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.

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<th>Health Concern</th>
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| **Altered Pain Threshold – Decreased Pain Sensitivity/High Pain Threshold**  
- Pain may be diminished or absent - even in severe injuries.  
- Fatigue or irritability may be a sign of illness.  
- Increased bruising & swelling is common. |  
- 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. | **Skin Picking**  
- Common problematic behavior seen in students of all ages.  
- Open sores common.  
- May pick at various openings of body |  
- 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. |
| **Altered Temperature Regulation**  
- 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. |  
- 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. | **Behavior – Emotional Problems**  
- 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. |  
- 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. |
| **Increased Food Drive/Food Seeking/Low Metabolism**  
- 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 food issues in the classroom. |  
- 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. | **Severe Stomach Illness – Lack of Vomiting**  
- 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. |  
- 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. |
| **Osteoporosis**  
- High risk due to hormone abnormalities & dietary limitations. |  
- At high risk for fracture – assess injuries for possible sprain/fracture. May require x-ray to rule out fracture. | **Increased Sensitivity to Medications**  
- More sensitive to medications that can cause sedation or sleepiness |  
- Be aware of all medications that student is taking. Report any problems to parents. |
| **Daytime Sleepiness**  
- Common to see in students. Often symptom of sleep apnea.  
- May be result of weak chest muscles-poor air exchange. |  
- 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. | **Scoliosis and Other Spine Problems**  
- Common to see scoliosis and other spine deformities in students’ w/PWS.  
- Often difficult to detect if obese.  
- May require bracing. |  
- 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. |
| **Strabismus**  
- Often seen in younger students.  
- Poor muscle tone/control in eyes  
- Glasses, patching and in some cases surgery is needed. |  
- Look for signs during vision screening.  
- Refer to eye specialist if needed  
- Make sure students wears glasses and/or patches if needed. | **Dental Problems – Dry Mouth**  
- Common problems:  
  - thick, sticky saliva,  
  - teeth grinding,  
  - rumination and cavities |  
- Teach and encourage good dental care and water.  
- Assist in referral to dentist if needed. |