

Guidelines for Behavior Management

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Positive behavior support is an essential tool for all caregivers of a person with Prader-Willi syndrome. It is most effective to implement positive behavior strategies early in a child's life – even before behavior challenges emerge. Many individuals with PWS feel anxious and that anxiety can lead to challenging behaviors. Managing and reducing anxiety will lead to less behaviors.

Create Consistent Routines

Consistency and routines help individuals with PWS to feel safe and secure in their environment. When they know what to expect, they feel less anxious. Using visual schedules and providing verbal prompts can be helpful. Develop a daily routine and weekly or weekend schedules that are posted.

- It is important to include meal and snack times on the schedule; reducing worry about when the next meal or snack will be.
- Include chore times, bedtime routines as well as all other activities and expectations; schedule the least preferred before the most preferred i.e., exercise/chore before lunch or dinner.
- Communicate any changes in the schedule or routine in advance.

Note: Some children cannot handle a lot of advance notice about changes, use your best judgement, you know your child best.

Create Clear Rules

Individuals with PWS tend to be rule followers; rules help them feel safe and know what expectations are, just like consistent routines. Additionally, rules provide a guideline as to what is expected and how to behave. Once a rule is explained, it's important to practice what that rule means and looks like. For example, if the rule is "all shoes get put in the closet after you take them off," practice taking your shoes off together and then putting them away. Provide a lot of praise along the way.

- Once a rule is established, it's important to be consistent and not give in. If no sometimes means yes, your child will feel more anxious and increase their perseveration on that issue waiting for no to become yes.
- Life happens. Establish the rule that parents can change the rule if needed, however this practice should be limited.
- Encouraging your child to have a voice in the rule making, will increase their desire to follow the rules.

Create Clear Boundaries

Establish clear and consistent boundaries around expectations and teach your child what is acceptable behavior, and by default, what is not. Always say what you mean, clearly and in language that they will understand. Avoid making threats that you are unable to follow through with. For example – “put your shoes away right now or you won’t ever go to grandmas again.” Following through on what you say will increase their trust and sense of security.

- Offer preferential limited choices rather than giving positive and negative consequences. For example – “Do you want to wear your blue jacket or your red jacket?” The choices do not include, not wearing a jacket. Offering options sets clear boundaries related to what you want them to do, while giving them a sense of control.
- Avoid ambiguity and using phrases such as “maybe later,” or “we will see.” These are too vague and increase anxiety.

Be consistent! If you give into a tantrum today, tomorrow’s tantrum will be worse. By giving in to the tantrum, you are reinforcing the negative behavior that you are trying to prevent. If you have given in to a tantrum in the past, there are steps you can take to minimize the effect.

- Apologize – “I made a mistake and should not have done that, I’m sorry.”
- Explain to your child how giving in was not helpful in the past, and what to expect in the future.
- Stay strong. When working to change someone’s behavior, they will likely push harder to get you to bend the rules. Expect it to get worse before it gets better.
- It will get better!

Create a Calm Environment

Many individuals with PWS are hyper-reactive to the environment and external stimuli. The best environment is one that is calm with a calm, supportive person. Create an environment that fits your child’s specific needs.

- Limit auditory stimuli by avoiding having the radio and television on in the same room.
- Encourage the use of noise-canceling headphones in environments that you are unable to control.
- Create a safe space to go to when feeling overstimulated such as a bedroom.
- Keep sensory calming items accessible such as a swing or rocking chair, tactile items (squishy balls, brushes, vibrating stuffed animals or pillows) and calming smells such as scented lotions or essential oils on fabric.
- Keep lighting soft

Responding to a Meltdown or Tantrum

Despite your best efforts your child will have moments of upset and engage in challenging behavior. It's most effective to remain calm, matter of fact and keep a neutral affect during these situations. Some individuals are reinforced by the reaction they elicit from others during a tantrum. Paying little to no attention to unwanted behaviors will help extinguish them. Responding with compassion, while validating their feelings but not the behavior can help deescalate the situation. Remain calm on the outside, despite how you are feeling on the inside, be patient and stay firm. Once your loved one has calmed, praise them for calming. Avoid trying to talk someone out of being upset, they can't process the situation while having a tantrum or meltdown, and it will likely increase their upset.

Create Positive Consequences

Positive reinforcement is much more effective than negative reinforcement. Positive reinforcement involves providing a positive consequence to a wanted behavior, making it more likely that the behavior will occur again in the future. Praise the good, no matter how small.

Positive Behavior + Positive Reinforcement = Increased Positive Behavior

If you are struggling to manage your child's behavior, call (941) 312-0400 and ask to speak with a Family and Medical Support Counselor.

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