



Strategies for Improving Behavior in the Classroom

Do's and Don'ts When Teaching and Playing with the Student Who Has Prader-Willi Syndrome

The following information is being provided to you because _____
Student's Name

has Prader-Willi syndrome (PWS), a rare, non-inherited genetic disorder that causes individuals to always feel hungry no matter how much food is eaten. At the same time, their bodies metabolize the foods they eat at about half the normal rate, which means that people with PWS gain weight very, very quickly. **Children with PWS cannot be expected to manage their behavior when they know that any type of food or beverage is obtainable; the compulsion to eat is too strong and will affect behavior and school performance. It is imperative to limit the child's access to food at all times.**

People with Prader-Willi syndrome generally have a difficult time managing themselves when they feel frustrated or anxious. It is important to know a little about the general Do's and Don'ts when working and playing with someone who has PWS so that you can help them manage themselves better.

DO'S

- DO** Keep food inaccessible at all times other than lunch. Children with PWS cannot fight their compulsion to get it. A child with PWS may need to be continuously monitored so that he does not visit the cafeteria or eat food discarded in trash cans. Know that it is exceptionally difficult for the child with PWS to watch others enjoying foods and treats he is denied.
- DO** Keep sight of the fact that the hand of a child with PWS is quicker than your eye!
- DO** Inform all school staff, cafeteria staff, janitors, bus drivers, and anyone who needs to know that the student has Prader-Willi syndrome and must not be given any food outside of the regular lunch hour.
- DO** Provide a set of the rules, preferably written, to the student with PWS. Read and discuss them so they are clearly understood. "Contracts" written with the student with PWS can be very helpful.
- DO** When there is a power struggle or supposed misunderstanding, go to the written program and allow no argument. Always maintain a calm demeanor.
- DO** Keep in mind to praise and recognize good performances. A lot of mileage can be obtained with a few positive words and smiles.
- DO** Establish a positive reinforcement program, particularly on an individual basis, using rewards as often as possible, or using withdrawal of privileges as needed and understood. Do not use food as a reward or punishment.
- DO** Try to help the child understand his behavior and take steps to improve it. Most children with PWS will try with varying degrees of success to improve, particularly if those around them show understanding, concern, and empathy.
- DO** Keep in mind that logic and reason will not prevail when the child with PWS gets upset and/or "stuck" on an idea or position.
- DO** Listen to the child who needs to talk. The time it takes may alleviate or prevent unpleasantness later.
- DO** Keep the daily routine as structured as possible. It is important for a child with PWS to know of change, however minute, in advance.
- DO** Treat each child with respect and dignity.

- Continued on Back -



- Continued from Front -

Strategies for Improving Behavior in the Classroom
Do's and Don'ts When Teaching and Playing with the
Student Who Has Prader-Willi Syndrome

DO NOT'S

- DO NOT** leave food accessible. It is important to lock the cafeteria, vending machines, and other food sources to remove temptation. Food issues are one of the most common reasons for misbehavior and tantrums.
- DO NOT** try to talk someone out of their upset or disappointment. If you try to reassure or talk the child out of their upset too soon, they will escalate their behavior to try to get you to understand their upset. Instead, repeat back their upset; go completely “with” their upset until they appear more calm. Only then can you begin to pursue how to work things out.
- DO NOT** get into an argument. If the child with PWS is building up to a disagreement, try to walk away or guide the person to a private area and discuss it there. Frequently discussions can be ended if you give them the last word. Try to make the statement, “I will make one more comment and then you can make one more comment and then the subject is closed.”
- DO NOT** tease or be sarcastic. Children with PWS find it difficult to assimilate such tactics and could cause them to become orally abusive or even physically assaultive. At the same time, do not treat children with gloves or ten-foot poles! They want to belong and have fun. Some good-natured teasing is accepted, enjoyed, and looked forward to.
- DO NOT** promise anything that you cannot or will not do. Children with PWS are uncomfortable with inconstancy and uncertainty. If changes are necessary, prepare the person so they do not feel deserted or threatened.
- DO NOT** ignore the child with PWS who has an obvious need to talk.



*Excerpted from Op Cit, Thompson, Dorothy C., et al, pages 125-127 and
Prader-Willi Syndrome Association, Prader-Willi Syndrome Management pamphlet*



MEDICAL ALERT INFORMATION

Hyperphagia (Excessive Appetite): Insatiable appetite may lead to life threatening weight gain, which can be very rapid and occur even on a low-calorie diet. Individuals with PWS must be supervised at all times in all settings where food is accessible.

Respiratory Concerns: Individuals with PWS may be at increased risk for respiratory difficulties. Obesity adds to these concerns.

Body Temperature Abnormalities: Idiopathic hyper- and hypothermia have been reported. Hyperthermia may occur during minor illness and in procedures requiring anesthesia. Fever may be absent despite serious infection.

Severe Gastric Illness: Abdominal distention or bloating, pain and/or vomiting may be signs of life-threatening gastric inflammation or necrosis and is more common in PWS than in the general population. Rather than localized pain, there may be a general feeling of unwellness. If a child with PWS has these symptoms, especially following a known or suspected binge-eating episode, immediately notify parents and prepare for immediate hospitalization.

Lack of Vomiting: Vomiting rarely occurs in persons with PWS. The presence of vomiting may signal a life-threatening condition. If poisonous materials are ingested, emetics may be ineffective and repeated doses may cause toxicity.

Adverse Reactions to Some Medications: People with PWS may have unusual reactions to standard dosages of medications. Use extreme caution in giving medications that may cause sedation.

High Pain Threshold: Lack of typical pain signals is common and may mask the presence of infection or injury. Someone with PWS may not complain of pain until infection is severe or may have difficulty localizing the pain.

Skin Lesions and Bruises: Because of a habit that is common in PWS, open sores caused by skin picking may be apparent. Individual with PWS also tend to bruise easily.

FOR MORE INFORMATION ABOUT PRADER-WILLI SYNDROME CONTACT

PRADER-WILLI CALIFORNIA FOUNDATION (800) 400-9994

PRADER-WILLI SYNDROME ASSOCIATION (USA) (800) 926-4797