



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

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▪ *Most have aversion to water.*

▪ Assure compliance with use and care of bite guard if camper has one.