



## Health Concerns and the Student w/ 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 educational experience. Health concerns along with some strategies are summarized below.

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