

The Student Who Has Prader-Willi Syndrome Information for Transportation Personnel

(Compiled by Barb Dorn, Consultant on PWS)

We all want a positive, successful educational experience for every student as they are transported to school. The ride to/from school often sets the tone for the student's attitude and outcome for a positive day. Transportation personnel are a very important part of the education team. The purpose of this handout is to help transportation personnel gain an understanding of Prader-Willi syndrome and help him/her understand what steps may help to make this a safe, enjoyable experience for everyone.

What is Prader-Willi Syndrome (PWS)?

PWS is a complex developmental disability that results from a defect on the 15th chromosome. Because of an abnormality in the area of the brain called the hypothalamus, these students face challenges in learning, behavior and controlling their appetite. The message of fullness never reaches their brain and they are always hungry. The intensity of their food drive can vary, but all students require support and understanding if/when they attempt to seek food. "Food security" must be provided during the times when these students are being transported to and from school.

Why Does this Student Qualify for Transportation Services?

Many students with PWS have a cognitive impairment and may lack good judgment in making safe decisions in crossing the street and walking to school. In some cases, they may need transportation services to keep them safe so they do not seek food on their way to school. They may take food from garbage cans; steal food and/or money at stores along the way; and eat their lunch before arriving at the school building. Overeating – especially binge eating - can result in choking and other very serious health situations. They also face behavioral challenges and can be easily targeted by other students. They are often a target for bullies who get enjoyment out of having these students eat large quantities of food. Students with PWS may also become angry and upset with adults who may be trying to help them and keep him/her healthy and safe. At times, when it comes to food issues, they are often irrational and have difficulty listening to rational explanations.

What Can Transportation Personnel Do to Assist the Student with PWS?

Get to know this student; become their friend. Your attitude, understanding and acceptance are so helpful. You may be asked to store his/her lunch with you during the ride to

school. You can provide assurance that you will keep it "safe" until the arrival at the school building. Ask school personnel to assist you in educating other students about "no trading or sharing of food" – especially on the bus. It is often helpful to assign a seat in the front row or close to the driver so you can keep an eye on things during the ride. Having a friendly conversation is often helpful in providing diversion for other food that may be present. If this seems too overwhelming for the student, please communicate this to the parent and/or education staff. There have been times when the student with PWS has requested to stop to use a bathroom on the way to school. (This has occurred when a smaller transportation service is used). During these stops, the student accessed and stole food. The situation was stopped with a "no stop" rule and making sure that this need was taken care of before using transportation services.

What Do I Do If the Student Steals Others' Food, Money or Becomes Upset?

Don't be confrontational; turn the matter over to the teacher or parent. Typically, these students need supervision from the bus to the building. However, not all students have the same intensity in food seeking so this may vary. If you notice that the student is wandering, pushing or starting to get upset, it is often helpful to direct them to "stay in their seat", or "keep their hands to themselves" and/or "take some deep breaths and close their eyes". Communicate the behavior you want to see. Using the word "don't" is not always helpful. When they are becoming upset, it can be hard for them to take a "don't statement" and turn it into a "do action". Some students with PWS require extra help and supervision on the ride to school so don't be afraid to communicate this.

Transportation personnel are an important part of the educational team that helps support the student with PWS. If you have questions about any of the behaviors you see or how to handle any situations, feel free to ask the educator or parent.

