

# PWS Behavior Management Strategies for the Family

## Overview Session



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Foundation

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### Physiological Symptoms That Can Impact Behavior

- **Hypotonia** - Weak muscle tone
- **Problems with Strength, Balance, Coordination, Motor Planning**
- **Abnormal Growth** (short stature, small hands & feet)
- **Respiratory Issues**
- **Cognitive Limitations, Impaired Judgment**
- **Hyperphagia** - Dysfunctional appetite regulating system
- **Metabolic Issues**
- **Gastrointestinal Issues** – Gastroparesis (slow emptying stomach), slow emptying bowel, lack of vomit reflex. **Never use Imodium or Pepto Bismol as these can be lethal.**
- **Temperature Regulation Dysfunction** – Irregularities regulating internal body temperature can cause persons to become too hot (hyperthermia) or too cold (hypothermia). Individual may be ill and register no fever.
- **High Pain Threshold** interferes with accurate identification of discomfort or pain
- **Self-Injurious behaviors** most often skin picking
- **Hypopigmentation** in Deletion – very fair hair, skin and eye color
- **Dental Problems** – dry mouth symptoms cause “stringies” and “crusties” around corners of mouth. Use dry mouth products to treat.
- **Speech and Language Problems** increase frustration
- **Scoliosis and other orthopedic abnormalities**
- **Incomplete Sexual Development**
- **Disordered Sleep** causes daytime sleepiness, irritability
- **Social / Psychological / Psychiatric symptoms** **Anxiousness**, OC behaviors, perseveration, impulse control disorder, intermittent explosive disorder, ODD, elopement, psychosis, **lying and/or confabulation**
- **Medication Sensitivity** requires lower doses given more slowly

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### Overview of PWS Hyperphagia

**Dysfunctional appetite regulating system:** physiological, neurological drive to eat or obtain food that lasts throughout the lifetime.

**The brain functions as if the body is starving:**

- It drives the individual to eat/find as much food as possible.
- It blunts satiety / feeling full
- It stores consumed food as fat
- It lowers the metabolic rate to almost half in order to conserve energy

Unmanaged hyperphagia + slow metabolic rate causes rapid weight gain, potential for premature death from stomach and/or bowel perforation or necrosis, potential for morbid obesity, and behavior problems. **Death can occur from a single overeating episode.**

**PWS is not an eating disorder. PWS is a medical disorder.**

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## PWS Hyperphagia con't

- No known medication or intervention treats PWS' hyperphagia food drive. There is no learning to control food intake. **Current management is 24/7/365 supervision and adherence to the Principles of Food Security.**
- There are currently a number of pharmaceutical companies that are conducting promising and exciting medication trials to treat the hyperphagia symptom.
- Until such time as there is a medical intervention to treat the hyperphagia symptom, life must be lived in the family home or a PWS-designated residential setting for the duration of the lifetime because **no one known to be diagnosed with PWS can successfully live independently.** Those who have tried have either become morbidly obese or died.
- PWS's hyperphagia food drive underlies many maladaptive behaviors but there are a multitude of neurological issues that contribute to unwanted behaviors as well.

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## Overview of GI Issues

- **Gastroparesis**, slow emptying stomach.
  - **Treatment** consists of low dose antibiotic (metoclopramide) and diet.
  - **Never administer Pepto Bismal or similar medications as it can cause serious injury or even death.**
- **Slow bowel motility** causes *both* diarrhea *and* constipation.
  - Slow motility makes stool harder, feel itchy at sphincter which may cause picking behaviors.
  - **Treatment** consists of regular use of Miralax or lactulose, probiotics and diet.
  - **Never administer Imodium or similar medications as this can cause serious injury or even death.**



	Type 1 Separate hard lumps, like nuts hard to pass
	Type 2 Sausage-shaped, but lumpy
	Type 3 Sausage-shaped, but with cracks on surface
	Type 4 Sausage or snake like, smooth and soft
	Type 5 Soft blobs with clear-cut edges (easy to pass)
	Type 6 Puffy pieces with ragged edges, mucusy
	Type 7 Watery, no solid pieces (entirely liquid)




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## GI Issues Continued

- **Swallow Problems** are presumed common
  - Epiglottis appears not to close properly allowing liquid and food into the lungs
  - Higher incidence of choking, pneumonia and other lung-related illnesses
  - Treatment: "drinking sips of liquids during a meal or snack *might* clear the mouth and throat of any remaining, undetected residue. Taking additional saliva swallows may also be beneficial in clearing food residue." *Roxann Diez Gross, Ph.D.*
- **Liver metabolizes slowly, almost at half the normal rate.**
  - Start all **medications** at low dose, increase dose slowly.
- **Enuresis and gall bladder problems** are not uncommon
- **Sporadic or complete inability to vomit.**
  - **Never administer ipecac syrup or similar medication in attempt to induce vomiting.**




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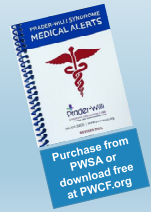
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### PWS Hyperphagia con't

#### PWS Medical Alerts Booklet Can Save a Life



- Vomit reflex is absent. The body does not expel consumed poisons, rotten food, too much food. Few people exhibit a fever despite severe illness.
- Due to higher pain tolerance there may be a significant illness or injury with little expressed discomfort. General feeling of unwellness or lethargy, or lack of interest in eating the next meal may signal illness.
- Abdominal distention, bloating, pain, and/or vomiting may be signs of life-threatening perforation or necrosis.
- Chronic gas or prolonged gas pain can signify a severe bowel issue.
- If an individual with PWS has these symptoms, especially following a known or suspected over-eating episode, **prepare for an ER visit.**
- **Always bring the PWS Medical Alert booklet to the ER so personnel understand the seriousness of symptoms.**

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Anything -- or anyone -- that raises anxiety has the potential to cause a behavior problem

Which means that YOU have the potential to *cause* a behavior problem...



And YOU have the potential to *reduce* that behavior problem...

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### Punishment Does Not Work with Persons with PWS

- Punishment does not change future behavior or teach a new skill. Instead it escalates unwanted behaviors and creates potential for a meltdown.
- Most persons with PWS lack impulse control.
- Most persons with PWS are often predisposed to react stubbornly to negative consequences and can shut down completely in response to a negative consequence.
- Because persons with PWS can adjust to unpleasant situations some care providers perceive this as the need to apply more and more severe consequences which lead to larger and larger temper outbursts.
- **NEVER withhold food as a punishment** as this shatters Food Security and escalates maladaptive behaviors.



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What DOES work?

**Positive Reinforcers!**

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PWS  
Anxiousness

- Almost everyone with PWS has a high level of anxiousness – excessive worry, fear, unrealistic view of problems, feeling out of control – that lurks just below the surface, ready to react to the next real or *perceived* stressor
- Anxiety can *cause* of maladaptive behaviors:
  - ✓ Arguing and defiance
  - ✓ Verbal and physical aggression
  - ✓ Elopement
  - ✓ Repeated questions
  - ✓ Excessive talking
  - ✓ Skin picking
- The more you're aware of what might be going on *underneath* the behavior and how the individual with PWS *thinks*, the greater success you'll have to intervene and avoid an unwanted behavior.

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Top 10  
PWS Behavior  
Management  
Strategies  
Toolkit

1. PWS Environmental Basics
2. Empathy as Intervention
3. Paint the Picture
4. Fix a Past Goof
5. Preferred Choices
6. Disguise The No's
7. Allow for the Possibility of Rightness
8. Use Egocentrism to Your Advantage
9. Motivate Externally
10. Use Transition Prompts to Increase Flexibility

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#1

PWS  
Environmental  
Basics

- A. Food Security
- B. Routines
- C. Rules
- D. Boundaries
- E. Calm Responses



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**Environmental Basic A: Food Security**

**NO DOUBT**  
No doubt when the next meal or snack will be served  
*Consistent routines for food consumption*

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**NO HOPE or CHANCE**  
No hope or chance to obtain extra/unauthorized food  
*Eliminate access to food to reduce anxiety and behavior problems*

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**NO DISAPPOINTMENT**  
No disappointment that extra food is not available  
*No disappointment means no behavior problems!*

*The Principles of Food Security is a term coined by Janice Forster, MD and Linda Gourash, MD of The Pittsburgh Partnership Specialists in PWS www.pittsburghpartnership.com*

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**No Doubt**  
*No doubt when the next meal or snack will be served*

- Establish consistent routines for food consumption. Determine when food will be served (every 2 ½-3 hours)  
Breakfast / Morning Snack / Lunch / Afternoon Snack / Dinner
- Write the food schedule on a notebook until it's learned.
- Pre-determine your response when asked for food before it's scheduled: "I hear you'd like your lunch. Lunch is at noon/after exercise. What time is it now? That means lunch is in 15 minutes/right after exercise. Let's set the timer and then finish this project."

**Scheduled food should be as reliable as breathing air.**  
NEVER use food as a reward  
NEVER use food as a bribe  
NEVER withhold food for poor behavior

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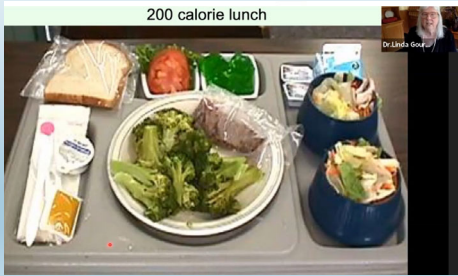
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**200 Calorie Lunch Sample**




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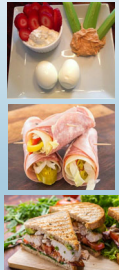
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**Plate Samples for Higher Protein/Lower Carb Meals**

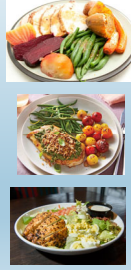
**Breakfast**



**Snack / Lunch**



**Supper**




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**No Hope or Chance**

*No hope or chance to obtain extra food*

Access to food creates hope. Hope creates anxiety. Anxiety creates the potential for unwanted behaviors. If food is available, the individual can do little else but anxiously think of ways to get that food.



**Eliminate access to food to reduce anxiety and behavior problems**

- Eliminate access to food to reduce behavior problems.
  - Lock refrigerator, pantry, medicine cabinet, money, and alcohol cabinet.
  - No bowls of food on the dinner table. Plate food at counter.
- Establish rules for type, quantity of food especially prior to attending parties, restaurants, etc.
  - No second helpings unless you ALWAYS do seconds.
  - No one should eat in front of the individual with PWS if food is not also available for the person with PWS.

**Put a lock on the thought that unauthorized food is available.  
NEVER Give in to a Tantrum -- Especially for Food**

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**The most loving thing you can do is lock your refrigerator and food pantry**

- Restricting access to food with locks reduces the individual's anxiety, helps them feel safer and more secure, and reduces the potential for behavior problems.

- Anxiety is present *even if you don't see it.*
- When you install locks it is almost *always* harder on you than the individual with PWS.



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**If Unauthorized Food is Known or Suspected:**

1. Do not question the consumption: *"Did you eat those chips?"*
2. Rather, presume food was eaten and state as a fact: *"I see the chips are gone."*
3. Take responsibility for the individual gaining access to the food: *"I'll make sure it doesn't happen again so you stay safe."*
4. Secure the food source.
5. Without the individual knowing, reduce calories in future meals to compensate for additional consumed calories.

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**Food Security Insights**

- Higher cognitive abilities and verbal skills do not mean the individual can override the brain's insatiable drive to obtain food.
- People with limited intellectual functioning can be brilliant at obtaining food.
- The ability to plan and execute complicated arrangements to obtain food may not generalize to abilities in other areas of life.
- Even the most honest person with PWS may lie, fib, or steal when it comes to food. This is simply a symptom of PWS.
- Behavior problems are often related to unsecured food sources *somewhere*. Once all food sources are locked, anxiety is reduced and behavior problems are often reduced in *all* areas.
- Do not remove food – or *any* item – from the hands of someone (unless dangerous or poisonous) as this will almost always create a behavioral outburst.

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### Environmental Basic B: Routines

Consistency and routines help people feel safe and secure. When people know what to expect they don't have to worry. Routines reduce anxiety. Persons with PWS have a high need for routine, predictability, consistency, and sameness in the environment.



#### Create routines to reduce anxiety

- Create routines for: bedtime, wake up time, meals & snacks, chores, etc. **Minimum 7-9 hours sleep each nite!**
- Create written or visual schedules or charts for daily activities, chores.
- Refer to written schedule to avoid disagreements
- Provide advance notice, as appropriate to the individual, about changes in plans

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### Environmental Basic C: Rules

Knowing the rules makes it easier to obtain success. Knowing the rules reduces anxiety. Persons with PWS are rule followers.



#### Establish the rules to reduce anxiety

- When something is understood as a rule, it is more likely be adhered to, *especially* if individual had input to create the rule!
- Establish the rules for chores (make bed in the morning, set table for supper), hygiene (wash hands after restroom), exercise/activity (walk first then snack), social rules (greetings, sharing), shopping (no whining), food rules: restaurant rules, buffet rules, party rules... *everything!*
- Post the rules so they're visible or easily seen until they are learned.
- Be sure to establish the rule that parents/providers can change a rule if necessary!

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### Environmental Basic D: Boundaries

Boundaries define limits and provide structure to relationships. Boundaries establish what behavior is and is not acceptable. **Firm boundaries reduce anxiety and help people feel safe. Boundaries are critically important to persons with PWS.**

#### Create clear and firm boundaries to reduce anxiety



*Boundaries feel like buoys that keep the individual afloat, and feeling safe and free from life's free-floating anxiety*

#### Define and uphold your boundaries with authority:

- **Boundary Appropriate Vocal Expressions:**
  - Well-mannered, polite, assertive, direct. NOT whining, demanding, passive, aggressive, passive-aggressive
- **Boundary Physical Proximity:**
  - With strangers, acquaintances, friends, family
- **Boundary How to Access Property:**
  - Permission v. theft

**Do Not Give the Individual with PWS Too Much Power.** If you give-in too often the hierarchy of power is turned upside down, safety is breached, anxiety is increased, and unwanted behaviors will increase and escalate in intensity.

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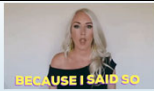
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## Boundaries continued

Goal is to be the Authority: "We need to do it" *not* Authoritarian: "Do it because I said so." Authoritarian-styles *cause* behavior problems by inherently *removing* control from the individual and activating PWS's natural oppositional thinking and behaviors.



- **Say What You Mean, Mean What You Say.** State and stick to your boundaries re: time limits, rules, routines, permissible language and behavior. E.g., *I want sugar in my coffee.* "You like sugar, don't you, I totally understand! We don't use sugar.... You don't have to have coffee today, that's ok." *"The Day Stops Here."*
- **Stop asking permission!** E.g., "It's almost time to get in the car, okay?"
- **Say what specific behavior you want, not only what you don't want.** E.g., "Stop jumping on the bed. Put your feet on the floor please." "I don't understand whining. Please use a clear voice." "I've answered that questions 3 times so as I told you, I won't talk about that anymore. Let's find something else to talk about."
- **Do not repeat requests more than 3 times.** At your third request, physically and calmly begin to intervene. E.g., Walking over to individual while stating, "It looks like you need help to keep your feet on the floor."
- **Don't threaten to remove a privilege.** Removing privileges or taking something away does *not* teach cooperation but usually lead to *more* behavior problems. If a privilege or item is revoked, *immediately* provide the opportunity to earn it right back.
- **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 a behavior problem increases. *Use The Day Stops Here\** to manage refusal behaviors (tantrum, sit down strike): progress through the day's schedule proceeds when the current task/chose is finished (or at least attempted and partially finished).

\*Term coined by Dr. Janice Forester and Linda Gouch to manage avoidance tantrums.

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## Environmental Basic E: Calm Responses

Anxiety is significantly increased by raised, critical, accusatory, or angry-sounding voices.

**Always speak calmly despite how you feel on the inside, especially during emotionally charged exchanges.**

- No matter how upset the individual with PWS is, a calm response from YOU reduces their anxiety and potential for increased behavior problems. **Use self-calming strategies to reduce your reactivity. Breathe!**
- Listen to the individual who says, 'Leave me alone.' Don't say anything else, don't look directly at them, don't stand close. Monitor with peripheral vision and let them cool down.
- Remember to match the demands on the individual to their ability.

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## Calm Responses Continued

- Ignore unwanted behaviors, while monitoring for safety, to extinguish them as quickly as possible.
- Respond to a tantrum or unwanted behavior with indifference, boredom.
- Persons with PWS typically like "drama." Some people are "pot stirrers." Don't engage. Supervise and monitor for "drama" and "gossip" and intervene as needed.
- Lying to avoid blame or gain an audience, and confabulation (making up stories) are common symptoms of PWS.



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### Don't Give In To A Tantrum

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.

Giving in today over a "little thing" will lead to a larger tantrum tomorrow. The peacefulness and overall quality of your household depends upon upholding the established limits and boundaries. Think long term! Don't give in to a tantrum.

### Don't Give In To A Tantrum

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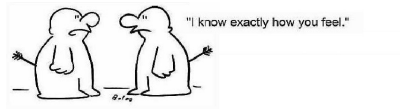
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#2

Empathy as Intervention



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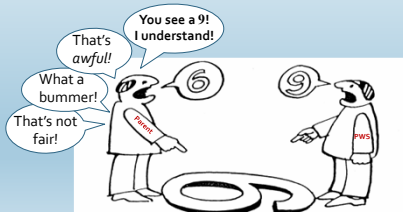
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### Empathy is a Powerful and Critical Intervention

- Empathy is the ability to see another's perspective, understand and share the feelings of another.
- Most persons with PWS do not possess the ability to see things from another's perspective.
- We have to see things from *their* perspective to manage interactions

Empathy is a **powerful and critical** intervention for PWS



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## Empathy is Successful Because...

Empathy gets to the core of anxiety, disappointment, or frustration, gets you *out* of a power struggle, and puts you and the individual with PWS *on the same side of the same team*.



At its most basic form, an empathetic response can simply be repeating the *exact* words used by the individual.

- "You want xyz. I get it. You want xyz."
- "It sounds like you would like to xyz. Is that right?"
- "Xyz won't work. No, xyz won't work."

Other phrases that can immediately convey your empathy or understanding:

- "What a bummer!"
- "What a disappointment!"
- "That's not fair!"

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## Empathy Steps

Empathy is not agreeing, or disagreeing, or giving in; it is simply communicating you understand the *individual's* perspective, want, need or concern.

If your offer of comfort is not effective, go *immediately* to Empathy.

- 1) **Get into the mindset of the individual:** What's *their* concern from *their* perspective? What do things look like from *their* perspective?
- 2) **Match emotional intensity of individual's concern:** Don't be afraid to match the intensity of their concern! If it's "awful" to the individual, you must convey you understand how awful it feels to *them*. Genuine empathy will not make things worse!
- 3) **Assess for reduction of emotional reaction:** Once the individual knows you understand their concern there is less need for them to work harder – get louder or more aggressive – to get you to understand them, and they will begin to calm.
- 4) **After reduction of emotional reaction, begin to problem solve:** Only *after* you see the individual is calming or has calmed should you begin to share *your* concern and begin to problem solve.
- 5) **Repeat from Step 1** if the individual's upset increases.

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## Empathy Steps Example

**Individual:** "I neeeced to go to the library today!" | **Parent:** "The library's closed today, we'll go tomorrow."

If your response is not effective, go *immediately* to Empathy:

- 1) **Get into the mindset of the individual:** "I hear you needed to go to the library today! I get it! Thank you for letting me know you neeeced to go today. I understand! Can you tell me why you neeeced to go today?"
- 2) **Match emotional intensity of individual's concern:** "Ohhhh, I understand! Your book is due today and you cannot return it late! That would be TERRIBLE if your book is late. That would be AWFUL if your book is late! I get it! I would NEVER want you to turn it in late! That's unacceptable! Absolutely not ok!"
- 3) **Assess for reduction of emotional reaction:** Continue Empathy until the individual knows you truly understand their concern. The need for them to work harder – get louder or more aggressive – to get you to understand them, will decrease and they will begin to calm.
- 4) **After reduction of emotional reaction, begin to problem solve:** "I'm proud you're taking responsibility to turn your book in on time! Today is Sunday and the Library is closed so you won't be late. I know you want to turn it in TODAY though! Would you like to drop it in the book slot today or tomorrow morning?"
- 5) **Repeat from Step 1** if the individual's upset increases.

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### Collaborative Problem-Solving and Empathy

Once you have employed Empathy and the individual has become visibly more calm, you can begin to work to resolve the problem collaboratively.

- 3 Types of Problems, 3 Types of Provider Responses

Safety Problem	It Doesn't Matter Problem	Work It Out Problem
↓	↓	↓
Safety Response "It's not negotiable"	It Doesn't Matter Response "Yes you can do what you want."	Work It Out Response "You want x, I want y. How can we work it out?"
		




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### 3 Steps to Solve Problems Collaboratively

Step #1: Define the Problem: "What's your concern?"  
A "problem" is two concerns that have yet to be reconciled. Defining the problem ensures that the concern of the person with PWS is understood and "on the table" for discussion and resolution.

Step #2: Implement Your Response  
"I understand! Your concern is xyz."  
Demonstrate an understanding of and empathy for the want/problem of the individual with PWS.

Step #3: Invite a mutually agreeable solution  
"My concern is abc. How can we work this out?"



If upset increases while working to resolve the problem, immediately employ Empathy Interventions

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### Empathy and Problem-Solving Tips

- Don't try to talk someone out of their upset;** they'll just feel they need to express *more* upset so that you understand. If your offer of comfort is not effective, *immediately* use Empathy.
- Don't continue to use logic and reasoning.** You are constrained by logical reasoning, but the individual with PWS is *not!* Give up trying to think of brilliant ways to convince the individual that you are right... *all they hear is you telling them they are wrong* which will increase their upset. Use Empathy.
- Use fewer words.** More words do *not* make it better and usually *increase* upset.
- Don't engage in a Power Struggle.** Learn when to disengage. Disagreements can often be ended if you allow the individual with PWS to have the last word. "I'll say one more thing, and then you can say one more thing, and then let's talk about something different." **Don't say another word!**
- Don't argue. You can't win.** Use "You might be right." Use "Interesting thought" or "You think x and I think y." Use Empathy.
- Distraction after empathy** can be effective.




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#3  
Preferred  
Choices



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### Preferred Choices

**PWS causes oppositionalism.** The brain's automatic reaction is typically to respond with "NO!" This looks like oppositional, defiant, argumentative behavior.

- **Avoid "Yes/No" questions. Offer Win-Win Preferred Choices** to reduce oppositionalism and improve cooperation. Make *everything* the individual's choice within the preferred win-win options you present to give the *experience* of control but not too much *actual* control.
  - *Do you want to take your shower now or at the commercial?" "Do you want to work on your homework for 15 minutes or 20 minutes before taking a break?" "Do you want to leave for your work program at 8:00 a.m. or 8:15 a.m. in the morning?" "Do you want to set the timer or watch me set the timer?"*
- Avoid open-ended questions as they can be difficult to process and create anxiety.
- Avoid ambiguity. "We'll see" or "Maybe later" are vague and may create anxiety. If you don't know, say, "I don't know, and I'll let you know as soon as I do."
- Avoid hurrying with your words. Instead, use music and games to motivate or hurry.
- Allow lots of time to process past the brain's oppositionalism. Build in extra time *everywhere* you go.

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### Preferred Choices to Manage Obsessive-Compulsive Tendencies

The brain believes 'if 1 is good, 100 is better.' Many people with PWS collect or "hoard" items. Sorting, pulling, tearing, stealing, and skin picking can be associated with the brain's obsessive and compulsive tendencies.

If the obsessive thoughts or compulsive behaviors don't interfere with the flow of the day or anyone, ignore them. Otherwise:

- Give limited, preferred choices.
- Provide lots of empathy.
- If the individual has a history of stealing items from neighbors or stores you may wish to introduce your child and his diagnosis to everyone, including your local police department.
- Engage the individual with activity involving their hands if skin picking. "Can you do me a favor and carry this over the dining room table for me please?"
- Medication can be necessary for some individuals.

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#4

Paint the Picture



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### Paint the Picture

Knowing what to expect reduces anxiety and reduces the potential for unwanted behavior

**Paint the Picture** before entering *any* situation, explain in detail what will happen, what things will look like, expectations for behavior, what the plan is if unwanted behavior occurs, etc.

**Paint the Picture: Restaurant**

**Before leaving the house**, check the restaurant's menu online. Offer 2-3 preferred choices for main course. Make sure you identify two choices in case the restaurant doesn't have their first choice!

**Establish restaurant rules.** Discuss *every imaginable detail beforehand* so there is no room for disagreement. Write it down until it becomes routine.

- What will the beverage be? How many beverage refills?
- Is bread allowed? Butter? How much bread or butter?
- Will the entire meal be consumed in the restaurant or will a portion be taken home? How will this be managed?
- Is dessert authorized? What options for dessert?
- Discuss table manners and expectations.
- Discuss protocol re: if behavior problem
- Praise throughout the meal for all appropriate behaviors!



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### Paint the Picture

**Paint the Picture: Family Gathering, Holiday**

**Before leaving the house**, establish what food options there may be. **Identify every single detail imaginable beforehand so there is no room for disagreements.**



- Appetizers? How many and who will assist.
- Main course? How much and who will assist.
- Beverage? How many beverage refills?
- Is dessert authorized? What options for dessert?
- Discuss table manners and expectations.
- Discuss protocol re: if behavior problem
- Make certain there are plenty of activities for individual so they are occupied between and after meal!
- Praise! Praise! Praise! throughout meal for all appropriate behaviors!
- Giving *too much* advance notice creates anxiety for some people. Not giving *enough* advance notice creates anxiety for others. Finding the right timing for the loved one in your care is critical... though not always easy.
- Anticipate that what you do or what happens *this* time will be expected to occur *next* time. Disappointment will result if it *doesn't* occur, if not fixed first.

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#5

Fix  
A  
Past  
Goof



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### FIX A PAST GOOF

Anything that has occurred in the past is expected to occur in the future. If something that occurred in the past needs to change, it is important to provide advance notice for the change and what that will look like. **Fix a Past Goof** and paint a *new* picture to create appropriate future expectations.

#### Fix a Past Goof Guidelines

1. Bring up issue that needs fixing.  
*"Remember last time when we went to the library and got a lollipop on the way out?"*
2. Incorporate empathy. Remind individual how wonderful (or bad) it was for individual last time.  
*"That was a nice, unexpected treat, wasn't it?"*
3. Preface fix with reminding individual of benefit to them.  
*"We always want to do what's best for you because we care about you."*
4. Introduce the fix.  
*"This time when we leave the library we will not get a lollipop on the way out because that's not healthy for you."*

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#6

Disguise  
Your  
"No's"



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### Disguise "No" as a Positive

Anything that looks, sounds, or smells like a frustrator could lead to a behavior problem. The word "No" is a frustrator. The word "but" is a frustrator.

**Use "No" and "But" sparingly and disguise them whenever possible!**

- Individual: "I want supper now."
- Provider: "Me too! I love supper! We're having a Chef Salad with hard boiled eggs tonight! Will you put your Bolthouse Ranch or Cucumber dressing on it? After you set the table and take your shower it'll be time for supper!"
- **Use Empathy.** Be gently and compassionately unswerving.
- **Use the broken record technique.** "Yes! As soon as you set the table and take your shower it'll be time for supper!"
- **Schedule non-preferred tasks/activities before preferred tasks/activities.** "First you set the table and shower, then we'll have supper."
- **Keep the individual "thinking" versus spiraling deeper into the negative feeling.** "What do you think we should do about that, x or y?" "What options do we have, x or y?" "I wonder if we could x or y"

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#7

Allow for the Possibility of Rightness



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### Need to be Right | Good | Competent

Most people with PWS have a strong need to be right at all times and at all costs. Disagreements can quickly turn into power struggles that have a "life or death" feel to them because being "wrong" to the person with PWS feels deathly intolerable.

**Allow for the possibility of the individual's "rightness" to avoid power struggle arguments**

- "You might be right." "I like how you think!"
- "Interesting thought." "Isn't that interesting. You think x and I think y"
- "I never thought of that!" "So you think x and I think y. I wonder why?"

- **Anticipate denying guilt or lying to get out of trouble.** Acknowledge simply or ignore self-defending statements. E.g., Person with PWS: "Don't blame me!" You: "I heard you."
- Many people with PWS believe they should already know something not yet learned so their response may be to fake or argue. **Teach as if you believe they know what you're teaching.** "You know the routine at the end of the day, right? You brush your teeth and we pull out your clothes for the next day and lay them on your chair. You know that, right? Great job!"
- **Role model that it's ok to make a mistake:** "I goofed!"

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#8

Use Their  
Egocentrism  
to Your  
Advantage

It's All  
About  
ME!!!



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### Egocentric Thinking

PWS neurochemistry typically interferes with the ability to see things from another person's perspective which can look like self-centeredness and egocentrism. **People with PWS generally think about themselves first and foremost.**

**Use PWS' egocentrism as a strategy to increase cooperation.**

- Don't say, "If you don't hurry, Brother will be late to his soccer game." Do say, "If we get Brother to soccer on time, we'll have time for a movie!"
- Don't say, "Your yelling is disturbing the neighbors." Do say, "I hear you want xyz. When you speak softly and calm your body we can talk about what you want."
- Teach the other's perspective. "What do you think they're thinking?" "What do you think they meant?" Teach "on purpose" vs "on accident."
- Utilize egocentric thinking to your advantage! "Now that you're 10 years old, I wonder if you're mature enough to do your own laundry. I'm not sure though... Do you think you're mature enough?"

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#9

Motivate  
Externally



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## Motivate Externally

Most persons with PWS typically have low internal motivation. **Motivate externally using:**

- Verbal praise, encouragement, high-fives
- Earning privilege to be a 'special helper'
- Special time earned with someone
- Token rewards, stickers, collectibles, reward system
- **Do NOT use food as a motivator, incentive, reward, or punishment!**

Remember that **Executive Functioning deficits are common**. Individuals will need support throughout the lifetime with planning, prioritizing, organizing, problem-solving, self-monitoring, self-regulating, paying attention, beginning tasks, multi-tasking, meeting deadlines, time management, and short-term memory.

- **Have appropriate expectations.** Higher cognitive abilities don't necessarily mean improved judgment, "common sense", or problem-solving skills, all of which are typically impaired. **Specifically teach metaphors** (The snow is a white blanket), idioms (cold feet = nervous), slang (Bae).
- **Watch, pause, talk about tv cartoons, shows, commercials to teach social competence**
- Abstract concepts like time and time management can be especially difficult due to concrete thinking. **Use visuals, visual schedules, egg timer, Time Timer, alarms, Change Card, etc.**
- **Guide to conclusions rather than solving problems for the individual**
- **Remain vigilant "delusional grandiosity" and monitor for safety**

\* Term coined by Janice Forster, M.D. and Linda Gourash, M.D.

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#10

Use Transition Prompts to Increase Flexibility




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## Transition Prompts

Many people with PWS have attentional deficits. At the same time, they often exhibit hyper-focus on what they're doing *in the moment* which makes it difficult to move to the next activity even if moving to a preferred activity. Common challenges include non-stop writing, torn paper from continuous erasures, etc.

- Use **limited, Preferred Choices**
  - "Do you want to stop in 3 minutes or 5 minutes?"
- Use **Transition Prompts to help the brain prepare to move to the next task or activity.**
  - "5 minutes until we leave. 3 minutes, let's put shoes on. 1 minute until we leave. Good job!"

- Use a "Change Card"
- **Praise! Praise! Praise!**



- **Provide lots of empathy**
  - "I know it's really, really hard to stop. You don't want to stop. I understand. And you chose 5 minutes so it's time to stop."

- **Participate in activities alongside the individual**

- **Lead Like a Momma Duck\*** Use your body movements to "pull" your loved one to follow you.

\*Strategy applied to PWS by Katherine Crawford

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## Excessive Talking, Repeated Questions?

**Determine the function.**

**May reflect short-term memory deficit:** Answer question 2-3 times then ask the individual what *he* thinks answer is. Confirm then let him know the question is all done being asked and answered.

**May reflect anxiety:** Work to reduce stressors.

**May reflect desire to connect:** Engage the individual in conversation, steer from monologue to dialogue, to another topic. Help individual engage/play with peers.

**May reflect a learning style or disability (NLD):** The individual may need to talk out loud in order to better understand their situation or environment. Gently guide their understanding with reflections, clarifying questions or statements.

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## Final Thoughts

Bear in mind that *everyone* has a bad day now and again, including persons with PWS, and that even the most brilliantly managed intervention won't be successful *all* of the time. That's just PWS... and that's just life!

When you incorporate the strategies you've learned today, however, you will create an environment that inspires greater overall cooperation, increased fun with your loved one with PWS, and reduced stress for *everyone!*

Want more in-depth training? Join us for the Family Behavior Management Focus Sessions Series! Contact PWCF to learn more.

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