

NM PRADER-WILLI SYNDROME PROJECT

MAY 2020

Gastric Complications in PWS

Dr. Scheimann is a Gastroenterologist and expert on PWS. Ann is a PWSA (USA) medical consultant on PWS Gastrointestinal (GI) issues.

The prevalence of GI issues in persons with PWS of all ages is quite high. In addition to early feeding difficulties, reflux and aspiration symptoms are frequent problems in infancy. Problems with digestion affect approximately 35% of adults; constipation and diarrhea problems occur in 20-35%. Gastroesophageal reflux disease, GERD, is common.

Dr. Scheimann outlined suggestions to treat GERD in infants: use thickened feedings, avoid overfeeding, use more prone positioning, and eliminate all exposure to tobacco smoke. For older children and adults she recommended: avoid lying down after eating a meal, elevate the head of the bed, lose weight, avoid all tobacco, and avoid foods and medications that may cause reflux. Fundoplication is a surgical option when lifestyle changes and medications aren't enough.

Oral problems are common, including small mouths causing teeth crowding and enamel erosion. Salivary flow is generally far less than normal [dry mouth products such as Biotene can be helpful]. Factors predisposing someone to choking, a serious and not uncommon occurrence in persons with PWS, include hyperphagia (high drive for food), thick saliva, weak pharyngeal muscles, and reflux. Use of the "pace and chase technique for liquid consumption with meals is helpful in preventing the symptoms of esophageal dysphagia and choking. Dr. Scheimann advises all care providers to learn the Heimlich maneuver, treat reflux and gastritis symptoms, encourage chewing during meals, and, of course, supervise persons with PWS at all times.

Risk factors for developing gallstones, also not uncommon, include obesity, low fiber/high fat diet, and diabetes mellitus. 70-80% of normal adults in one study had no biliary symptoms when their gallstones were detected- the majority of healthy adults did not require treatment for gallstones unless symptoms arose such as right sided abdominal pain or pain after meals.

Constipation and encopresis (involuntary fecal soiling) are common problems. Factors that add to constipating conditions include developmental factors (cognition, genetics, fluid intake, etc.) and alter anatomy (low muscle tone, malrotation, etc.). Rectal ulcers can occur when there is chronic constipation. General guidelines to treat constipation in infancy include the careful use of glycerin suppositories or softening agents such as Karo syrup and the increase of fiber intake when solids are introduced. She cautioned against using enemas, suppositories and finger dilations unless recommended by the physician. For the school age child and adult, her suggestions included a cooked fiber-rich diet plus water and the continuous use of medications, such as Miralax with appropriate amounts of fluid on a daily basis rather than intermittent dosing.

Gastric motility (the rate at which the stomach empties) and an impaired vomit reflex (controlled by the central nervous system) contribute to serious stomach expansion and stomach rupture problems that can cause death. Warning signs and immediate hospitalization or ER evaluation for potential gastric rupture or gastric necrosis included a binge eating episode followed by abdominal discomfort, recent history of gastritis or ulcer.

While a variety of bariatric surgery techniques have been attempted in persons with PWS, the long-term results have been very poor. Research continues to explore viable treatment options, but bariatric surgery is not currently one of them.

Finding the Right Help During the COVID-19 (coronavirus) Outbreak

The COVID-19 (coronavirus) outbreak has presented many challenges for people across the United States. The Benefits.gov Program recognizes the difficulties that many are facing and wants to help citizens find the assistance they need, whether it be unemployment, healthcare, temporary assistance, or food and nutrition. Benefits.gov hosts information on over 1,000 federal and state benefits and aims to increase the ease of access to assistance programs for people in need. Considering the coronavirus outbreak, Benefits.gov has compiled a list of resources citizens may find helpful. Below you will find assistance programs available for eligible individuals, spanning from food stamps, unemployment benefits, healthcare benefits, emergency business loans, and more.

Unemployment Resources

Many Americans are facing unemployment or a lapse in employment as social distancing policies are enacted to decrease the spread of the coronavirus. There are resources available for individuals who need unemployment assistance, including [Unemployment Insurance](#), which provides unemployment benefits to those who lose their job through no fault of their own. Pre-check your eligibility for Unemployment Insurance using the questionnaire at the bottom of the page. Depending on your circumstances, you may qualify for [Disaster Unemployment Insurance](#). Check your eligibility using the short questionnaire at the bottom of the page or using the [Benefit Finder](#).

Check out the [Unemployment Assistance](#) category on Benefits.gov and filter by state to see what unemployment benefits are available to you.

Healthcare Coverage

Many Americans may be concerned about their healthcare coverage at this time. For workers – and their families – who have had a lapse of employment or who have become unemployed during the outbreak, [COBRA Continuation Coverage](#) may be the right choice for you.

Many citizens may also be interested in exploring their options in [Medicare and Medicaid](#). Understanding the [key differences](#) between Medicare and Medicaid can help you find the best options for you and your family. The [Medicare](#) program typically provides health insurance for people who are 65 and older while the [Medicaid](#) program provides insurance to low-income individuals, families and children, pregnant women, the elderly, and people with disabilities. Use the [Benefit Finder](#) to prescreen your eligibility for both programs and more. Browse the [Healthcare and Medical Assistance](#) category to explore different programs.

Resources for Families in Need

The coronavirus has had an impact on everyday life, and families have been challenged to adjust. For families requiring temporary assistance during the outbreak, the [Temporary Assistance for Needy Families](#) program can help provide financial assistance and related support.

The [Supplemental Nutrition Assistance Program \(SNAP\)](#) serves millions of people annually, ensuring that they and their families have access to nutritious food options. The [SNAP for Women, Infants, and Children \(WIC\)](#) provides for the special dietary needs of nursing and pregnant women, infants, and children under the age of five. Read our helpful articles on how [SNAP](#) and [WIC](#) benefits can help you and your family and how to apply. To explore more options, visit our [Food and Nutrition](#) category to find what best suits your situation.

For assistance with heating and cooling expenses, the [Low Income Home Energy Assistance Program \(LIHEAP\)](#) helps provide low-income families with their heating and cooling energy costs. If you're curious about other options for utility assistance, browse the [Housing and Public Utilities](#) category to find programs for your needs.

Use our [Benefit Finder](#), an online questionnaire, to discover more benefits that you and your family may be eligible for and learn how to apply.