

Unwanted, maladaptive behaviors are one of the greatest challenges of the myriad symptoms associated with Prader-Willi syndrome. Implementing the PWS Environmental Basics is the first step to help reduce anxiety and the potential for behavior problems.

What is it	Why it's helpful	How to implement it
<p><b>Principles of Food Security</b></p>	<p><b>No Doubt</b> + <b>No Hope</b> = <b>No Disappointment*</b></p> <p><b>Persons with PWS need consistency and reliability in regard to food.</b></p> <p><small>*Concept by PWS Specialists Drs. Janice Forster and Linda Gourash now considered throughout the world as standard of care</small></p>	<p><b>No Doubt</b> when the next meal or snack will be served</p> <ul style="list-style-type: none"> <li>▪ Establish consistent routines for food consumption. E.g., Breakfast   Snack   Lunch   Snack   Dinner</li> <li>▪ Scheduled food should be as reliable as breathing air. <ul style="list-style-type: none"> <li>• Never use food as a reward.</li> <li>• Never use food as a bribe.</li> <li>• Never withhold food for poor behavior.</li> </ul> </li> <li>▪ You can “pause” the food schedule until a requested task is completed: <ul style="list-style-type: none"> <li>• “After your shower we’ll have lunch.”</li> <li>• “It’s not safe for you to eat while you’re yelling/crying. As soon as your body is calm you can have your lunch.”</li> </ul> </li> </ul> <p><b>No Hope</b> or chance to obtain extra or unauthorized food</p> <ul style="list-style-type: none"> <li>▪ If food is available, the individual will feel increasing anxiety and often can do little else but think of how to get that food. Eliminate access to food to reduce anxiety and behavior problems. <ul style="list-style-type: none"> <li>• Lock refrigerator, pantry, medicine cabinet, money, alcohol, etc.</li> <li>• No one should eat in front of the person with PWS if food is not also available for the person with PWS.</li> <li>• No bowls of food on the dinner table. Plate food at counter.</li> <li>• No second helpings unless you ALWAYS do seconds.</li> </ul> </li> </ul> <p><b>No Disappointment</b> with means no behavior problems!</p>
<p><b>Routines</b></p>	<p>Routines help people feel safe and secure. Routines reduce anxiety.</p> <p><b>Persons with PWS have a high need for routine, predictability, consistency.</b></p>	<ul style="list-style-type: none"> <li>▪ Create routines for: bedtime, wake up time, meals &amp; snacks, chores, etc.</li> <li>▪ Create written or visual schedules or charts for daily activities, chores.</li> <li>▪ Refer to the written schedule or charts to avoid arguments.</li> <li>▪ Provide advance notice about changes in plans as appropriate to the individual.</li> </ul>
<p><b>Rules</b></p>	<p>Knowing the rules makes it easier to obtain success. Knowing the rules reduces anxiety.</p> <p><b>Persons with PWS are typically rule followers</b> They’d like others to follow the rules while they may choose to break them!)</p>	<p>When something is understood as a rule, it is more likely be followed, <i>especially</i> if the individual had input to create the rule.</p> <ul style="list-style-type: none"> <li>▪ Establish rules for chores (make bed in morning), hygiene (wash hands after restroom), exercise/activity (walk first then snack), social rules (greetings), shopping (no whining), and food rules: restaurant rules, buffet rules, party rules, etc.</li> <li>▪ Post the rules so they’re visible or easily seen at least until they are learned.</li> <li>▪ Be sure to establish the rule that parents/providers can change a rule if necessary.</li> </ul>

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<p><b>Boundaries</b></p>	<p>Boundaries define limits and provide structure to relationships. Boundaries establish what behavior is and is not acceptable. Boundaries reduce anxiety and help people feel safe.</p> <p><b>Boundaries are critically important to persons with PWS.</b></p>	<p>Clear and firm boundaries feel like a safety line. Boundaries protect the individual from feeling free-floating anxiety. Boundaries make the world feel safer.</p> <ul style="list-style-type: none"> <li>▪ Parent with Authority. Care providers <i>must</i> be experienced as the authority and inhabit the Authority Position so that the child/adult can feel safe and protected.</li> <li>▪ Define and uphold your boundaries with authority. <ul style="list-style-type: none"> <li>• Stop asking permission. E.g., “It’s almost time to get in the car, <i>okay?</i>” Instead, use preferred choices: Do you want to get in the car in 2 minutes or 3 minutes?</li> </ul> </li> <li>▪ State and stick to your boundaries re: time limits, rules, routines, permissible language and behavior. E.g., <i>I want sugar in my coffee.</i> “You like sugar, I know! We don’t use sugar in your coffee though. You don’t have to have coffee today, that’s ok.”</li> <li>▪ Don’t repeat requests more than 3 times. At your third request, physically and calmly begin to intervene. E.g., Walk over to individual while stating, “It looks like you need help to turn off the tv.”</li> <li>▪ Say what you mean and mean what you say. Don’t promise anything you don’t intend to follow through on. You <i>must</i> be the reliable authority.</li> <li>▪ Don’t lie in attempt to avoid a situation <i>especially</i> if it’s possible your deceit will be discovered. E.g., If you’re eating something don’t say, “No, I’m not eating anything.” You <i>must</i> be perceived as honest and reliable.</li> <li>▪ Avoid ambiguity. “We’ll see” or “Maybe later” are vague and often create anxiety. If you don’t know, say, “I don’t know and I’ll let you know as soon as I do.”</li> <li>▪ Avoid open-ended questions that can be difficult to process and create anxiety. Give 2-3 preferred choices.</li> <li>▪ Use transition cues such as auditory alarms, visual countdown timers, verbal countdown prompts (5-3-2 more minutes”, “the show is almost over”).</li> <li>▪ Don’t threaten something you don’t intend to follow through with. Removing privileges or taking something away is <i>extremely</i> tricky and generally does <i>not</i> teach cooperation but rather leads to <i>more</i> behavior problems. If appropriate, provide opportunity to earn a revoked privilege right back.</li> <li>▪ Give the individual with PWS the perception of control over their life with preferred choices; do not give the individual too much actual power. If you feel like you’re constantly “walking on eggshells”, the hierarchy of power is likely turned upside down which means safety is breached, anxiety is increased, and unwanted behaviors will increase and escalate in intensity. <ul style="list-style-type: none"> <li>• Uphold your boundaries with Empathy</li> </ul> </li> <li>▪ Don’t allow yourself to be manipulated. When the individual believes they have manipulated you, they no longer feel safe, their anxiety increases, and the potential for behavior problems is increased. <ul style="list-style-type: none"> <li>• If appropriate in response to a behavior problem intended to avoid an unpreferred task or activity, use <i>The Day Stops Here*</i> intervention. Do not proceed to the next task or activity until the unpreferred task or activity is completed.</li> </ul> </li> </ul> <p>*Term coined by Drs. Janice Forster and Linda Gourash that addresses avoidance tantrums.</p>

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<p><b>Calm Responses</b></p>	<p>Anxiety is increased by raised, critical, accusatory, or angry-sounding voices.</p> <p><b>Always speak calmly despite how you feel on the inside, especially during emotionally-charged exchanges.</b></p>	<ul style="list-style-type: none"> <li>▪ No matter how upset the individual with PWS, a calm response from the care provider reduces their anxiety and the potential for escalating behavior problem. This is where parent/caregiver Self Calm strategies are critical!</li> <li>▪ Listen to the individual who says, 'leave me alone.' Don't say anything else, don't look directly at them, don't stand too close (to avoid injury). Monitor with peripheral vision and let them cool down.</li> <li>▪ Match the demands on the individual to their ability. Most persons with PWS have Executive Functioning deficits and will need help throughout their lifetime to plan, prioritize, organize, problem-solve, self-monitor, self-regulate, pay attention, begin tasks, multi-task, meet deadlines, manage time. <ul style="list-style-type: none"> <li>• Remember that "common sense" and judgment are typically impaired</li> <li>• Continuously remind to slow down eating, speak softly, etc.</li> <li>• Guide to conclusions rather than solving problems for the individual</li> <li>• Remain vigilant for safety</li> </ul> </li> <li>▪ Persons with PWS typically like "drama." Some people are "pot stirrers." <ul style="list-style-type: none"> <li>• Don't engage. Supervise and monitor for "drama" and "gossip" and intervene as needed.</li> </ul> </li> <li>▪ Don't Give-In to a Tantrum <ul style="list-style-type: none"> <li>• Respond to a tantrum or unwanted behavior with indifference, boredom.</li> <li>• Ignore unwanted behaviors, while monitoring for safety, to extinguish them as quickly as possible.</li> </ul> </li> </ul> <p>If you give in to a tantrum you have taught the individual all they need to do to get what they want is yell louder, be more aggressive, wait you out longer, and eventually you will give in.</p> <p>Giving in today over a "little thing" will lead to a larger tantrum tomorrow. The peacefulness and overall quality of life of everyone in the household depends upon upholding the established limits and boundaries. Think long term! Don't give in to a tantrum.</p>

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Contact PWCF for more information about PWS and behavior management strategies

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