

Health Concerns and the Individual with Prader-Willi Syndrome



Individuals with Prader-Willi syndrome (PWS) may experience some unique health issues. It is important for professionals to be aware of these in ensure that the individual has a safe, healthy environment. Health concerns along with some strategies are summarized below.

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"> ▪ All injuries need to be assessed by an adult. ▪ Report all injuries or changes in behavior to the parent or caregiver. ▪ Person may require examination by a physician to rule out fracture or other health problem. ▪ Apply ice to injuries as 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"> ▪ Assist in making sure the person 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 person is appropriately dressed and does not spend a long time outside. ▪ If illness is suspected, notify parent. Fever may not be present.
<p>Increased Food Drive/Low Metabolism</p> <ul style="list-style-type: none"> ▪ Because of an abnormality in the hypothalamus, persons with PWS do not register the feeling of fullness and have varying degrees of food seeking. ▪ Many will sneak and/or steal food – often putting them at great risk for choking. ▪ Can gain weight on ½ calories of other peoples; require calorie restricted diet with supervision around all food. 	<ul style="list-style-type: none"> ▪ Receive/follow prescription from health care professional for calorie-restricted diet. ▪ Supervise person 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>Severe Stomach Illness – Lack of Vomiting</p> <ul style="list-style-type: none"> ▪ Severe stomach illness has been noted in people who have had a binge eating episode. ▪ Symptoms: abdominal bloating, vomiting, pain may or may not be present, general feeling of not feeling well. ▪ It is rare for a person with PWS to vomit. 	<ul style="list-style-type: none"> ▪ If symptoms of stomach illness are present, notify parent. Individual should be urgently evaluated by a health care professional. ▪ Any incidence of vomiting should be reported to the parent. ▪ Encourage the person to share honestly if they have had a binge episode. The person should not be punished if this has occurred.
<p>Behavior – Emotional Problems</p> <ul style="list-style-type: none"> ▪ Peoples 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 medications are administered at school at the appropriate times.
<p>Osteoporosis</p> <ul style="list-style-type: none"> ▪ High risk due to hormone abnormalities and 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.

Health Concern	Strategies
<p><i>Increased Sensitivity to Medications</i></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 individual is taking that could cause this. Report any problems to parents.
<p><i>Skin Picking</i></p> <ul style="list-style-type: none"> ▪ <i>Common problematic behavior seen in persons 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><i>Daytime Sleepiness</i></p> <ul style="list-style-type: none"> ▪ <i>Common to see in people. 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 individual 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><i>Strabismus</i></p> <ul style="list-style-type: none"> ▪ <i>Often seen in younger people.</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 person wears glasses and/or patches if needed.
<p><i>Scoliosis and Other Spine Problems</i></p> <ul style="list-style-type: none"> ▪ <i>Common to see scoliosis and other spine deformities in persons 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><i>Dental Problems – Dry Mouth</i></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 individuals with Prader-Willi syndrome contact:

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