

Never Spank the Child with Prader-Willi Syndrome

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with Janice Forster, MD, Linda Gourash, MD,
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Discipline is in fact a form of education. As parents, our job is to teach our children the safe and proper thing to do in any given situation. We aspire to teach them right from wrong, safe from danger, and to respect their neighbor. The manner in which we teach our children depends a lot on how we grew up as kids. If our parents came from the school of “spare the rod, spoil the child,” odds are that we are more likely to use hitting as a form of discipline. The reason why? *Children imitate what they see their parents do.* It is difficult to teach your child not to hit others when they are hit by you! On the subject of disciplining the child with Prader-Willi syndrome, the rule to follow is **Do Not Hit**.

Whether or not we philosophically believe in spanking, swatting or hitting a child’s bottom, hand or any other body part as a form of punishment, *it is an ineffective form of behavior modification, counterproductive, and physically dangerous to do so with a child with PWS.* According to developmental pediatrician and PWS expert Linda M. Gourash, M.D. of the *Pittsburgh Partnership, Specialists in Prader-Willi Syndrome*, “With a high pain threshold and small muscles in the bum, the risk of real injury could arise before any learning takes place. Even if it seems to “work” in the short run, the cost is going to be horrendous in overall increase in tension and anxiety, the major contributors to PWS behavior problems. Our overwhelming experience is that people with PWS do not learn from negative consequences” and that “yelling and scolding [are also] very counterproductive strategies.” Dr. Gourash likes to say, “Speak calmly and firmly, not sternly”.

Janalee Heinemann, M.S.W., Director of Research and Medical Affairs for Prader-Willi Syndrome Association (USA), warns that “Spanking will usually *not* calm the child with PWS down but [instead will] only accelerate their acting out behaviors. The parent is then at risk for losing control of his or her own emotions and going beyond the limits of a “spanking” and become truly physically abusive. Because our children with PWS often bruise more easily than typical children, a “spanking” may leave bruises, thus leaving the parent vulnerable for being reported for child abuse – and any marks left on a child (or disabled adult) is legally considered abuse.”

In general, people with PWS are very concrete, black-and-white thinkers. That’s just how the brain is wired for most people with the syndrome. They rely on hard and fast rules and tend to feel very anxious with the “gray” areas. For a child with PWS, knowing the rules and following the rules reduces overall anxiety. Reduced anxiety leads to better overall behavior. PWS expert Mary K. Ziccardi, Administrator of REM Ohio, Inc., adds, “In order to learn from consequences a

person needs insight and the ability to problem-solve, use memory, logic, and sequential thinking, be able to compare and discriminate information, and discern the value of an experience in order to learn from it. We know that PWS compromises or impairs most of these needed skills.” PWSA (USA) Crisis Counselor Evan Farrar notes that “the perseverative quality of people with PWS predisposes them to react stubbornly to negative consequences. In the most severe cases, a person with PWS may shut down completely in response to a negative consequence.”

If you wish to teach a child with PWS not to hit - and it is *critical* to teach the child with PWS not to hit - then you must teach the child that hitting is *never* ok. That’s the rule. Children and adults with PWS may not be able to differentiate in what situation it is “ok” to hit and in what situation it is not ok. For them, it’s either ok to hit or it’s not ok to hit. Swatting, spanking, etc. are all forms of hitting, and they are *never* okay to be used on a child with PWS.

Children with PWS need to be taught *directly* what you want them to learn. Hitting the child’s hand will *not* teach him that touching a flame will burn. Hitting his hand *will* teach him that hitting is ok. Later on, that hitting could be on another person or on some object, whether it’s a toy, wall, table, etc. Instead of slapping/hitting the hand that is nearing the flame, immediately physically move his hand away from the flame. Teach him with words that the flame will burn him.

People with PWS are very, very prone to feeling overwhelming amounts of frustration and anxiety. Unfortunately, they are more prone to physically acting out their anxiety and frustration than typically developing kids and even other kids with developmental disabilities. And unfortunately, they are more prone to hitting. Dr. Gourash advises that, “Food Security, Daily Schedule, Incentive plans, meeting sensory needs and low expressed emotion appear to be the key components of PWS behavior management.”

Dr. Jan Forster, a developmental neuropsychiatrist and “the other half” of the *Pittsburgh Partnership* says, “Learning in PWS is best accomplished through positive reinforcement. This means catching your child doing something *good* in a given situation and telling them that they have done a good job. This is much more effective than punishing them for a *bad* behavior. It also means that the next time they are in that situation they are far more likely to do the behavior that received the praise. That’s using the wiring in the PWS brain to our best advantage!” Dr. Forster also echoes the suggestions of Dr. Gourash and both agree that “low expressed emotion is one of the most useful tools in behavior management. Persons with PWS have difficulty processing

two things at once. So, if you use an angry (stern) tone with them while you are saying something meaningful, they will only process the anger, not the content of what you said! Or, if you hit them when they do something undesirable, they will only attend to the hitting, not the *reason* why you hit them. So when a child is doing something wrong, the best way to react is with neutral voice while you tell them the *appropriate* thing to do and if necessary move them to a safer place. Low attention to outrageous behavior is especially important because some children with PWS seem to thrive on their ability to create a stir.” Ms. Ziccardi and Mr. Farrar agree noting that “punishment does not teach a new skill, and may even increase the likelihood of the undesirable behavior because the negative attention is better than no attention.”

Research by Drs. Forster and Gourash and Marjorie Royle reveals that, “Stress is significantly higher among parents and other caregivers of people with PWS than it is in the population at large.” Disciplining is one of those parts of parenting a child with PWS that indeed may be quite stressful because we may have to learn a whole new way to discipline using a very different guiding philosophy than we were taught. It can be very difficult to incorporate these new strategies, particularly when we may not yet even believe in their effectiveness, or when we ourselves are under stress. But that's what good parenting is all about... doing what's in our *child's* best interest, not necessarily our own.

It is important, then, for parents and care providers to incorporate strategies that will help reduce and manage our own levels of stress so that we have adequate energy to sustain a calm and neutral response in the midst of any situation. As simple as it sounds, controlled deep breathing is a very effective tool to help immediately calm the mind and body. Breathe in slowly through the nose, then exhale slowly and fully. Repeat this simple breathing exercise three times, or until you feel calmer. This breathing technique is helpful in the heat of the moment and at any time throughout the day when you notice feeling stressed.

An extremely effective longer-term strategy to managing our own stress includes regular physical activity, even if it's just a brisk 15-minute walk around the mall in the afternoon or around the block after the kids go to bed at night.

Some parents find that sharing or “venting” to a select group of people such as a spouse, extended family member, best friend or therapist, is helpful to manage stress.

Building in extra cushion time throughout the day, by not scheduling activities or errands too close together is a great way to reduce stress.

When we incorporate these and other stress-reducing techniques into our daily lives we not only help ourselves, but we also help our children who, as children tend to do, imitate what they see us do.

Teaching our kids from a very, very early age that hitting is *never* ok at the same time we teach them *how* to manage their impulses and frustrations will serve them well throughout their lifetime.

For more information about Prader-Willi syndrome or to request PWS Training, please contact the PWCF Office at 310-372-5053 or info@pwcf.org.

