

## Health Concerns and the Camper w/ Prader-Willi Syndrome Information for Camp Staff



The camper with Prader-Willi syndrome (PWS) may experience some unique health issues. It is important for camp staff to be aware of these to ensure that the camper has a safe, healthy camp experience. A summary of common health concerns and some strategies are summarized below.

Health Concern	Strategies	Health Concern	Strategies
<p><b><u>Altered Pain Response – Decreased Pain Sensitivity, High Pain Threshold</u></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 and swelling is common.</li> <li>▪ Complaints of pain should be assessed.</li> </ul>	<ul style="list-style-type: none"> <li>▪ All injuries need to be assessed by an adult – even when injuries do not appear to be severe.</li> <li>▪ Report all injuries or changes in behavior to the parent or caregiver.</li> <li>▪ May require examination by a health care provider to rule out fracture or other health problem.</li> <li>▪ Apply ice and elevate injuries as needed.</li> </ul>	<p><b><u>Altered Temperature Regulation</u></b></p> <ul style="list-style-type: none"> <li>▪ Common to see unexplained high and low body temperatures.</li> <li>▪ Little or no fever may be present with illness.</li> <li>▪ Often experience low tolerance to high outside temperatures.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Make sure the camper does not overheat.</li> <li>▪ If extreme redness of the face and sweating is noted, remove to cool area; encourage cool water and/or cooling measures.</li> <li>▪ If illness is suspected, notify parent. Fever may not be present.</li> </ul>
<p><b><u>Severe Stomach Illness – Lack of Vomiting</u></b></p> <ul style="list-style-type: none"> <li>▪ Severe stomach illness has been noted in persons' w/PWS 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>▪ It is 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.</li> <li>▪ Camper should be urgently evaluated by a health care professional.</li> <li>▪ Any incidence of vomiting should be reported to the parent.</li> <li>▪ Encourage the camper to share honestly if they have had a binge episode. If confirmed, he/she should not be punished.</li> </ul>	<p><b><u>Behavior – Emotional Problems</u></b></p> <ul style="list-style-type: none"> <li>▪ Persons with PWS have problems regulating their emotions.</li> <li>▪ Most do not handle change well.</li> <li>▪ Some exhibit obsessive-compulsive tendencies.</li> <li>▪ Exaggerated emotional responses and extreme anger may be seen.</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 – foreshadow and prepare if possible.</li> <li>▪ Many benefit from a schedule put into writing.</li> <li>▪ Encourage 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>▪ Administer medications as ordered.</li> </ul>
<p><b><u>Increased Food Drive/Low Metabolism</u></b></p> <ul style="list-style-type: none"> <li>▪ Because of an abnormality in the hypothalamus, campers with PWS do not register the feeling of fullness and have varying degrees of food seeking.</li> <li>▪ Many will sneak and/or steal food – often putting them at great risk for choking and gastric illness (see below).</li> <li>▪ Require calorie restricted diet with 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 around all food sources. Keep food out of sight.</li> <li>▪ Do not use food as a reward or in camp activities.</li> <li>▪ It may be necessary to empty garbage cans that contain discarded food.</li> <li>▪ Staff should be trained in the Heimlich maneuver.</li> <li>▪ Camp staff should serve food to assist with portion control.</li> </ul>	<p><b><u>Skin Picking and Sun Sensitivity</u></b></p> <ul style="list-style-type: none"> <li>▪ Common problematic behavior seen in person's w/PWS of all ages. Open sores common.</li> <li>▪ May pick at various openings of body</li> <li>▪ Sensitive to sun</li> </ul>	<ul style="list-style-type: none"> <li>▪ Provide diversion activities – keep hands busy. Apply lotion.</li> <li>▪ Incentive program often needed to keep wounds covered.</li> <li>▪ Encourage/teach self care of wound.</li> <li>▪ Apply mosquito repellent routinely. Have camper wear long sleeves and pants for hiking or walks in the woods.</li> <li>▪ Monitor frequent trips to bathroom. Time limits and supervision in bathroom may be needed.</li> <li>▪ Apply sunscreen; encourage wearing hat &amp; sun glasses.</li> </ul>
<p><b><u>Scoliosis and Other Spine Problems</u></b></p> <ul style="list-style-type: none"> <li>▪ Common to see scoliosis and other spine deformities in persons' w/PWS.</li> <li>▪ Many require bracing.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Support and assist if brace is needed.</li> <li>▪ Adaptive measures may be needed for some physical activities.</li> <li>▪ Encourage good posture.</li> </ul>	<p><b><u>Daytime Sleepiness</u></b></p> <ul style="list-style-type: none"> <li>▪ Common to see daytime sleepiness</li> <li>▪ May be related to sleep apnea or weak chest muscle resulting in poor air exchange.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Get camper up and moving.</li> <li>▪ Some may require a rest time.</li> <li>▪ Some use Continuous Positive Airway Pressure (CPAP) mask/machine at night.</li> </ul>
<p><b><u>Dental Problems – Dry Mouth</u></b></p> <ul style="list-style-type: none"> <li>▪ Common problems: thick, sticky saliva, teeth grinding, rumination, cavities</li> <li>▪ Most have aversion to water.</li> </ul>		<ul style="list-style-type: none"> <li>▪ Make sure camper brushes and cares for teeth.</li> <li>▪ Encourage water. Most prefer flavored water – best if non-carbonated.</li> <li>▪ Assure compliance with use and care of bite guard if camper has one.</li> </ul>	