

Health Concerns and the Student with Prader-Willi Syndrome: Information for School Staff

The student with Prader-Willi syndrome (PWS) may experience some unique health issues. It is important for school staff to be aware of these issues to help ensure that the student has a safe, healthy, and educational experience. Health concerns, along with some strategies, are summarized below.

Health Concern	Strategies	Health Concern	Strategies
<p>Altered Pain Threshold – Decreased Pain Sensitivity/High Pain Threshold</p> <ul style="list-style-type: none"> Pain may be diminished or absent, even in severe injuries. Fatigue or irritability may be a sign of illness. Increased bruising and swelling is common. 	<ul style="list-style-type: none"> Assess all injuries by an adult. Report all injuries or changes in behavior to the parent or caregiver. Elevate and apply ice to injuries as needed. Examine by a physician to rule out fracture or other health problems. 	<p>Skin Picking</p> <ul style="list-style-type: none"> Common problematic behavior seen in students of all ages. Open sores common. May pick at various openings on the body. 	<ul style="list-style-type: none"> Provide diversion activities – keep hands busy. Encourage liberal application of lotion. Incentive program is often needed to keep wound covered. Teach the student self-care of wound if able. Monitor frequent trips to bathroom, set time limits; supervise in bathroom if needed.
<p>Altered Temperature Regulation</p> <ul style="list-style-type: none"> Common to see unexplained high and low temperatures. Little or no fever may be present with illness. Often experience low tolerance to high or low outside temperatures. 	<ul style="list-style-type: none"> Limit time outdoors during very warm and/or humid temperatures. Remove to cool area if extreme redness of the face and sweating is noted. Encourage cool water and/or utilize cooling measures. Limit exposure to colder climates and in colder climates, make sure student is appropriately dressed. Notify parents if illness is suspected. 	<p>Behavior – Emotional Problems</p> <ul style="list-style-type: none"> Students with PWS have problems regulating their emotions. Most do not handle change well. Some exhibit obsessive-compulsive tendencies, exaggerated emotional responses, and extreme anger. Some take medications to assist with mood stabilization. 	<ul style="list-style-type: none"> Minimize changes. When they do occur, talk through the changes with the student in detail if possible. Teach ways to appropriately share feelings and emotions. Practice and reinforce these strategies frequently. State behavior you want to see. Avoid using word “don’t”. Administer medications at the appropriate times.
<p>Increased Food Drive/Food Seeking/Low Metabolism</p> <ul style="list-style-type: none"> Because of a hypothalamic abnormality, students with PWS do not register the feeling of fullness. There are varying degrees of food seeking. Many individuals sneak and/or steal food and are at great risk for choking. Individuals affected by PWS gain weight on ½ the number of calories other students consume and require a calorie restricted diet and supervision around all food. 	<ul style="list-style-type: none"> Receive/follow prescription from health care professional for calorie-restricted diet. Supervise student around all food sources. Keep food out of sight. Avoid use of food in classroom activities or as a reward. Empty garbage cans promptly that contain discarded food. Train staff in the Heimlich maneuver. Develop a plan for how to handle food treats and other food issues in the classroom. 	<p>Severe Stomach Illness – Lack of Vomiting</p> <ul style="list-style-type: none"> Severe stomach illness has been noted in students who have had a binge eating episode. Symptoms: abdominal bloating, vomiting, pain may or may not be present, general feeling of not feeling well. Rare for a person with PWS to vomit. 	<ul style="list-style-type: none"> Notify parent if symptoms of stomach illness are present. Student should be urgently evaluated by a health care professional. Report any incidence of vomiting to the parent. Encourage the student to share honestly if they have had a binge episode. The student should not be punished if this has occurred.
<p>Osteoporosis</p> <ul style="list-style-type: none"> High risk due to hormone abnormalities and dietary limitations. 	<ul style="list-style-type: none"> Assess injuries for possible sprain/fracture due to high risk of fractures. May require x-ray to rule out fracture. 	<p>Increased Sensitivity to Medications</p> <ul style="list-style-type: none"> More sensitive to medications that can cause sedation or sleepiness. 	<ul style="list-style-type: none"> Be aware of all medications the student is taking. Report any problems to parents.
<p>Daytime Sleepiness</p> <ul style="list-style-type: none"> Common to see in students. Often symptom of sleep apnea. May be result of weak chest muscles - poor air exchange. 	<ul style="list-style-type: none"> Physical therapy evaluation for muscle strengthening. Get student up and moving if fatigue is noted. May require a rest time during the school day. Communicate any concerns to parent and health care provider. 	<p>Scoliosis and Other Spine Problems</p> <ul style="list-style-type: none"> Common to see scoliosis and other spine deformities in students with PWS. Often difficult to detect if obese. May require bracing. 	<ul style="list-style-type: none"> Refer to orthopedic specialist if concern is found. Support and assist if brace is needed. Adapt or modify for physical education classes/activities if needed. Schedule physical therapy evaluation for muscle strengthening.
<p>Strabismus</p> <ul style="list-style-type: none"> Often seen in younger students. Poor muscle tone/control in eyes. Glasses, patching and in some cases, surgery is needed. 	<ul style="list-style-type: none"> Look for signs during vision screening. Refer to eye specialist if needed. Make sure student wears glasses and/or patches if needed. 	<p>Dental Problems – Dry Mouth</p> <ul style="list-style-type: none"> Common problems include thick and/or sticky saliva, teeth grinding, and rumination and cavities. 	<ul style="list-style-type: none"> Teach and encourage good dental care and encourage drinking of water. Assist in referral to dentist if needed.