exhibit lying or confabulation and for those who do, the degree of severity will vary from person to person. This behavior runs counter to the values and morals that parents and care providers strive to teach our loved one and because it is so resistant to change, can be extraordinarily challenging to manage. It is, however, yet another symptom of PWS and must be understood as such.

For more information about PWS, or to request support or training contact:

Prader-Willi California Foundation
800-400-9994 | info@pwcf.org | www.PWCF.org

Prader-Willi Syndrome Association | USA
800-936-4797 | info@pwsausa.org | www.pwsausa.org



Lisa Graziano, M.A., LMFT is a Marriage and Family Therapist in private practice in Redondo Beach, California. She has been an educator and an advocate for the Prader-Willi Syndrome Association | USA and the Prader-Willi California Foundation for over twenty years. She is the proud parent of an accomplished young man who has PWS.