



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>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 & swelling is common. 	<ul style="list-style-type: none"> ▪ All injuries should be assessed by an adult. ▪ Report all injuries or changes in behavior to the parent or caregiver. ▪ Elevate and apply ice to injuries as needed. ▪ Student may require examination by a physician to rule out fracture or other health problem. 	<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 of body 	<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. 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. ▪ If extreme redness of the face and sweating is noted, remove to cool area; encourage cool water and/or utilize cooling measures. ▪ In colder climates make sure student is appropriately dressed and limit exposure to cold temperatures. ▪ If illness is suspected, notify parent. 	<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 – 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 to 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 is varying degrees of food seeking. Many sneak and/or steal food – are at great risk for choking. ▪ Gain weight on ½ calories of other students; require calorie restricted diet & 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 reward. ▪ Promptly empty garbage cans that contain discarded food. ▪ Train staff in the Heimlich maneuver. ▪ Have 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"> ▪ If symptoms of stomach illness are present, notify parent. 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 & dietary limitations. 	<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. 	<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 that 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 problem to parent & 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’ w/PWS. ▪ Often difficult to detect if obese. ▪ May require bracing. 	<ul style="list-style-type: none"> ▪ If found, refer to orthopedic specialist. ▪ Support and assist if brace is needed. Adaptive measures may be needed for physical education. ▪ 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 students wears glasses and/or patches if needed. 	<p>Dental Problems – Dry Mouth</p> <ul style="list-style-type: none"> ▪ Common problems: <ul style="list-style-type: none"> ○ thick, sticky saliva, ○ teeth grinding, ○ rumination and cavities 	<ul style="list-style-type: none"> ▪ Teach and encourage good dental care and water. ▪ Assist in referral to dentist if needed.