

Safety Tips and Techniques for the Holidays

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- **“If everyone is watching then no one is watching.”** This applies to all food-centric celebrations. Make sure there is an explicit understanding of who is supervising the person with PWS and when. Use a tag-team approach so that no single individual is overloaded with responsibility. If a relative is educated and aware of the challenges and techniques, include them in the tag-team chain.

- **Paint the Picture of What Your Child Can Expect** (no matter their age). Discuss the schedule of the day in terms of order of events rather than specific times. The chaos of the holidays makes it hard to predict that dinner will happen at 6 o'clock on the dot, but easier to predict that dessert will be served after the family card game.

- **Foreshadow the food routine with your child** (no matter their age). If dinner is a buffet, discuss in specific and unambiguous terms how you and your child will go through the line. “Pick reasonable portions” is open to subjective interpretation and by extension, open to argument. “Pick ½ cup of mashed potatoes, one slice of meat, ½ cup serving of cooked vegetables, and one slice of pie” is precise and *not open to interpretation or subjective opinion*. If this creates anxiety, it might be necessary to stipulate that your child wait politely at the table rather than stand next to you as you make up his plate in the buffet line. If you are preparing your child's plate (which is always a good option), you will have told them well in advance that this is the plan and you'll have reassured them of your criteria for plate design, e.g., “Don't worry, honey, I'll be sure to include a little bit of everything offered.”

- **Have a clear plan in case behaviors take a turn** and make sure that the plan is communicated with your child. If there are upsets or disappointments, **do not try to talk your child out of their upset or reassure them that everything will be all right because this will only cause them to increase their upset to get you to understand.** The most effective strategy to calm someone with PWS is to repeat what they are upset about so that they know you understand why they are upset. “I understand you want to eat right now and dinner is not ready yet. That's very upsetting. It's very hard to wait.” Do NOT follow up by reassuring them that it will be worth the wait, etc. but simply repeat your understanding of their upset. Without giving in, agree with the parts of their upset that are legitimate, e.g., “You're right, that's not fair that your cousin got two pieces of pie and you only get one. That's not fair.”

Remember that punishment is generally not effective in a population that has a hard time managing disappointment and connecting cause to effect, so don't try to use “leaving early” as a punishment. Instead, treat leaving early as a way to “keep the individual safe.” You might also include a certain amount of cool-down time in the car prior to actually leaving. If the person can get themselves back into thinking-mode, you may not have to leave early. If they do calm down, be sure to praise them for regaining their composure.

- **Reward good behavior.** In the same plan that outlines what to do in the case of unwanted behavior, include rewards for good behavior. Good behavior includes sitting patiently at the table while the parent or guardian prepares the meal, cutting food into small pieces before eating, practicing good manners, turn-taking in conversations, etc. Praise and attention are often the best rewards. Avoid major rewards like “if you follow your behavior plan at Aunt May's house, we'll go to Disneyland” which can create anxiety as the child starts worrying that they might not get to go to Disneyland.



- **Plan your visits strategically.** If Aunt May always has a big buffet followed by an open cookie and dessert table and this typically causes a great deal of unwanted behavior, you might time your visit to include just one or the other. Be sure to keep the lines of communication open with Aunt May who may be amenable to changing her food serving plan so that you and your family can stay longer. Otherwise, it might be best to invite Aunt May to a smaller Thanksgiving dinner at your house where food security can be more easily maintained.

- **For a champagne toast (or any serving of alcohol) be aware of potential drug interactions.** If in doubt, check with a pharmacist. This is easy to do when you pick up their prescriptions. The pharmacist can then take into account all of the medications and give you an informed recommendation.

- **Include food-free activities in your plans.** Arts, crafts, puzzles, and games are all great fun and encourage social interaction without triggering food anxiety.

- **Take the time to take care of yourself.** No one expects a car to run on empty, and the same is true of people. Do what it takes to refuel your energy. When you are at your best, you are better able to help your child. If you notice stress taking a toll on you, find a way to do something that eases the stress. For some people, that means getting out for a 15 minute walk in the park. For others, that might mean getting together for a guy's or gal's night out.

Special Tips for CHRISTMAS, HANUKKAH, NEW YEAR'S EVE AND ALL OTHER HOLIDAY CELEBRATIONS



- **For Christmas, stockings hung by the chimney with care don't need to include candy.** Little toys and seasonal knick-knacks are great stocking stuffers that don't cause any extra anxiety. Be sure to prime expectations though!



- **For the dreidel game,** use non-edible markers like poker chips instead of chocolate coins or similar edibles.



- **For a champagne toast (or any serving of alcohol) be aware of potential drug interactions.** If in doubt, check with a pharmacist. This is easy to do when you pick up their prescriptions. The pharmacist can then take into account all of the medications and supplements and give you an informed recommendation.

Enjoy your holiday celebrations and be safe! For more information or support please contact the Prader-Willi California Foundation.