

NM Prader-Willi Syndrome Project

NOVEMBER 2020

We have officially entered the *holiday season*! The holidays are generally a time to celebrate with our loved ones, but they can also be challenging for the person with PWS. It is crucial to plan and prepare so as to ensure the health and safety of the person you support.

Here are some strategies from PWSA:

- Develop a clear plan with the person with PWS on all food issues. Discuss what food the person will be able to eat including the quantity and timing for this. Include beverages. Be consistent.
- Plan the menu ahead of time. If you are inviting others, make sure they have a clear understanding of PWS and you know what everyone is bringing.
- 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.
- 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. You may decide it is better to have the food on a separate table or different space altogether.
- 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.

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.

Thanksgiving might look a little different this year, but however you are celebrating we wish you and your loved ones a happy and safe day.

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