



## Hidden Gut Issues

### Rethinking Food Choices and Meals for the Person with Prader-Willi Syndrome

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Researchers are discovering important problems in the gastrointestinal systems in persons with Prader-Willi syndrome (PWS). We have always known that persons with PWS of all ages can have problems with swallowing, choking, stomach issues and chronic constipation. Until recently, there had only been a few research publications to help us understand why this is happening.

Recent research studies have documented low production of saliva (6); a high risk of choking (7), high prevalence of constipation in adults with PWS (1), slow stomach emptying (gastroparesis) and gastric rupture (2, 3, 4). Dr. Roxann Gross, PhD, and her team at The Children's Institute of Pittsburgh published important information in 2016 – the first research into swallowing, which revealed a high incidence of serious swallowing abnormalities in persons with PWS. None of the 30 subjects were aware of food still in their throats after "swallowing" – which is a risk for choking and pneumonia.

We know that persons with PWS have low muscle tone. **Poor muscle tone can affect the entire gastrointestinal system – mouth, esophagus, stomach and intestines.** With this new knowledge, we need to rethink food choices, timing and food preparation practices for the person with PWS. Any person with PWS who is already experiencing problems with their gastrointestinal system, should be promptly evaluated by a health care professional and if needed, referred to a gastroenterologist (physician who specializes in the digestive system). Even if your loved one with PWS is not currently experiencing symptoms such as choking or difficulty swallowing, we recommend caution and a few simple adjustments.

| What can be done to prevent or manage digestive problems for the person with PWS?                          |   |
|--|---|
| <ul style="list-style-type: none"><li>• <b>Smaller quantities</b></li><li>• <b>More moisture</b></li></ul> | <ul style="list-style-type: none"><li>• <b>Softer consistency</b></li><li>• <b>Less fiber</b></li></ul> |










Gastroparesis is a condition where the movement and digestion of food in the stomach is slowed or stopped. Contractions in the stomach help crush the food and move it on to the small intestine, where further digestion and absorption of nutrients takes place. A person with gastroparesis may have food remain in their stomach for a very long period of time, which can support abnormal bacterial growth and the forming of a mass (called a bezoar) which can cause blockage or obstruction. Changing the diet to include food that are easier to digest, plus making meals smaller in size are recommended as the first treatment for slow stomach emptying.

Foods high in fat and fiber require more work and more time for the stomach to digest; and should be avoided. In most cases, fluids can pass through the stomach at a normal rate – even when gastroparesis is present. **Smaller-sized meals, foods that are semi-liquid or liquid and low fat, put less stress on the stomach and help the stomach to empty faster.** A soft, lower fiber diet may be safer, which is a change from the high fiber recommendation for constipation, which can be treated other ways.

Low production of saliva decreases the amount of moisture and lubrication needed for smooth passage of food from the mouth to the stomach. This issue, along with poor muscle tone contributes to problems with food lodging in the throat. Staying hydrated between meals, along with good dental health, can help to minimize the problems of low production of saliva. Adding more moisture to food may help to prevent choking.

In the past, a low calorie, high fiber diet was the mainstay in management for both the child and adult with PWS. A low calorie diet should continue, of course, but fiber should be reduced when slow gastric emptying is diagnosed or suspected. Since nutritional recommendations will vary based on age and other health issues of the person with PWS, it is important to receive specific dietary advice from a dietitian or from PWSA (USA) nutritional publications. These new recommendations can be adapted for any individual plan such a low carb, lactose free or vegetarian.

#### More Suggestions:

1. **Small, frequent meals. Avoid the three large meals per day; recommend three small meals and two snacks.**
2. **Liquids during and between meals.** Encourage water or fluids between bites of food and after the meal.
3. **AVOID: RAW vegetables and fruits, nuts and salads.**

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4. **DO PROVIDE:** Well-cooked vegetables (softened) and/or mashed, fruits in softer form – applesauce, canned fruits in natural juice, cooked cereal, smoothies, and soups.
5. **Probiotic foods:** Daily (yogurt, kefir, sauerkraut) to restore and maintain healthy bacteria in the stomach.
6. **Ground or cut up meat.** Turkey, chicken and/or beef
7. **Eggs – Scrambled, fried or baked as quiches.**
8. **Schedule the last meal as early in the evening as possible to allow time for food to be digested before bedtime.**
9. **Stay upright after eating; schedule a walk or other activity to improve digestion.**
10. **Work with your dietician to follow calorie, carbohydrate and other nutrient goals.**

| <b>Sample Planning for Meals/Snacks – 1000 Calories</b><br><b>This plan is not specific to any certain diet or nutritional choices you may make. Not designed for person with diabetes.</b><br><b>(Check calories on individual products you purchase)</b> |  |   |  |
|--|--|---|--|
| <b>Breakfast</b><br><br><b>Goal: 225</b>   | <ul style="list-style-type: none"> <li>○ Chopped Hard-boiled egg (70)</li> <li>○ 1 slice light bread - toast (45)</li> <li>○ ½ TBSP margarine (25)</li> <li>○ 3 oz. Dan-Active Probiotic drink (80)</li> <li>○ 1 cup flavored water / coffee</li> </ul>  | <ul style="list-style-type: none"> <li>○ 1 cup unsweetened cereal (100)</li> <li>○ ½ cup unsweetened plain almond milk (15)</li> <li>○ 1 light cheese stick (60)</li> <li>○ ½ cup light apple sauce (50)</li> <li>○ 1 cup flavored water / Coffee</li> </ul>  | <ul style="list-style-type: none"> <li>○ ½ cup light Activia yogurt (60)</li> <li>○ ½ lite English muffin (50)</li> <li>○ 1 TBSP light cream cheese (30)</li> <li>○ 1 cup V8 juice (50)</li> <li>○ 1 cup flavored water /Coffee</li> </ul>                                 |
| <b>AM Snack</b><br><br><b>Goal: 125</b>  | <ul style="list-style-type: none"> <li>● 1 light string cheese (60)</li> <li>● 3 crackers (60)</li> <li>● 1 cup flavored water</li> </ul>  | <ul style="list-style-type: none"> <li>● 1 cup light Activia Greek yogurt (80)</li> <li>● ½ cup light fruit (45)</li> <li>● 1 cup flavored water</li> </ul>   | <ul style="list-style-type: none"> <li>● 1 tortilla (80) with 1 TBSP light cream cheese (30)</li> <li>● 1 cup flavored water</li> </ul>  |
| <b>Lunch</b><br><br><b>Goal: 225</b>   | <ul style="list-style-type: none"> <li>○ WRAP - 1 tortilla (80), 3 oz. turkey lunch meat (50), 1 TBSP light mayo (20)</li> <li>○ ½ cup cooked green beans (20)</li> <li>○ ½ cup light Activia yogurt (60)</li> <li>○ 1 cup flavored water</li> </ul>   | <ul style="list-style-type: none"> <li>○ Egg salad sandwich using light mayo &amp; light bread (70+30+90)</li> <li>○ 1 cup cooked broccoli (30)</li> <li>○ 1 dill pickle (0)</li> <li>○ 1 cup flavored water</li> </ul>   | <ul style="list-style-type: none"> <li>○ 2 slices ham lunch meat (30) w/ 1 slice light cheddar cheese (50) on 1 bagel thin (100) w/ 1 tsp mustard (0)</li> <li>○ 1 ½ cup cooked cauliflower (50)</li> <li>○ ½ cup SF Jell-O (0)</li> <li>○ 1 cup flavored water</li> </ul> |
| <b>PM Snack</b><br><br><b>Goal: 125</b>  | <ul style="list-style-type: none"> <li>● ½ sandwich – 1 slice light bread (45), 2 slices ham (30)</li> <li>● ½ cup light fruit cup (50)</li> <li>● 1 cup flavored water</li> </ul>   | <ul style="list-style-type: none"> <li>● ½ cup light Activia yogurt (60)</li> <li>● ½ cup light fruit cup (50)</li> <li>● 1 cup flavored water</li> </ul>   | <ul style="list-style-type: none"> <li>● 1 light cheese stick (60) - wrap w/ham lunch meat (15)</li> <li>● ½ cup light fruit cup (50)</li> <li>● 1 cup ice tea</li> </ul>  |
| <b>Supper</b><br><br><b>Goal: 300</b>  | <ul style="list-style-type: none"> <li>○ 1 cup chili soup -Ground Turkey, crushed tomatoes, chopped celery, chili seasoning (200)</li> <li>○ 1 cup unsweet plain almond milk (30)</li> <li>○ 1 cup cooked cauliflower (30)</li> <li>○ ½ cup lite pears (50) (warm &amp; season with cinnamon)</li> </ul> | <ul style="list-style-type: none"> <li>○ Tacos – 1 tortilla (80) topped with 2 ounces ground beef (80) w/ taco seasoning (10)</li> <li>○ Top with ¼ cup salsa (25), ¼ cup light shredded cheese (70), small amount shredded lettuce</li> <li>○ 1 cup unsweet plain almond milk (30)</li> <li>○ ½ cup SF Jell-O (0)</li> </ul> | <ul style="list-style-type: none"> <li>○ Grilled tuna melt sandwich – 2 slices light bread (90) w/ ¼ cup tuna (50) mixed with 1 TBSP light mayo (30)</li> <li>○ 1 cup Vegetable Soup (90)</li> <li>○ 1 cup unsweetened plain almond milk (30)</li> </ul>                   |

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