



- MEDICAL ALERT -

GASTROINTESTINAL ISSUES IN INDIVIDUALS WITH PRADER-WILLI SYNDROME

Abdominal distention or bloating, pain and/or vomiting may be signs of life-threatening gastric inflammation or necrosis, more common in PWS than in the general population. Rather than localized pain, there may be a general feeling of unwellness. **If an individual with PWS has these symptoms following a known or suspected binge-eating episode, immediate hospitalization is advised.** An X-ray and an endoscopy with biopsy may be necessary to determine degree of the problem and possible need for emergency surgery.

Another consideration is **gastroparesis**, a delay in emptying stomach contents and a weakness of the stomach. This condition is common with PWS and **can be more life threatening than in a typical situation. Eating while the stomach is distended with gastroparesis can be very dangerous and even life-threatening.**

ACUTE GASTROINTESTINAL EPISODES CAN BE LIFE-THREATENING

Janalee Heinemann, Director of Research & Medical Affairs, PWSA (USA)

I recently received a call from a physician who told me that one of our mother's brought our Medical Alert articles with her to the emergency room. He said, "If she had not brought the articles and insisted I go to your web site, this child would have died. This information saved her life." His patient, a slim 15-year-old, had an episode of binge eating. She came in with vomiting and belly pain. The physician said normally, she would have treated it like the flu for a couple of days. Due to our alerts, they pursued this further, and found the girl with PWS had such a bad hernia that her spleen, stomach, and duodenum were in her chest. She is now recovering from surgery.

Unfortunately, not all parents carry the articles with them and not all physicians heed our warnings. In another recent situation, a slim young man had an episode of binge eating and the ER and hospital did not take his symptoms serious enough, soon enough. Even though we had one of our physicians called as a consultant and emphasized the urgent need for exploratory surgery, there was a fourteen to sixteen-hour delay in surgery before the local hospital physician believed how life threatening his condition was.

This young man had been doing very well prior to this incident and a few hours after the eating episode initially only exhibited signs of stomach pain and vomiting. See back page for Dr. Rob Wharton's article which was initially printed in PWSA's *The Gathered View* in 1999. What Dr. Wharton described was "**acute idiopathic gastric dilation.**" This is where part of the stomach tissue dies which is similar to a heart attack where part of the heart tissue dies. It comes on suddenly, is very life threatening and needs immediate surgery. I have been speaking to several people, including our GI specialist Dr. Ann Scheimann and the pathologist who did this report with Dr. Wharton (who is now deceased) about the cause. Our conjecture is that if a person with PWS greatly distends their stomach with food (slimmer people may be more at risk) and does not get the normal message of full or pain, they may distend it to the point that it cuts off the blood supply thus causing necrosis. (The stomach becomes blackened and dead.)

Another risk of binge eating that can create a serious medical emergency is GI perforation. In addition, when there is severe stomach pain, a physician should consider an ultrasound due to the possibility of gallstones and pancreatitis. Pancreatitis can be differentiated by chemistry analysis of the blood and a CT of the abdomen.

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