

Anxiety, Frustration and Anger Behavior Manifestations of Prader-Willi Syndrome

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Students with Prader-Willi syndrome (PWS) are individuals. Not all individuals exhibit the same behaviors in the same intensity or frequency. Because of an abnormality in the hypothalamus, many students with Prader-Willi syndrome (PWS) have tenuous emotional control. They have problems managing their feelings and appropriately exhibiting emotions.

Some of the common challenging behaviors that are often manifested in students with Prader-Willi syndrome include anxiety, frustration and anger. The most common precipitating factors seen in behavior outbursts are food and change. The appetite control center is located in the hypothalamus. When people with PWS eat, the message of fullness never reaches their brain. They are always hungry. The degree of hunger and the need to seek food can be very intense in some of these students. They are often irrational when it comes to anything having to do with food. Change can also cause extreme anxiety. Positive change as well as negative change may result negatively in these students.

Anxiety

Most students with PWS, young and old have a higher level of anxiety. Because of a strong need for structure and consistency, they often exhibit anxiety when there is change or perceived change. Students may worry about how a change impacts food. It is common to see them become worried regarding all aspects of a food situation – when, what, where and how much.

The presence of food, including the smell of food can cause extreme anxiety in some students. If food is present, these students will focus on it and not on academics or the task at hand. Can they have it? Can they take it? When can they take it? How can they get it? The anticipation and anxiety in the food seeking process can become overwhelming.

Providing one-on-one supervision; closing doors; removing food; locking up food sources; developing creative scheduling during food exposure times are all ways to prevent anxiety related to the uncontrollable urge. If there is someone watching, a person is less likely to seek food. If food is removed, there is greater chance of successful diversion.

Any change in routine, personnel, schedules or plans can result in emotional upheaval. Days when there is a field trip, a substitute teacher, an assembly or an alternate schedule can put students with PWS on edge and their emotional threshold may be very low. Prepare students for change and provide reassurance on how the change in one area will not result in change in another. Emphasize the areas of sameness. Provide visual representation of change. This

allows students to reorganize their brain to accommodate it. However, the emotional threshold may remain fragile.

People with PWS who have anxiety manifest this emotion in many ways. You may see irritability, tearfulness, crying, yelling and even aggressive behaviors as they attempt to cope and release it.

Frustration and Anger

Frustration often becomes a manifestation of anxiety. For example, when change occurs and students are unprepared for this change, they may exhibit frustration. Frustration can quickly escalate to anger. Threats feed the anger. Behavior can quickly go from words of anger – yelling and swearing – to action of words – pushing, property destruction and even personal attack.

Students with PWS often describe this anger as an uncontrollable “feeling that must come out.” Any conflict with food situations can quickly escalate to anger. Students require a controlled environment where all food issues are removed and/or monitored.

Students with PWS have a skill and knowledge deficit in how to handle frustration and anger. They require instruction on appropriate ways to handle their emotions. A helpful, empathetic approach has a more successful outcome. Educators must be clear in teaching what behaviors students should be demonstrating. Students require teaching, re-teaching, practicing and review of these strategies at a time when they are able to listen – not when they are in a stressful situation. Teach students what to do – not what they should not do. (When you are angry ... tell an adult; take a walk ; listen to music...)

Students with PWS have problems with short term memory. If teaching is done too long after an incident, educators have reported that students often do not remember what they did to warrant the suspension. These students lose the opportunity to receive meaningful education that could help them learn how to handle the negative expression of emotions.

Most students with PWS also have cognitive learning deficiencies and do not generalize across environments. That is why it is important to provide this learning and/or relearning of appropriate behavior in the school setting. It is more meaningful for them to learn this in the environment where the problem behavior occurred. Receiving instruction at home of how to act in school is frequently ineffective. It is helpful to have, parents and educators working together, teaching and using the same strategies to teach them how to manage their behavior. This should be the case at home, at school and in the vocational setting. Consistency is

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imperative and most successful.

Many students with PWS are visual learners. Using strategies that support this learning style should be utilized. Note cards, contracts and visual reminders can help to facilitate learning. Most are also motivated by rewards or incentives for doing the right thing. The key is to praise, reward and reinforce the positive behavior you are teaching. Your goal is to replace the negative response with more appropriate responses.

School administrators often wonder how to handle discipline in situations like this. In many cases, a one day suspension is reasonable. It allows all parties to cool down and should send a message to the student that it is never ok to hurt someone or break anything. The student should return to the school environment as soon as possible so that he/she

can receive intensive instruction on how emotions can and should be demonstrated when they have negative feelings. If a suspension is too long; the student may see it as rewarding. Any student with PWS who receives a suspension should have a behavior support plan as part of their Individual Education Plan. If the student does not have one; an IEP team meeting should reconvene to initiate a functional behavior assessment which identifies the problematic behavior issues as well as a plan to change these negative responses.

Anxiety, frustration and anger can be behavior manifestations of Prader-Willi syndrome. Managing these emotions can be a life long challenge for these students. We must attempt to reduce anxiety; alleviate frustration and prevent anger.

The Tenuous Emotional Continuum

- Anxiety – if not relieved causes frustration.
- Frustration – if not addressed escalates to anger.
- Anger – if not defused results in aggression

Dos and Don'ts in Teaching Positive Behavior Responses in the Student with Prader-Willi Syndrome	
DO:	DON'T
Take steps that plan for change and discuss these changes ahead of time. • Help students as they re-plan their approach to situations and events. • Eliminate food seeking opportunities and situations. • (If the student does steal or access food,) attempt to negotiate, substitute, trade and empathize with him or her. • Go back and evaluate the situation that allowed him/her to access food. If possible, prevent the problem from happening again. • Teach the student more appropriate ways to handle anger and frustration – what should he/she do. • Identify activities that the student enjoys doing – listening to music, reading a book, taking a walk... that he/she can use when they are starting to feel stressed. Replace this stress with an enjoyable activity. • Practice and review those strategies. (Taking a walk; going to the gym to do some physical activity; listening to music ...) • Use strategies that allow them to release negative energy or anger (Stepping outside and yelling; ripping up magazines; hitting pillows.) For some, this approach is more effective. • Encourage use of words not actions. Praise and celebrate when used. • Make out-of-school suspensions short so that the student with PWS can learn from the experience. • Focus on teaching, practicing and re-teaching strategies to handle negative emotions as part of the suspension process. Do this in the school setting.	• Attempt to physically remove food if the student takes food. (It most likely will result in an assault) • Threaten or eliminate future snacks or meals. Replace them with a lower calorie substitution. • Give suspensions that are longer than 24-48 hrs. – including non-school hours. The student will not remember why they have been suspended. You have lost the opportunity to have the student learn something from this experience. • Have food in the classroom. It only creates anxiety and emotional fragility.