



Information for School Staff: Supporting the Student Who Has Prader-Willi Syndrome

(Compiled by Barb Dorn, Crisis Counselor PWSA USA.)

All students with PWS are individuals. Each have varying strengths and needs.
This chart does **not** reflect the behavioral needs of all children & young adults.

Common Behaviors Often Seen in Students With PWS	Possible Management Strategies
<p><u>Rigid Thought Process</u> It is common for people with PWS to receive and store information in a very orderly manner. There is a strong need for routine, sameness, and consistency in the learning environment.</p>	<ul style="list-style-type: none"> ▪ Foreshadow changes and allow for discussion. Do this in a safe area where they can share feelings. (The student needs to time to adapt to this change) ▪ If there is a change -use visuals; put things in writing – lists, schedules ▪ If able, communicate changes in personnel ahead of time – but not too far ahead. ▪ Don't make promises you can't keep ▪ Break down procedures into concise, orderly steps. ▪ To resolve "stubborn issues" try using "compromise". Both the student and the educator have to come up with a totally new solution. Not only is this a successful problem-solving strategy – it can also be a form of diversion. ▪ Provide praise when being flexible
<p><u>Perseverative or Obsessive Thinking</u> This is the tendency to get "caught" on one issue or thought to the point where it overshadows the main theme of the learning or social event. This behavior can contribute to difficulty in transitioning from one topic/activity to another. Students often have an great need to complete tasks. It can lead to loss of emotional control.</p>	<ul style="list-style-type: none"> ▪ Use reflection – have student restate what you said ▪ Put in writing; use visuals. Carry a small notebook if needed. ▪ Less is best – give less amount of work at one time rather than more. Add to the work as time allows. ▪ Avoid power struggles and ultimatums ▪ Ignore (if possible) ▪ Don't give more information than is necessary especially too far in advance. ▪ Use "strategic timing" – time the activity that the student has difficulty ending right before snack or lunch. ▪ Set limits. "I'll tell you 2 more time, then we move on to next topic. This is #1."
<p><u>Tenuous Emotional Control</u> Any combination of life stressors can lead to emotional "discontrol". The result may be exhibited as challenging behaviors such as tantrums – yelling, swearing, aggression, destruction, self-injury.</p> <p>During these episodes, reasoning is lost.</p> <p>Recovery of control takes time and is often followed by sadness, remorse, and guilt.</p> <p>Because of a problem in sequence processing, students are not always able to turn <u>what not to do</u> into <u>what to do</u>.</p>	<ul style="list-style-type: none"> ▪ Be aware of "hallway over stimulation" – especially before the school day begins. Have student enter the building at a less popular entrance. If possible, have arrival time be 5-10 minutes after school starts. Dismiss early. ▪ Start the day off on the right foot by allowing time to go over the schedule for the day and work through any changes there may be. Putting the new schedule in writing often helps to decrease anxiety. ▪ At the start of the day – set daily goals <u>with</u> the student. Limit to no more than 3. Communicate behaviors <u>you wish to see</u>. Make it a cooperative task that provides concrete behavior expectations. Put goals in writing. Avoid the word "DON'T" ... focus on the word "WILL". (EX. "Please talk in a quiet voice ... instead of "Don't yell". When I feel frustrated, I will tell Mr. Smith or another adult.") ▪ Provide positive attention and praise when student is maintaining control, especially in difficult situations. Celebrate success! ▪ Encourage communication and acknowledging feelings. Words are important – LISTEN carefully! ▪ Include the student in behavior plans. Having their input elicits cooperation and a sense of support. ▪ Be a role model. "I always say "darn" when I am angry. Let's try that for you ... darn, darn, darn". Practice when the student is not agitated or angry. ▪ Depending on the student and the situation – use humor. It is often effective. ▪ Anticipate build up of frustrations and help him/her to remove self to "safe area" Create a key word or phrase that will alert the student that it is time to go. Practice using these words/phrases when the student is calm. ▪ Develop a plan and teach the student <u>what to do</u> if he/she feels angry or frustrated. Many students substitute a means of releasing this pent up anger – long walks/exercise, ripping paper, tearing rags, popping packaging bubbles... ▪ Don't try reasoning during times when out of control. Limit discussion. ▪ Have a plan in place if student becomes more violent. Safety for all is a priority. Consistency in approach is imperative ▪ Provide positive closure. Don't hold a grudge. ▪ If using consequences – they should be immediate and help the student learn from the outburst – saying "I'm sorry", sending a note to say they are sorry ...

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<p><u>Food Craving and Diet Restrictions</u> For people with PWS, the message of fullness never reaches the brain – they are always hungry. In addition to this craving for food, food is metabolized at a rate that causes extraordinary weight gain. Food must be monitored and the individual supervised in all environments.</p>	<ul style="list-style-type: none"> ▪ Make sure lunch is placed with a bus driver and /or an assistant on the ride to school. ▪ Educate and inform <u>all people</u> working with this student – including bus drivers, custodians, secretaries and volunteers. ▪ If the student states he/she has not had breakfast – call parents or caregiver before giving more food. (Often times they say this to get more food.) ▪ Supervise in lunchroom and in all food related areas – including vending machine areas. In some cases, student may need to eat in classroom (with peer/friend) ▪ Many require supervision in hallways or near unlocked lockers at all times. ▪ Avoid allowing the student to have money. Lock up all sources of money – including purses. Money buys food! ▪ Address any stealing or trading of food in private. ▪ Follow guidelines for treats or eating of extra food. Communication with home is very important. ▪ Follow calorie-controlled diet. If a special calorie diet is needed and served by the school, a prescription must be obtained from a health care provider and should be a part of the student’s educational plan. ▪ Don’t delay snack or lunch; if this is necessary discuss ahead ▪ Limit availability and visibility of food. Be aware of candy dishes. ▪ Avoid using food as a reward or incentive. ▪ Be aware of smells – there is nothing like the smell of popcorn to make a student with PWS agitated. ▪ When going on a field trip or other outing, discuss all food-related issues <u>ahead</u> of time. Will you bring snack along or will it be purchased? If purchased – what will it be? Will the outing interfere with the time of a meal or snack? ▪ Obtain weekly weight by school nurse if indicated. ▪ Daily exercise should be a part of student’s schedule. <p>If a student with PWS is caught with food in his/her possession that is stolen – DO NOT ATTEMPT TO PHYSICALLY TAKE IT AWAY. Try to compromise, trade or other forms of negotiation. Do not threaten. Evaluate what happened. Institute measures to prevent reoccurrence.</p> <ul style="list-style-type: none"> ▪ If it is discovered that student has had a binge episode and eaten a large quantity of food – contact parent immediately. This could result in a health emergency. ▪ Encourage to eat slowly – student may choke from eating too fast.
<p><u>Poor Stamina</u> People with PWS tire more easily and may fall asleep during the day. Morning is typically their optimal learning time, when energy level is highest.</p>	<ul style="list-style-type: none"> ▪ Get person up and moving. Send on errand. Take a walk. ▪ Schedule high energy, mobilizing activity after lunch ▪ Offer items /activities which stimulate large muscles and deep breathing - balloon blowing, party blowers ▪ Provide scheduled rest time or a quieter activity if needed
<p><u>Scratching and Skin Picking</u> These two behaviors are often seen in individuals with PWS and may be worse during times of stress. Combined with a higher pain threshold, these behaviors can result in tissue damage if not controlled.</p>	<ul style="list-style-type: none"> ▪ Use diversion - provide activities to keep hands busy (coloring, computer time, play dough, hand-held games, magazines, book...) ▪ Keep nails short. Apply lotion liberally – it keeps skin slippery and soft making it more difficult to pick. Applying lotion can also be an effective diversion. ▪ In extreme cases, provide constant supervision – even in the bathroom. Limit time in the bathroom. ▪ Cover area with bandaide or similar covering ▪ Don’t just tell him/her to stop picking – it won’t work. ▪ Apply mosquito repellent before any walks or outside activity.
<p><u>Difficulty with Peer Interactions</u> While children want and need other children and value friends, they often lack age-appropriate social skills. They often face challenges in issues of fairness and comparing themselves to others, often resulting in frustration and anger.</p>	<ul style="list-style-type: none"> ▪ Many do better in small groups. Benefit from verbal cues and guidance. ▪ Pre-plan outings. Keep time short ▪ “Supported recess or social outings” – planned activities with a friend ▪ Include child in planning activities that are of interest to him/her (board games, puzzles, computer games...) ▪ Provide social skill classes that emphasize sharing, taking turns... ▪ Role play and practice appropriate social situations. ▪ Clearly state and write do’s and don’t for social interactions w/ friends of opposite sex

Students with Prader-Willi syndrome are very caring, sensitive and conscientious. They want very much to be successful, have friends and be a part of their school community. Although they face some unique challenges, with proper support and understanding ... they are playing, learning, working and living successfully in our communities.