

How to Thrive Through the Holidays *and every celebration!*

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PWCF
General
Education
Meeting
2026



Words of

Provide guidance and boundaries
Provide supervision
Plan enjoyable activities
Have fun!

Words of

If You Fail to Prepare
Prepare to Fail

Can't We Just Relax and Enjoy Ourselves at a Holiday Event?

Yes! We *can* relax... with preparation, food management, and supervision!

But PWS doesn't 'relax' at events. In fact, symptoms can *intensify*, especially when there's any change in routine and when food is accessible, or when food is *believed* to be accessible, or when there is *hope* that food will be accessible.

Guiding Principles to Make *All* Events Safe and Fun

- We must manage our loved one with PWS differently than individuals who don't have PWS.
- Designated supervision is essential; when everyone is watching, no one is watching. More accidents occur at large events and family gatherings when there is no *designated* supervision.
- Punishment is not effective with most persons with PWS and typically escalates unwanted behavior.
- Positive reinforcers and PWS Behavior Management Strategies are quite effective.

The more we understand how PWS affects our loved one and the more competent we become at using PWS Behavior Management Strategies, the more we'll avoid maladaptive behaviors and effectively manage them.

Proactively
Manage
Food
Stressors



Food is Stress

PWS Hyperphagia

Hyperphagia is a complex neurochemical drive that encompasses much more than just "overeating." The brain functions as if food is scarce, the body is starving, and survival is at risk.

- The brain drives the individual to eat or save to eat later as much food as possible
- The brain blunts satiety / feeling full despite quantity or interval of food intake
- The brain tells the body to store consumed food as fat
- The brain lowers the metabolic rate to almost half the normal rate to conserve energy

The degree of hyperphagia varies from person to person and varies within the same person over time. Continuous talking about food is a degree of hyperphagia.

PWS is not an eating disorder. PWS is a genetically-based medical disorder.

If we fail to recognize hyperphagia symptoms *and* we do nothing to manage this symptom, it will negatively effect our loved one.

The Principles of Food Security provide us with a roadmap to proactively manage food!

Principles of Food Security

The **Principles of Food Security** is a concept developed by PWS specialists **Janice Forster, MD** and **Linda Gourash, MD** and are considered a **Standard of Care throughout the world**.

The Principles of Food Security guide us to ensure that the individual with PWS has:

NO DOUBT

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

+

NO HOPE or CHANCE

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

=

NO DISAPPOINTMENT

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

NO DISAPPOINTMENT MEANS NO BEHAVIOR PROBLEMS!



No Doubt

No doubt when the next meal or snack will be served

Consistent routines for food consumption are essential. Meals and snacks generally served every 3 hours: Breakfast / Morning Snack / Lunch / Afternoon Snack / Dinner

- Do not breach Food Security during celebrations – *incorporate* Food Security into the day/event. Create and carry the written Food Plan with you. More tips later on **How to Create a Food Plan**.
- Pre-determine your response when asked for food before it's scheduled: *"I hear you want to eat now. I do too! We'll all eat together some time after everyone arrives. I'll let you know as soon as we can eat. What do you want to do until it's time to eat, your Diamond Art or play cornhole in the back yard?"*

NEVER use food as a reward
NEVER use food as a bribe
NEVER withhold food for poor behavior

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.



- Reduce or eliminate access to food to reduce or eliminate anxiety and behavior problems**
- Most effective strategy is to restrict access to food: frig, pantry, money.
- Provide Continuous Supervision. Strategies depend upon individual's tolerability and impulse control.
 - Maybe arrive to the party later, just before food is likely to be served. Or plan to leave shortly after the meal has concluded.
 - More tips later on **How to Create a Supervision Plan**
- Keep the individual busy!
 - Assign helpful and/or fun tasks for the individual, e.g., *"Your job is it entertain Baby Emma!"*
 - Pack plenty of toys, games, activities to play or engage with during non-eating times.
- Never give in to a tantrum -- *especially* for food. More later on **How to Create a Behavior Plan**.

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, overall quality of your household, and ability to successfully participate in future events 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

Important Note: When we begin to hold to boundaries better, behaviors often get worse before they get better. Practice implementing and holding to boundaries long before your celebrations and events! Stay strong, maintain boundaries, and behaviors will improve!

If Unauthorized Food is Known or Suspected:

1. Do not question the consumption: *"Did you eat those cookies?"*
2. Rather, presume food was eaten and state as a fact: *"I see the cookies are gone."*
3. Take responsibility for the individual gaining access to the food: *"I'll make sure that can't happen again so you stay safe. Let's go play in the other room."*
4. Secure the food source or increase supervision or leave the party so that additional food cannot be taken or eaten.



Tips:

- Unless the food is dangerous or poisonous, do not take it out of the individual's hands as this will almost *always* induce a meltdown behavior.
- If you see the individual in the midst of eating unauthorized food, use your Authoritative Voice to direct them to put it down. *"Those cookies are not yours. Please put them down. If you choose to eat them now, you will have less food later."* If they put the food down, praise the behavior. *"Great decision. Very mature. I'm proud of you."* If they do not put the food down, continue to use your Authoritative Voice to direct them to put it down, monitor for safety, and implement your Food Plan for unauthorized taking of food. Provide less food later to help compensate for the additional calories. Don't talk more about it. Let it go.

The Principles of Life Security

Because for most persons with PWS “Enough of *anything* is Never Enough” – food, beverages, video games, shower time, toilet paper, asking questions... *anything* – Apply the *Principles of Food Security* to *all parts of life* to create LIFE SECURITY!

- No Doubt about *anything* +
- No Hope or Chance for *anything* prohibited or inaccessible =
- No Disappointment-related behavior problems!
- I have No Doubt I will open my stocking on Christmas morning +
- I know there is No Chance there will be any candy in my stocking =
- I won't be Disappointed when there's no candy. I'll feel happy to play with what's there!

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



And YOU have the potential to *reduce* or *eliminate* behavior problems!

Strategies
to
Proactively
Manage
All
Stressors



Emotional Dysregulation & Hyper-Reactivity

Individuals with PWS typically have a hard time managing their emotions and tend to over-react to stressors, leaving the individual

- A stressor consists of anything that is experiencing a continuous state of anxiousness.
 - is unknown, out of routine or schedule, unexpected ("that can hurt/confuse me")
 - is disappointing ("that prevents me from having/doing what I want/need")
 - feels out of control ("and can hurt/confuse/prevent me from having/doing what I want")
 - critical or accusatory ("that sounds or looks like I made a mistake or did something wrong")
- A stressor/anxiousness can cause maladaptive behaviors that look like:
 - ✓ Arguing and defiance
 - ✓ Verbal and physical aggression
 - ✓ Elopement
 - ✓ Repeated questions
 - ✓ Excessive talking
 - ✓ Skin picking

When we reduce or eliminate the **cause** of the stress,
we reduce or eliminate the **maladaptive behavior!** Plan Ahead! Be Proactive!



Paint the Picture



Paint the Picture

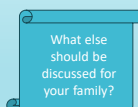
Knowing what to expect reduces anxiety and reduces unwanted behavior.

Paint the Picture so the Individual knows what to expect at the event.

Collaborate. Don't dictate! The more we include your loved one in the preparation process, the greater the potential they will cooperate. "Mom and Dad were wondering if this year you might be mature enough to participate in the planning of our visit to Aunt Sally's. We're not sure though... do you think you're mature enough to participate in this year's planning? Terrific! Let's talk about making a plan so we all have fun!"

Paint the Picture by discussing:

- Where you're going, who's coming, what's going to occur, flow of the day, sequence of events or activities for the *entire* day. **Factor in timing:** Giving *too much* advance notice creates anxiety for some; not giving *enough* advance notice creates anxiety for others.
- Create a written **Food Plan**.
- Create a written **Supervision Plan**.
- Create a written **Behavior Plan**.
- Discuss activity options during non-eating times. Bring activities -- toys/books/puzzles/games/coloring/diamond art. Use electronics with caution.
- Praise! Praise! Praise!** throughout the planning process for any and all enthusiastic, calm, and cooperative behavior!



How to Create a Food Plan

Create a Food Plan working with the individual about how food will be managed throughout the day/event. **Collaborate, don't dictate!** The more we include our loved one in the process, the greater the potential they will cooperate. *"Because we want you to enjoy as much food as possible, we need to make a Food Plan!"*

- Discuss with your loved one in great detail:
 - Eating at a family home or going to a restaurant?
 - Appetizers? Bread? Butter? Chips? Salsa? How many and who will assist?
 - Main course? How much and who will assist?
 - Beverages? What kind? How many refills? Could a Cirkul water bottle help?
 - Is dessert authorized? What options for dessert?
 - Table manners and expectations.
 - Create a non-shaming system to remind or prompt regarding the Food Plan and behavior.
- Without the individual knowing, you may wish to reduce calories a few days prior to the event to help compensate for increased calories consumed on event day.
- **Praise! Praise! Praise!** all cooperative behaviors throughout the Creating a Food Plan process!

What else should be in Your Food Plan?

Choose the Healthiest Options Available!

Whether you bring your own appetizers and food items, enjoy what is brought by others, or enjoy restaurant food, make the healthiest choices available. The recommended "PWS Diet" is low cal, low carb, higher protein: Lean meat, fresh veges, small carbs, small whole grains), small to no dessert.

Appetizers: Pickles, olives, raw veges,

Meats: Leaner meats: turkey, chicken, fish, duck, lamb, pork. Serving Size: depends upon person; think "a deck of cards".

Vegetables: Cooked (steamed, baked, no sauces). Serving Size: half the plate

Fruits: Berries are lowest in calorie: blueberry, raspberry, strawberry. Portion size: no more than 2 fruits for the day.

Carbohydrates: Complex carbs: brown rice, quinoa, wheat bread, potatoes, sweet potatoes, peas, corn, yams, beans, lentils, chickpeas, and peas. Portion size: small

Desserts: Bowl of berries with whipped cream. Portion size: very small



How to Create a Supervision Plan

More serious accidents and deaths occur during large gatherings and celebrations because when everyone is watching, no one is watching!

Create a Supervision Plan for the day.

- **Collaborate. Don't dictate!** The more we include our loved one in the preparation process, the greater the potential they'll cooperate. *"Because we want you to stay safe, we need to make a Supervision Plan!"*
- Assign Supervision shifts so no one person is overburdened. **No supervision gaps.** *"Would you like Dad to supervise first, or Mom to supervise first? Great! Would you prefer that Aunt Sally or Uncle Henry supervise you next? Terrific. We're all done! Great job helping to create our Supervision Plan!"*
- Provide 1:1 supervision even with a low-food-drive individual who may not be able to stop themselves from taking unauthorized food that is opportunistically available.
- Write the Supervision plan on paper to refer to later if needed.
- **Praise! Praise! Praise!** all cooperative behaviors throughout the Create a Supervision Plan process!

What else should be in your Supervision Plan?



How to Create a Behavior Plan

Create a Behavior Plan for the day. Collaborate, don't dictate! Working with the individual, establish a plan for a successful celebration: social rules (greetings, be polite, share), chores (help set the table, take your dish to sink), hygiene (wash hands after restroom), etc. Talk about every aspect of the event that potentially needs an agreement and address it in your Plan.

"We'd like to work with you to create a Behavior Agreement Plan that will help us make sure you have a great time! Only individuals who are mature and responsible enough may enter into an agreement though. Do you think you're mature and responsible enough to enter an Agreement, or no? Terrific! Let's create a Plan together so we all have fun!"

- Clearly define "appropriate", "not appropriate", "cooperative", "not cooperative". Write it on your Plan!
 - *"We wouldn't want Aunt Sally or anyone to yell at you. That would not be appropriate. Do you agree? Great! Let's put that on our Agreement. It's fair, then, that none of us should yell at Aunt Sally or anyone, right? Great! Let's put that on our Agreement."*
 - *"We're thinking that 'cooperating' is when we ask you start to put away your activities in 5 minutes, and we set a timer, and when the timer goes off you begin to put away your activities. What do you think of our definition of 'cooperating'? Do you have anything to add?"*



How to Create a Behavior Plan continued

- If maladaptive behaviors occur during the process of making a Behavior Plan – or any of the Plans – simply take a break and invite the individual to let you know when or if they're ready to continue planning. *"Your voice is getting loud, so we'll take a break. Just let us know when you're ready to resume our planning!"*
- Make a Plan for how unwanted behavior will be managed at the event. *"If Mom or Dad is disruptive to the party, we would need to leave, right? Do you want to write that on the Plan, or do you want me to write it? If you are disruptive to the party, would you like some time to calm your body first and try to rejoin the party, or would you prefer to just leave? Who would you like to take you to the car to calm your body, Mom or Dad? Ok, we can do one retry."*
- Create a non-shaming system to remind or prompt regarding behavior. *"If we need to remind you about our Behavior Agreement, how can we do that so you won't feel embarrassed?"*
- Will there be any rewards for appropriate, cooperative behavior? Can the individual earn "extra points" for "great behavior"?

"We want to make sure you have a great time at the party! We were thinking we could create a reward for each appropriate, cooperative, and helpful behavior we see you do. What do you think of that idea? What rewards do you think you'd like to earn – stickers toward a movie or bowling outing perhaps?"

What else should be in your Behavior Plan?

Behavior Agreement Plan

Only individuals who are mature and responsible enough may enter into an Agreement. Do you think you're mature and responsible enough to enter an agreement, or no?"

What does the Individual want?

What is the Provider's concern about what the individual wants?

How can you work it out? Brainstorm possible solutions. There are NO BAD IDEAS!!!

Write down agreed upon plans. Be specific and detailed.

Individual's Signature

Provider's Signature

Adhere to Your Plans

You must follow through on all Plans you create.

Sticking to your agreed upon Plans will reduce your loved one's anxiety and will reduce unwanted behaviors!

- **Don't allow yourself to be manipulated.** When the individual believes they have manipulated you -- fooled you, tricked you, or convinced you to give in -- they know you can't keep them safe, their anxiety will increase, and the potential for a behavior problem will increase.

- "Dad said I could have it." ⇒ "Lovely, I'll just check with Dad."
- "Mom said it was ok." ⇒ "Great, I'll just check with Mom."



Clearly defining and upholding your family's Plans (boundaries) will help your loved one feel safer, less anxious, and therefore they'll exhibit improved behavior!



Paint the Picture

Long-Term memory for most persons with PWS is amazing, so don't think your loved one won't remember something from years ago. Chances are, they will!

Anticipate that whatever happened *last year* -- good or bad -- will be expected to occur *this year*.

And that what you do or what happens *this year* at *this event* will be expected to occur at *all future events* --

If something that happened last year will be or *needs* to be different this year, you must correct your loved one's expectation and **Paint a New Picture**.



Fix
A
Past
Goof



Fix a Past Goof

Anything that 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 when we went to Aunt Sally's house and people were giving you extra food?"
2. **Incorporate empathy.** Remind individual how wonderful (or bad) it was for individual last time.
"That was pretty surprising, I imagine! And pretty nice, I also imagine!"
3. **Preface fix with reminding individual of benefit to them.**
"We love you a whole lot and want you to be safe and healthy and have lots of fun at parties!"
4. **Introduce the fix.**
"So this year, we have already let everyone know that they may not give you any extra food, and we'll have our Supervision Plan in place so you stay safe as you have a great time!"

How to Fix a Past Tantrum Goof

We've all given in to a tantrum before! But it's extremely important **not** to give in to a tantrum and **Fix the Past Goof of giving in to a tantrum**.

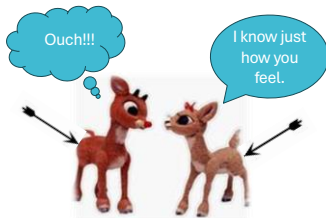


Steps to Fix A Past Tantrum Goof

1. Explain that your past giving in has not been helpful to *the individual*. *"Last year when you cried/yelled for more food, we gave in to you, didn't we."*
2. Explain that from now on, *for the individual's benefit*, you won't give in and you'll work hard to keep them safe. *"And now we know that's really not good for you. Giving in to you when you're drying or yelling actually hurts you and we never want you to be hurt!"*
3. When a tantrum begins, calmly remind the individual their behavior won't get them what they want, and that you will not give in because that's not fair to him/her. *"So we want you to know that this year, no matter what you may do, we will not give in and give you more food because that's not good for you/fair to you."*
4. **Stay strong and don't give in!**

Remember to practice defining and holding boundaries long before your events so your loved one learns no matter what they do, you will no longer give in to their tantrum behaviors!

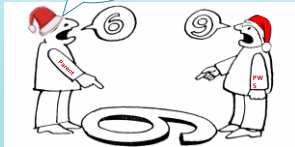
Empathy Intervention



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



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 your cousin's toy. I understand. You want your cousin's toy."
- "It sounds like you'd like to go outside right now. Is that it?"
- "Waiting until later won't work. No, it won't."

Other phrases that can immediately convey your empathy or understanding:

- "What a **bummer** Cousin won't let you play with her dolly!"
- "What a **disappointment** we're not ready to leave just yet! It's sooo hard to wait!"
- "That's **not** fair he has more than you're able to have!"

Empathy Steps

Individual: "I neeeeed to wear my purple shoes to the party!" | **Parent:** "Oh no! Your purple shoes broke last month! This is terrible that your purple shoes broke and you can't wear them!"

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

- 1) **Get into the mindset of the individual:** "I hear you neeeeed to wear your purple shoes! I get it! Thank you for letting me know you neeeeed to wear your purple shoes. I understand! Can you tell me why you neeeeed to wear the purple shoes?"
- 2) **Match emotional intensity of individual's concern:** "Ohhh, I understand! Auntie Sally said she loves your purple shoes, and you want to look special for Auntie Sally! You think *ONLY* your purple shoes will make you look special to Auntie Sally. No other shoes in your closet will make Auntie Sally see you as special! The pink shoes won't work. The blue shoes won't work. Nope, only the purple shoes!" **Genuine Empathy will NOT make it worse!**
- 3) **Assess for reduction of emotional reaction:** Continue the Empathy Intervention until the individual knows you truly understand their concern. If you're doing it right, they will begin to calm because the need for them to work harder to get you to understand – get louder or more aggressive – is no longer necessary.
- 4) **After reduction of emotional reaction, begin to problem solve:** "I'm proud you're taking responsibility to dress nicely for the party! I do believe Auntie Sally will know you're special even without your purple shoes. I know it's sooooo disappointing that you're not to be able to wear them. Do you want to wear your beautiful pink or the gorgeous blue shoes today to show Aunt Sally?"
- 5) **Repeat from Step 1** if the individual's upset increases.

Empathy 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, **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.**
- **Don't argue. You can't win.** Arguments are power struggles. Use "You might be right" or "Interesting idea". Disengage after 3 back-and-forths. 3). Disagreements can often be ended if you **allow** the individual to have the last word. *I'll say one more thing, then you can say one more thing, and then let's talk about something else."* Or *"You know what your options are, so I won't talk about this with you anymore. I'm happy to talk about something else with you though."* **Don't say another word!**
- **Use fewer words.** Unless you're expressing Empathy, more words do *not* make it better and usually *increase* upset.
- **Distraction *after* empathy** can be effective.

Empathy and Problem-Solving Tips

Empathy is what we use to help comfort and calm upsets. *"Santa didn't bring the toy I really wanted."* *"Aunt Jane's not here. She promised she'd see my new red shoes!"*

But Empathy alone doesn't fix a problem that *is* solvable.

Collaborative Problem-Solving is what we use to help fix a problem that *can* be solved. *"I can't find my new red shoes!"* or *"My toy just broke!"*

- Collaborative Problem-Solving means we are working to resolve a problem *with* the individual. We are *not* solving the problem *for* the individual or dictating the solution. *"Oh no! We've got to find your red shoes! How can I help you look for them?"* or *"Oh no! That's awful! Would you like me to try to fix it now, or would you like to play with something else now?"*

Don't try to fix the problem *for* the individual. If we try to solve a problem *for* the individual, especially when they are upset, we will likely be met with *"No, that won't work!"* (neurocognitive wiring toward oppositional thinking).

Incorporate Empathy into *every* interaction as you work to resolve problems collaboratively.

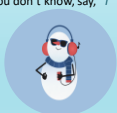
Preferred Choices



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 your preferred win-win options to give the individual the *experience* of control but not too much *actual* control. "Do you want to wear the brown pants or the black pants?" "Do you want to bathe/shower in 5 or 7 minutes?" "Do you want to sit on Mom's left or right side?"
- Avoid open-ended questions as they can be difficult to process, create anxiety, and may give the impression whatever they answer is an option. "What do you want for supper?"
- 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. Use music and games to motivate or hurry.
- Skin picking? Engage the individual's hands. "Can you do me a huge favor? Please take this to Uncle Henry in the back yard? Thank you! Now, can you please take this to Aunt Sally in the family room? Great!"
- Build in extra time for *everything*.



Disguise Your "No's"



Disguise Your "No" as a Positive

Anything that looks, sounds, or smells like a frustrator could lead to a behavior problem. The words "No" and "but" are frustrators.

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

- Individual: "I want to eat now."
- Provider: "Me too! I can't WAIT till it's time to eat! We'll have delicious food, won't we?! Do you think Aunt Mae will bring her famous mashed potatoes or sweet potatoes? We'll leave for the party around 3:00 p.m. which gives us all enough time to take showers and get dressed and then leave for Aunt Mae's!"
- Use **Empathy**. Be gently, compassionately, and empathetically unswerving. "It's soooo hard to wait till 3pm, I get it! Do you want to take your shower first or lay out your clothes first?"
- Use the **broken record technique**. "Yes! As soon as we're showered and dressed, we'll leave for Aunt Mae's!"
- **Boundary your responses to 3 times**: "We've already talked about when we leave for the party so I won't talk about that with you anymore. We can talk about something else though!" ["What's your name?"]
- **Schedule non-preferred tasks/activities before preferred tasks/activities**. "First we shower and dress, then we'll go to the party."
- **Keep the individual "thinking" versus spiraling deeper into the negative feeling**. "What do you think could help us get dressed more quickly, playing a song from my phone, or singing a song ourselves?"

Allow
for
the
Possibility
of
Their
Rightness



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!"

"That interesting. You think x and I think y. I wonder why..."

- **Anticipate denying guilt, shifting blame, or lying to get out of trouble.** Acknowledge simply or ignore self-defending statements.
- **Don't argue.** Your loved one cannot be wrong or let it go which means you need to be able to do so!

Use
Their
Egocentrism
to
Your
Advantage



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, we'll run into a lot of traffic!" Do say, "If we get to the party on time, you'll be able to show Uncle Henry the pictures you made!"
- Don't say, "Your yelling is bothering everyone." Do say, "I hear you want xyz. When you speak softly and calm your body we can talk more about what you want."
- Utilize egocentric thinking to your advantage! "Now that you're 5/13/27/39/58 years old, I wonder if you're mature enough to shake everyone's hand/hug them when we arrive at the party. I'm not sure though... Do you think you're mature enough?"

Motivate Externally



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 reward systems, collectibles, etc.
- **NEVER use food as a motivator, incentive, reward, or punishment!**
- **Executive Functioning deficits are common** so individuals will need some degree of support with planning, prioritizing, organizing, problem-solving, self-regulating, paying attention, beginning tasks, multi-tasking, time management, and short-term memory.
- **Have appropriate expectations.** Higher cognitive abilities don't always mean improved judgment, common sense, or problem-solving skills.
- **Teach and praise social competence.** Teach and practice table manners, greetings and goodbye handshakes, eye contact, etc.
- Abstract concepts like the passage of time are difficult due to concrete thinking. **Use concrete tools** – visual schedule, timers, auditory alarms, written Agreements, etc.
- **Guide to conclusions** rather than trying to solve problems *for* the individual. Think "Preferred Choices"!



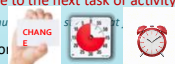
Use Transition Prompts to Increase Flexibility



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.

- Use limited, Preferred Choices
 - "Do you want to stop what you're playing in 3 minutes or 5 minutes to wash your hands for supper?"
- Use Transition Prompts to help the brain prepare to move to the next task or activity.
 - "Ok, 5 minutes until we stop playing. 3 more minutes. 1 more minute."
- Use concrete prompts! Change Card, Visual Timer, Audiotape
- Praise! Praise! Praise! "Great job stopping on time. I'm proud of you!"
- Provide lots of empathy
 - "I know it's reeeeeeally hard to stop. You don't want to stop! I get it! You chose 5 minutes and 5 minutes is up, so it is time to stop."
- Participate in activities alongside the individual. "Time to clean up! Let's see who can put it away faster!"
- Lead Like a Momma Duck* Use your body movements to "pull" your loved one to follow you.



Brief Overview of Special Medical Considerations



Brief Overview of Special Medical Considerations

- **Gastroparesis** Presume some degree of slow emptying stomach.
 - Assess: abdominal distention, bloating, pain, and/or vomiting may be signs of life-threatening perforation or necrosis.
 - **Never administer Pepto Bismal or similar medications as it can cause serious injury or even death.**
- **Slow bowel motility** Presume some degree of slow emptying bowel. Harder-to-evacuate stool can cause constipation; chronic constipation can cause diarrhea.
 - Assess: chronic gas or prolonged gas pain can signify a severe bowel issue.
 - **Never administer Imodium or similar medications as this can cause serious injury or even death.**
- **Sporadic or complete inability to vomit.**
 - **Never administer ipecac syrup or similar medication to induce vomiting as this can cause serious injury.**
- **Faulty Epiglottitis** Presume some degree of **swallow problems** that can increase incidence of choking, lung-related illness
 - Encourage small bites, slow eating, sip liquids during and after meal.
 - **Never leave individual unsupervised while eating.**
- **Use the PWS Medical Alert booklet to inform ER personnel of potential seriousness.**



The Future is Brighter Than Ever!

- The first medication targeting PWS's hyperphagia symptom – **Vykat XR** – was approved by the FDA in March 2025. Effective for many, not effective for all.
- **Other promising research** targeting hyperphagia, excessive sleepiness, maladaptive behaviors, and other PWS symptoms is underway around the world by dedicated researchers and physicians.
 - Aardvark Therapeutics: ARD-101
 - Tonix Pharmaceuticals: TNX-2900 (oxytocin)
 - Harmony Biosciences: Pitolicant
 - Rhythm Pharmaceuticals: Setmelanotide
 - VNS4PWS: Vagus Nerve Stimulation
 - Montefiore: Cannabidiol (CBDV)
 - Gedeon Richter: RGH 706
 - Palobiofarma: PBF-999

The future of persons diagnosed with PWS is brighter and more hopeful than at any other time in history!



Start Preparing Today to Enjoy Your Holiday Celebrations!

Start Preparing Today!

Practice these PWS Behavior Management Strategies for a *wonderful* and safe season of family celebrations!

Prepare for an Easier Life!

Apply these PWS Behavior Management Strategies to ALL PARTS OF LIFE!



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Questions