

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 in ensure that the student has a safe, healthy educational experience. Health concerns along with some strategies are summarized below.

Health Concern	Strategies
<p><i>Altered Pain Threshold – Decreased Pain Sensitivity/High Pain Threshold</i></p> <ul style="list-style-type: none"> ▪ <i>Pain may be diminished or absent - even in severe injuries.</i> ▪ <i>Fatigue or irritability may be a sign of illness.</i> ▪ <i>Increased bruising and swelling is common.</i> 	<ul style="list-style-type: none"> ▪ All injuries need to be assessed by an adult. ▪ Report all injuries or changes in behavior to the parent or caregiver. ▪ Student may require examination by a physician to rule out fracture or other health problem. ▪ Apply ice to injuries as needed.
<p><i>Altered Temperature Regulation</i></p> <ul style="list-style-type: none"> ▪ <i>Common to see unexplained high and low temperatures</i> ▪ <i>Little or no fever may be present with illness. Often experience low tolerance to high or low outside temperatures.</i> 	<ul style="list-style-type: none"> ▪ Assist in making sure the student does not overheat. ▪ If extreme redness of the face and sweating is noted, remove to cool area and encourage cool water and/or cooling measures. ▪ In colder climates make sure student is appropriately dressed and does not spend a long time outside. ▪ If illness is suspected, notify parent. Fever may not be present.
<p><i>Increased Food Drive/Low Metabolism</i></p> <ul style="list-style-type: none"> ▪ <i>Because of an abnormality in the hypothalamus, students with PWS do not register the feeling of fullness and have varying degrees of food seeking.</i> ▪ <i>Many will sneak and/or steal food – often putting them at great risk for choking.</i> ▪ <i>Can gain weight on ½ calories of other students; require calorie restricted diet with supervision around all food.</i> 	<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. ▪ Do not use food as a reward or in classroom activities. ▪ It may be necessary to empty garbage cans that contain discarded food. ▪ Staff should be trained in the Heimlich maneuver. ▪ Talk with family on how to handle food treats and other food issues in the classroom.
<p><i>Severe Stomach Illness – Lack of Vomiting</i></p> <ul style="list-style-type: none"> ▪ <i>Severe stomach illness has been noted in students who have had a binge eating episode.</i> ▪ <i>Symptoms: abdominal bloating, vomiting, pain may or may not be present, general feeling of not feeling well.</i> ▪ <i>It is rare for a person with PWS to vomit.</i> 	<ul style="list-style-type: none"> ▪ If symptoms of stomach illness are present, notify parent. Student should be urgently evaluated by a health care professional. ▪ Any incidence of vomiting should be reported 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><i>Behavior – Emotional Problems</i></p> <ul style="list-style-type: none"> ▪ <i>Students with PWS have problems regulating their emotions.</i> ▪ <i>Most do not handle change well.</i> ▪ <i>Some exhibit obsessive-compulsive tendencies, exaggerated emotional responses and extreme anger.</i> ▪ <i>Some take medications to assist with mood stabilization.</i> 	<ul style="list-style-type: none"> ▪ Minimize changes. When they do occur – prepare 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”. ▪ Make sure medications are administered at school at the appropriate times.
<p><i>Osteoporosis</i></p> <ul style="list-style-type: none"> ▪ <i>High risk due to hormone abnormalities and dietary limitations.</i> 	<ul style="list-style-type: none"> ▪ At high risk for fracture – assess injuries for possible sprain/fracture. May require x-ray to rule out fracture.

Health Concern	Strategies
<p>Increased Sensitivity to Medications</p> <ul style="list-style-type: none"> ▪ <i>More sensitive to medications that can cause sedation or sleepiness</i> 	<ul style="list-style-type: none"> ▪ Be aware of medications that student is taking that could cause this. Report any problems to parents.
<p>Skin Picking</p> <ul style="list-style-type: none"> ▪ <i>Common problematic behavior seen in students of all ages.</i> ▪ <i>Open sores common.</i> ▪ <i>May pick at various openings of body</i> 	<ul style="list-style-type: none"> ▪ Provide diversion activities – keep hands busy. ▪ Encourage liberal application of lotion. ▪ Incentive program often needed to keep wound covered. ▪ Teach self care of wound if able. ▪ Monitor frequent trips to bathroom. Time limits and supervision in bathroom may be needed.
<p>Daytime Sleepiness</p> <ul style="list-style-type: none"> ▪ <i>Common to see in students. Often symptom of sleep apnea.</i> ▪ <i>May be result of weak chest muscles-poor air exchange.</i> 	<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. ▪ Assist in communicating problem to health care provider if problematic.
<p>Strabismus</p> <ul style="list-style-type: none"> ▪ <i>Often seen in younger students.</i> ▪ <i>Result of poor muscle tone/control in eyes</i> ▪ <i>Glasses, patching and in some cases surgery is needed.</i> 	<ul style="list-style-type: none"> ▪ Provide careful attention to this during eye screening. ▪ Refer to eye specialist if needed ▪ Make sure students wears glasses and/or patches if needed.
<p>Scoliosis and Other Spine Problems</p> <ul style="list-style-type: none"> ▪ <i>Common to see scoliosis and other spine deformities in students' w/PWS.</i> ▪ <i>Often difficult to detect if obese.</i> ▪ <i>May require bracing.</i> 	<ul style="list-style-type: none"> ▪ If suspected, recommend referral to orthopedic specialist. ▪ Support and assist if brace is needed. Adaptive measures may be needed for physical education.
<p>Dental Problems – Dry Mouth</p> <ul style="list-style-type: none"> ▪ <i>Common problems: thick, sticky saliva, teeth grinding, rumination, cavities</i> 	<ul style="list-style-type: none"> ▪ Teach and encourage good dental care and water. ▪ Assist in locating a dentist if needed.

For more information about supporting the students with Prader-Willi Syndrome, contact:

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