

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. **Parents and caregivers are encouraged to fill in pertinent information and strategies for the individual camper.** Concerns and a few strategies are summarized below.

Camper's Name: _____ Camper's Date of Birth: _____
 ALLERGIES: _____ Medical Conditions: _____

Health Concern	Strategies
<p><u>Altered Pain Threshold – 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. 	<ul style="list-style-type: none"> ▪ All injuries need to be assessed by an adult – even when injuries are severe. ▪ Report all injuries or changes in behavior to the parent or caregiver. ▪ May require examination by a health care professional to rule out fracture or other health problem. ▪ Apply ice to injuries as needed.
Please note any specific instructions or helpful hints for this camper:	
<p><u>Altered Temperature Regulation</u></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 outside temperatures. 	<ul style="list-style-type: none"> ▪ Assist in making sure the camper 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. ▪ If illness is suspected, notify parent. Fever may not be present.
Please note any specific instructions or helpful hints for this camper:	
<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. ▪ Can gain weight on ½ calories of others; 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. ▪ May need to have food served up for him/her to assist with portion control.
Please note any specific instructions or helpful hints for this camper: Calories Camper should receive daily: _____	
<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 that 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. He/she should not be punished if this has occurred.
Please note any specific instructions or helpful hints for this camper:	

Health Concern	Strategies
<p><u>Behavior – Emotional Problems</u></p> <ul style="list-style-type: none"> ▪ <i>Persons with PWS have problems regulating their emotions.</i> ▪ <i>Most do not handle change well.</i> ▪ <i>Some exhibit obsessive-compulsive tendencies.</i> ▪ <i>Exaggerated emotional responses and extreme anger may be seen.</i> ▪ <i>Some take medications to assist with mood stabilization.</i> 	<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”. ▪ Make sure to administer medications at the appropriate times.
<p>Please note any specific instructions or helpful hints for this camper:</p>	
<p><u>Skin Picking and Sun Sensitivity</u></p> <ul style="list-style-type: none"> ▪ <i>Common problematic behavior seen in persons w/PWS of all ages. Open sores common.</i> ▪ <i>May pick at various openings of body</i> ▪ <i>Sensitive to sun</i> 	<ul style="list-style-type: none"> ▪ Provide diversion activities – keep hands busy. Apply lotion. ▪ Incentive program often needed to keep wound covered. ▪ Encourage/teach self care of wound if able. ▪ Apply mosquito repellent routinely. ▪ Monitor frequent trips to bathroom. Time limits and supervision in bathroom may be needed. ▪ Apply sunscreen; encourage wearing hat and sun glasses.
<p>Please note any specific instructions or helpful hints for this camper:</p>	
<p><u>Daytime Sleepiness</u></p> <ul style="list-style-type: none"> ▪ <i>Common to see in campers. Often symptom of sleep apnea.</i> ▪ <i>May be result of weak chest muscles-poor air exchange.</i> 	<ul style="list-style-type: none"> ▪ Get camper up and moving if fatigue is noted. ▪ May require a rest time during the day. ▪ Some use Continuous Positive Airway Pressure mask/machine at night.
<p>Please note any specific instructions or helpful hints for this camper:</p>	
<p><u>Scoliosis and Other Spine Problems</u></p> <ul style="list-style-type: none"> ▪ <i>Common to see scoliosis and other spine deformities in persons w/PWS.</i> ▪ <i>May require bracing.</i> 	<ul style="list-style-type: none"> ▪ Support and assist if brace is needed. Adaptive measures may be needed for some physical activities.
<p>Please note any specific instructions or helpful hints for this camper:</p>	
<p><u>Dental Problems – Dry Mouth</u></p> <ul style="list-style-type: none"> ▪ <i>Common problems: thick, sticky saliva; teeth grinding, rumination, cavities</i> ▪ <i>Most have aversion to water.</i> 	<ul style="list-style-type: none"> ▪ Make sure camper brushes and cares for teeth. ▪ Encourage water. Most prefer flavored water – best if non-carbonated. ▪
<p>Please note any specific instructions or helpful hints for this camper:</p>	
<p><u>Other Health Issues:</u> Please list any other health issues the camper may have along with strategies to assist the counselor or nurse.</p>	