



## Medical Alert: Stomach Problems Can Signal Serious Illness

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We have recently recognized and reported\* an important medical condition in individuals with Prader-Willi syndrome which families and other care providers should know more about. Although the condition is not common in individuals with PWS, it is much more common in these individuals than in anyone else. It is important to recognize the condition because it can cause severe medical problems when diagnosis and treatment are delayed. The condition can be successfully managed, however, when recognized in a timely fashion.

We have called the condition acute idiopathic gastric dilatation. The condition often begins suddenly in individuals in their 20s or 30s. There is generally no known cause. The first symptoms of illness are vague central abdominal discomfort or pain and vomiting. Bloating of the abdomen, caused by swelling or distention of the stomach, may also appear at this time. The person's temperature may also begin to become elevated at this point. In addition, the individual often begins to look and feels quite ill.

Individuals in whom these symptoms appear should receive immediate medical attention:



**Abdominal Pain**

**Bloating or Distention, and/or**

**Vomiting**

A simple X-ray or CT scan of the abdomen should be taken to look for abdominal distention. If abdominal distention is present and the individual has pain but is relatively well appearing, a test called an endoscopy should next be performed to test the person's stomach lining for signs of inflammation. If the individual has distention on X-ray and is quite ill, emergency surgery might be necessary to more closely examine the person's stomach for signs of inflammation and necrosis [death or decay] of the tissue lining the stomach wall. When severe distention and necrosis is present, treatment consists of surgical removal of a significant portion of the stomach.

Anyone who has knowledge of other individuals who have had severe stomach problems or would like more information can get in touch with PWSA (USA) 1-800-926-4797

\* Wharton RH et al. (1997) Acute idiopathic gastric dilation with gastric necrosis in individuals with Prader-Willi syndrome. *American Journal of Medical Genetics*, Dec. 31; Vol. 73(4): page 437-441.

