

Holiday Alert

Dear Parent/Guardian:

The holidays are here and the PWSA (USA) staff, along with the Clinical and Scientific Advisory Boards, wishes you and your family a happy holiday. It is a time of year people travel from far and near to celebrate the holidays with their families. This is also true for those adults with Prader-Willi syndrome in alternative residential settings. Like all of us, for those adults with Prader-Willi syndrome in alternative residential placements, “going home for the holidays” is routine at this time of year. And, giving, receiving and indulging in those delicious “Christmas goodies” is central to many celebrations.

While an occasional “goodie” may be allowed, a note of caution must be sounded. Without exception, adults in residential care have their daily meals carefully managed in order to meet the special dietary requirements associated with having Prader-Willi syndrome. This usually means smaller portions and a reduced overall daily caloric allowance. It has become clear that adults who have had solid and consistent dietary management for some time are at risk for serious health consequences if they are then allowed to eat quantities that exceed what they are used to. **Several deaths have occurred following holiday visits home where food intake was not carefully monitored.** As a result, these individuals consumed both individual portions and an overall quantity of food that exceeded their usual daily intake at the group home. These deaths usually occur because the stomach is unable to accommodate and process the increased quantity of food, resulting in gastric dilatation and even perforation. Some have also involved food going down the airway and into the lungs. We want to caution you that dietary monitoring while home that is consistent with the usual daily intake of the residential placement is critical for long term health, but more importantly to prevent short term, possibly life threatening, health consequences from increased intake.

We know that despite vigilance, many adults sometimes successfully obtain extra food. If your adult complains of any symptoms such as his/her stomach hurting or cramping, or has nausea and vomiting, or refuses food and appears ill, he/she should be immediately taken to an emergency room where the staff need to be told about the abdominal concerns associated with PWS. They should go to our web site at www.pwsausa.org and then go to the site titled Medical Alert. The staff of PWSA (USA) and the members of the Clinical and Scientific Advisory Boards are available to assist Emergency Room personnel when needed.

Again, our best wishes for a safe and joyous holiday season.

Holiday Alert

Dear Parent/Guardian:

The staff of _____ wish you and your family a happy holiday. We know you will enjoy having X home with you to celebrate this joyous season. We would, however, like to raise a note of caution. While in care with us, our residents have their daily meals carefully managed in order to meet the special dietary requirements associated with his/her Prader-Willi syndrome. As a result, they have been restricted both in portion size and overall daily calorie count for quite some time.

It has come to our attention that adults who have been managed in this way for some time are at risk for serious health consequences if they are then allowed to eat quantities that exceed what they are used to. Indeed, **several deaths have occurred following holiday visits home where food intake was not carefully monitored.** As a result, these individuals consumed both individual portions and an overall quantity of food that exceeded their usual daily intake at the group home. These deaths usually occur because the stomach is unable to accommodate and process the increased quantity of food, resulting in gastric dilatation and even perforation. Some have also involved food going down the airway and into the lungs. We want to caution you that dietary monitoring while home that is consistent with usual daily intake -- both for long term health goals -- and more importantly to prevent short term, possibly life threatening, health consequences from increased intake. We know that despite your vigilance your loved one with PWS may sometimes successfully obtain extra food. If this happens and there are complaints of any symptoms such as their stomach hurting or cramping, nausea and vomiting, or refusal of food and an appearance of being ill, he/she should be immediately taken to an emergency room and told about the abdominal concerns associated with PWS. They should go to our web site at www.pwsausa.org and then go to the site titled Medical Alert.

We look forward to having our resident return from his/her holidays, having enjoyed the time with family, and in continued good health.

The staff of XXX

I have read and understand the risk factors involving my family member with PWS.

Name: _____

Signature: _____

Date: _____