



Prader-Willi Family NEWSLETTER

Spring 2023 Edition



NUTRITON UPDATE: Navigating Behavior

Tips to decrease battles around food

by Emely Reyes, RDN, CDCES

- Create a menu and post it where your child can see it. Include serving sizes, times, and locations where the child will eat. Include a plan for unforeseen circumstances and discuss this with your child. Reassure them that even if the plan changes, the child will not go hungry. Consider easy-to-say phrases they can remember like “There is always peanut butter” if they express anxiety about things like power outages or other events where they fear they will not have food.
- Create a similar plan for outings or parties and discuss them ahead of time. Setting clear expectations helps to reduce the hope they will get more food and this helps them to feel more food secure.
- If there are a lot of arguments at the table, consider a monthly family meeting where the child can express their concerns. Be clear that food will not be discussed at the table and remind them of the day and time of the meeting. You as the parent can decide if some changes to their meals can be made while acknowledging their feelings. (“You’re right, it isn’t fair. But this is what you need to eat to stay healthy.”)
- Reinforce “my food/your food”. Try to be as neutral as possible that everyone’s body needs different things to be healthy.
- Do not reward or bribe with food. Food is very rewarding for people with PWS and creates high anxiety to seek more. Consider non-food rewards like spending time with a friend or playing with a preferred toy.
- No unplanned treats- even sugar-free or diet ones! For the person with PWS, the brain gets

the same sense of reward regardless of the calories or sugar a food contains. The chance they can get an unexpected treat creates hope that they can get more which leads to more food-seeking behavior.

- Do not give your child foods you will have to limit later, especially sweets. Kids with PWS tend to really crave high-carbohydrate foods like sweets and bread. If you have a little one, consider not introducing these foods and you may avoid some battles down the road.



But what if the child is already sneaking food?

- Consider making a pre-planned, unchanging consequence that does not change with the amount or type of food snuck. Discuss with the child and consider posting this. Do not take away the food they have snuck if they are eating it or take away meals as this can create more anxiety and more sneaking.

An example of this could be removing a 100-calorie portion of carbohydrate food for one meal. The child will still receive a meal but will get a moderate loss of calories to help reduce the effect of sneaking. (See the recipe for an example of this)

- Discuss the importance of not giving in to behaviors with all the child's caretakers and/or teachers.
- If you haven't already done so, consider using locks or cameras. While some families can manage without them, they can make a big difference in limiting access to food.

RECIPE CORNER: Asian Tilapia with Stir-Fried Green Beans



Ingredients:

4 4-5 oz tilapia fillets
¼ cup reduced-sodium soy sauce
1 tbsp grated fresh ginger
1 tsp toasted sesame oil
1 clove garlic, minced
¼ cup water

1-pound fresh green beans, trimmed, if desired
2 tbsp water
1 tbsp canola oil
1 non-stick cooking spray
1 tablespoon sesame seeds, toasted
¼ cup thinly sliced green onions

Directions:

1. Thaw fish, if frozen. Rinse fish; pat dry with paper towels. Place fish in a shallow baking dish.
2. For marinade, stir together soy sauce, ginger, sesame oil, and garlic in a small bowl. Pour marinade over fish, turning to coat. Cover with foil and marinate at room temperature 20 minutes. Drain fish, reserving marinade. Add the 1/4 cup water to the reserved marinade.
3. In a large nonstick skillet, combine green beans and the 2 Tablespoons water. Cook, covered, over medium-high heat for 5 minutes, stirring occasionally. Add canola oil. Cook, uncovered, about 5 minutes more or until beans are crisp-tender, stirring frequently. Transfer beans to a serving platter; cover and keep warm.
4. In a large nonstick skillet, combine green beans and the 2 Tablespoons water. Cook, covered, over medium-high heat for 5 minutes, stirring occasionally. Add canola oil. Cook, uncovered, about 5 minutes more or until beans are crisp-tender, stirring frequently. Transfer beans to a serving platter; cover and keep warm.
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Nutrition Facts: Serving Size: 1 fish fillet and 1 cup green beans Per Serving: 212 calories; protein 26.1g; carbohydrates 10.5g; dietary fiber 3.2g; sugars 5.4g; fat 7.8g; saturated fat 1.3g; cholesterol 56.7mg; vitamin A IU 752.3IU; vitamin C 13.7mg; folate 66.3mcg; calcium 57.6mg; iron 1.9mg; magnesium 64.8mg; potassium 587.8mg; sodium 617.9mg. <https://www.eatingwell.com/recipe/267022/asian-tilapia-with-stir-fried-green-beans/#nutrition>

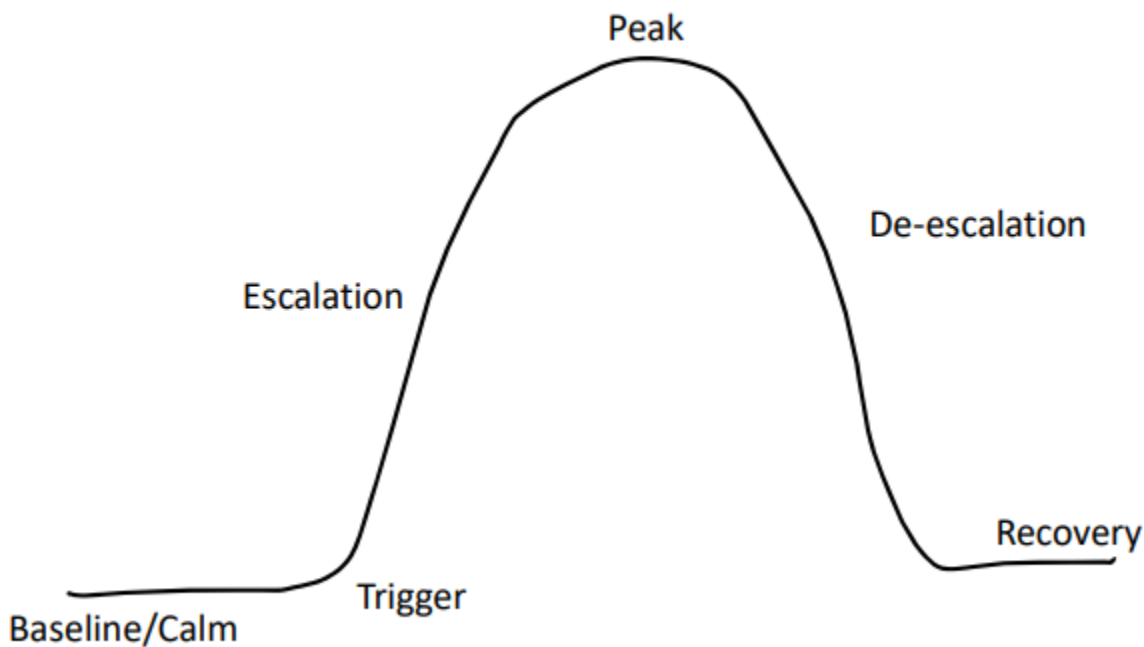
Behaviorist Corner: Understanding the Cycle

by Peter J Chung MD, FAAP

Developmental-Behavioral Pediatrician

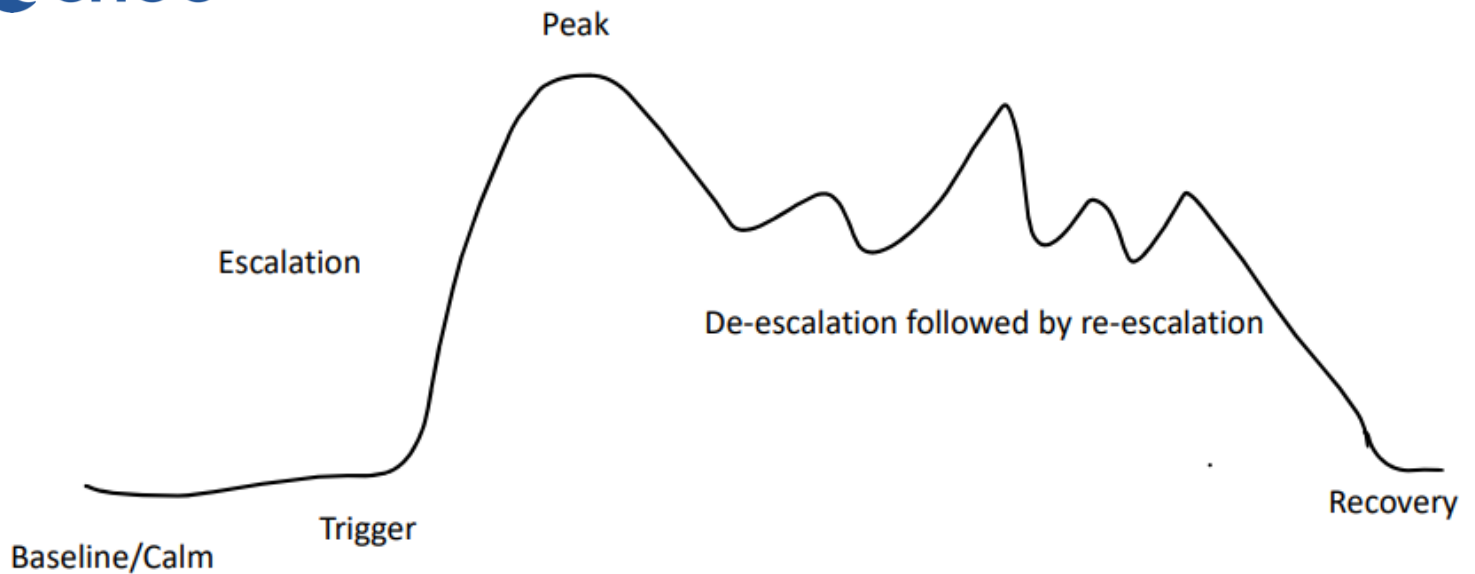
The Escalation Cycle

Individuals with PWS often have challenging behaviors and emotional outbursts. It can be helpful to think about the emotional outbursts through the lens of the escalation or “acting out” cycle. (Apologies for the crude drawings below!)

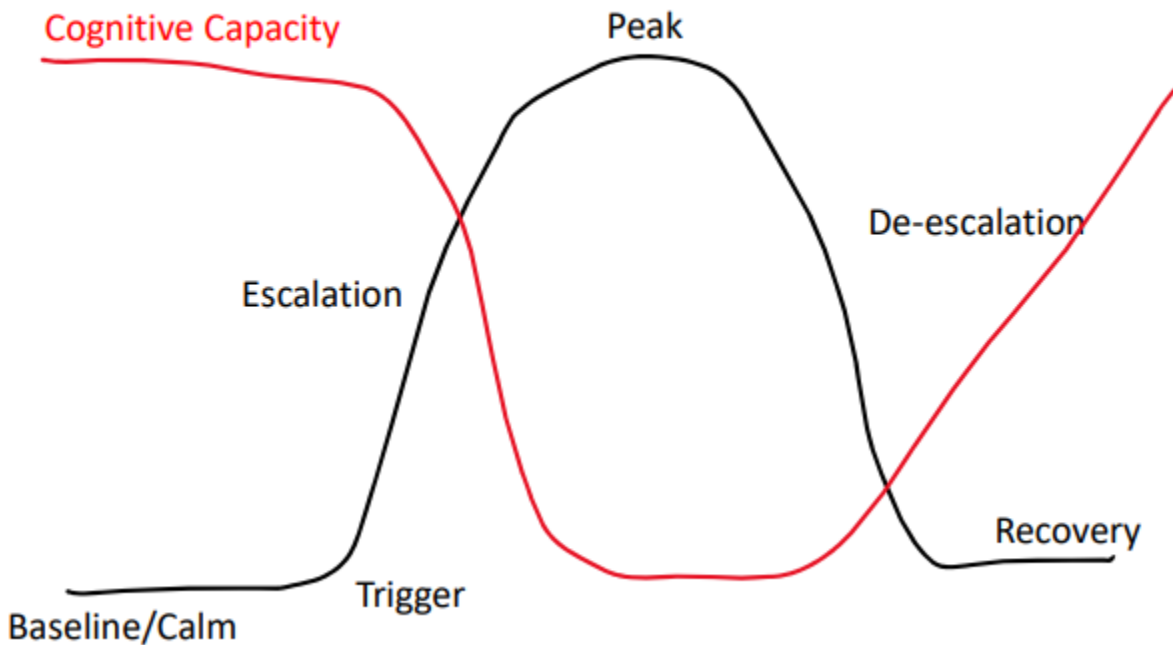


At the beginning of the cycle, the individual is calm and at their baseline. However, a triggering event (denied access, having to do a non-preferred activity, anxiety attack, etc) begins a period of escalation and increased emotion. Someone with good control of their emotions may be able to use self-regulation or calming activities to decrease their behavioral escalation and prevent themselves from getting more upset. However, if those self-calming attempts don't work, the person might progress to getting more upset until they reach their peak behavior. That can look like yelling and screaming, eloping, property destruction, disrobing, physical aggression, self-injurious behavior, or other challenging symptoms. A person cannot sustain that high degree of behavior forever—eventually the individual will tire out and enter a phase of de-escalation, followed by recovery to their baseline.

Of course, real life isn't always as straightforward as the diagram. Sometimes people can escalate very rapidly and reach their peak behaviors in an instant. Other times people may start de-escalating after the peak and then get upset again, entering back into a period of escalation that lasts another long period of time.



However, this model can be helpful when combined with the understanding of how these escalations affect the individual's ability to use their higher-level thinking (i.e. executive function) and reasoning.



When calm, a person might be able to use their logic and reasoning to control their emotions. As someone becomes more escalated, however, the brain's capacity to apply executive function skills decreases. By the time someone has reached their peak behavior, it can be incredibly challenging for someone to manage their own behavior (e.g. while they're "seeing red"). Only after the individual has fully recovered to their baseline will that person be able to use the full extent of their higher order thinking again.

How does this help us understand managing behavioral outbursts?

- Firstly, the best time to intervene on a problem behavior is *before* the outburst happens. If there are known triggers that might set off a person, is it possible to avoid the trigger completely (e.g. complete control over food; no doubt + no hope = no disappointment)? If not, can the individual be "primed" or prepared for the potential trigger? For example, visual schedules and routines are one way to help support



someone who is easily upset by transitions. Sometimes people are triggered by hearing the word “no”, and so using “first/then” statements or framing things positively can be helpful.

- Secondly, as escalation is happening, there is an opportunity for utilizing self-calming activities, especially if the individual has practiced them before. Things like sensory breaks, deep breathing, and mindfulness activities could be utilized to head off an emotional outburst before it happens.
- Finally, when someone is at their outburst peak, they may not be able to think clearly, so making threats (“you’re going to lose iPad time”) or escalating in turn (e.g. yelling at them) is unlikely to help the individual get to their recovery. It’s better to have a behavioral system in place to prevent the behaviors and to save any discussion about consequences once the individual has returned to their baseline.

There is a lot more that can be said about behavioral support and management in PWS. Here are some excellent resources that may provide additional support in managing challenge behaviors for individuals with Prader Willi Syndrome.

The Prader Willi Syndrome Association of New Zealand has tips on managing common behavioral challenges:

<https://www.pws.org.nz/support-management/behaviour>

The Prader Willi California Foundation has a toolkit with some principles that may influence an individual with PWS and how they see the world: <https://www.pwsausa.org/wp-content/uploads/2016/02/Behavior-Tool-Kit-from-Prader-Willi-California-Foundation.pdf>

In addition, the Prader Willi California Foundation has a simple list of “dos” and “don’ts”: <https://pwcf.org/wp-content/uploads/2018/02/Behavior-Strategies-for-Improving-Behavior-2018.pdf>

Social Worker’s Corner: What Is SSI?

by Bobbi McGann, LCSW

SSI is a federal program which supplements monthly payments to children younger than 18 who are disabled in childhood. These conditions include physical, mental or a combination of the two.

SSI looks at the functioning ability of the child and not just the diagnosis. Therefore, they ask for the parents to fill out a questionnaire and obtain all records from their medical provider and any school testing/IEP’s. This questionnaire is very detailed and reviews daily activity skills or their ability to function in life at home and school.

In some cases, when children are very young, it is difficult to determine the disability, so in some cases you may be denied when your PWS child is an infant or toddler.

Parents income is reviewed to qualify for this program, many working parents may not meet the income requirement.

SSI does require reviews every 1 to 3 years to continue to maintain the benefits.

If you do not meet the income criteria when your child is under 18, your child can apply at age 18 and may then become eligible as they no longer require parent’s income.

How do I apply?

You can go to your local Social Security Office, visit the website or call (800) 772-1213 between 7 AM and 7 PM.

www.socialsecurity.gov



Social Worker's Corner cont.

IHSS, In Home Supportive Services

by Bobbi McGann, LCSW

The purpose of the IHSS program is to provide supportive services to persons who are aged, blind, or disabled, and who are limited in their ability to care for themselves and cannot live at home safely without assistance. Services include personal care, cooking, cleaning, and shopping. There is a para-medical program that helps pay for medical care needed for the patient, including medications and growth hormone injections.

Applicants must meet the following criteria to qualify for this program:

- Be disabled, blind or 65 years of age and older (PWS diagnosis does qualify)
- Be unable to live at home safely without help.
- Meet the programs financial criteria.
 - If you qualify for SSI, then you will qualify for this program.
 - However, if you do not receive SSI, income, assets, and limits do apply.

There is also a separate program called protective supervision. The eligible person must have a mental illness or mental impairment that impairs their judgement, memory, or orientation. Examples would include those children that can put themselves in harm's way if they are not supervised at all time. Many of our PWS patients qualify for additional hours under this program. However, you must provide examples of instances where you child was potentially in a dangerous situation, these could include struggles with elopement, food seeking, stranger danger, and impulsiveness.

How do you apply?

- Call (714) 825-8000 in Orange County
- Call (951) 791-3250 in Riverside County
- Call (866) 985-6322 in San Bernardino County
- Call (213) 744-4477 in LA County (they also have a helpline at (888) 822-9622)

IHSS will conduct a needs assessment and require medical forms to be completed by your provider. If you qualify, and an assessment is completed the IHSS program will determine the number of hours you qualify for. Payments can be directly to you, or a family member. IHSS is evaluated yearly and requires continued documentation from your provider.

If you have questions, please reach out to Bobbi McGann, LCSW at (714) 509-4379.