



## **Food Security: Planning for the Holidays, Family Gatherings and Parties**

Holidays, family gatherings, parties and FOOD go hand in hand. With thoughtful planning and proactive preparation, these events can be successful, healthy experiences for everyone. It's important that everyone is prepared and knows the game plan. Without a plan, the person with PWS may experience anxiety, meltdowns and even a life-threatening health emergency can occur. There is a great variability in the food drive of persons with PWS. Some will ask or beg for more food, but make no significant attempts to sneak food. However, some will go to great extremes to get food, and are incredibly clever at doing so. Each family must judge what works best for their child.

During the holidays and at other social gatherings, most of us overeat. When we do, our stomach sends a message to our brain, giving us the message of fullness and tells us to stop eating. When people with Prader-Willi syndrome (PWS) eat too much, this message of fullness never reaches the brain. They don't recognize or receive the message to stop eating. In addition, many have stomachs that empty very slowly and can "over fill". Their stomach may appear enlarged or distended. In some cases, the stomach can rupture. They also don't feel pain accurately. They may NOT complain of a stomachache, even when a problem is present. In addition, people with PWS rarely vomit. If someone does vomit, especially if they have just overeaten, he/she should be immediately evaluated by a health care professional.

Many people do not understand that it isn't just about the calories. Limiting the quantity of food consumed at one time is also very important. Food related issues can cause extreme anxiety and behavior escalations. The person with PWS needs reassurance that they will be able to have food in a controlled way to allow for inclusion and to ensure their health and safety.

### **Develop a clear plan with the person with PWS on all food issues.**

- Develop a clear food plan. Discuss what food the person will be able to eat including the quantity and timing for this. Include beverages. Be consistent.
- Assign a "food coach" that will partner and supervise the person with PWS at all times. Inform the person with PWS that all food must be approved by this individual. Dr. Linda Gourash has stated, "When everyone is in charge – no one is in charge." You can rotate this responsibility as long as there is a clear hand off of who is taking charge.
- For some people with PWS, these events cause too much anxiety and are too difficult to handle. Some families have made alternate plans that are more successful for the person with PWS and their family.

### **Educate and communicate with the host.**

- Be sure you have communicated your plan to the host and they have a clear understanding of PWS.
- Make sure you know what everyone is bringing. Ask for the menu ahead of time, so you are able to plan for food choices. If able, emphasize there is not a need to serve a lot of different food.
- Check on the timing for the serving of food. You may want to arrive a little late to lessen the time the person with PWS is exposed to snacks and appetizers. Waiting in these situations can also cause anxiety.
- Offer to bring a small, low-calorie item that is a favorite of the person with PWS. If able, check to see if it is possible to limit time for the serving of appetizers. Assist the host in removing food items once this time has expired.
- Review seating arrangements to make sure the person with PWS is seated next to his/her "food coach". Some have requested the person be seated close to the table centerpiece rather than in front of food.
- When the meal is done, make sure food is put away or constantly supervised. It may be a good time for the person with PWS to take a break in another room.