

The Student with Prader-Willi Syndrome: Information for Transportation Personnel

A positive, successful education experience for every student begins the moment they step on the bus each morning. 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, although often neglected, part of the education team. The purpose of this handout is to provide transportation personnel with an understanding of Prader-Willi Syndrome (PWS) and the steps they can take to ensure a safe and enjoyable experience for everyone.

What is Prader-Willi Syndrome (PWS)?

Prader-Willi syndrome (PWS) is a variable and complex genetic neurobehavioral disorder resulting from abnormality on the 15th chromosome. It occurs in males and females equally and in all races. Prevalence estimates range from 1:15,000 to 1:25,000.

PWS typically causes low muscle tone, short stature if not treated with growth hormone, cognitive deficits, incomplete sexual development, problem behaviors, and a chronic feeling of hunger which, coupled with a metabolism that utilizes drastically fewer calories than normal, can lead to excessive eating and life-threatening obesity

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

The following acronym was developed by Latham Centers to enable transportation personnel to engage in safe travel practices.

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| D - Driver keeps all food secure | S - Safety is the #1 priority |
| R - Review the expectations before you drive | A - Ask the person how they are feeling |
| I - Intervene immediately | F - Find an activity |
| V - Vehicle Safety/ Environmental Checklist | E - Enjoy each other's company |
| E - Expect a Challenge | |

Transportation personnel can follow the tips below when implementing the above acronym.

- All food and drinks, including those of the drivers and staff, must always be secured and out of sight.
- The student's lunch should be given to the bus driver or bus aide when getting onto the bus. This will keep the food secure and prevent the student with PWS from eating the food prior to arriving at school.
- Food should not be used to reward good behavior on the bus. Try using stickers, erasers, or even a high-five and verbal praise.

- Implement a no-food and drink policy for all persons on the bus - no exceptions.
- Review the safety behaviors that you want to see from the student while the bus is in motion.
- If negative behaviors occur on the bus, pull over and call for help.
- The bus should be cleared of all food, food remnants, food containers, drinks, drink cups, including food remnants that may be stuck to the floor (e.g., gum) prior to the student with PWS boarding the bus.
- Build a friendly relationship with the students by engaging them in conversation upon arrival on the bus and throughout the ride, as appropriate. Know the student's name and a little about their daily lives and interests. *[Note: Avoid teasing, sarcasm, and abstract humor as it is often misunderstood. On the other hand, feel free to make fun of yourself as you will surely get a smile and laugh].*
- Give concrete answers to questions from the student (e.g., *Student:* Why is my aide not on the bus? *Driver:* Your aide was not feeling well today.)
- Assign the student to an important job on the bus. For example, the student may be responsible for taking attendance for all the students as they board and get off the bus each day. This will keep the student with PWS engaged in a positive and meaningful activity.

Transportation personnel are an important part of the education team that helps support the student with PWS. For additional information about PWS, please call the Prader-Willi Syndrome Association | USA (PWSA | USA) at (941) 312-0400 or visit www.pwsausa.org.

Revised August 2022