

Mental Health and Behavior Changes: When should parents seek help?

Janice Forster, M.D., and Linda Gourash, M.D. (The Pittsburgh Partnership), and Kathy Clark, R.N., M.S.N.

The possibility of psychiatric illness increases during the teen years and young adulthood in PWS. This is also a time of increased stress for them and for their parents. Behavior patterns in PWS are quite unique to the syndrome, so it may be hard for parents to sort out what is a mental health “problem” from what is “just PWS.” As stress increases, coping strategies diminish, and “typical” PWS behavior intensifies. This behavior change is met by a response from parents, teachers, aids, and other caregivers in the environment. This response can either help to manage the escalating behaviors or add to the cycle of stress and make them worse. When a person’s behavior becomes “atypical” and it interferes with their ability to function over time, it becomes a “symptom” that requires evaluation by a psychiatrist or mental health clinician.

PWS Behavior



© Pittsburgh Partnership

Undiagnosed medical problems can also increase stress and cause behavior changes. Not every new behavior signals a psychiatric diagnosis, but all new problematic behaviors should be evaluated by a physician. The approach to improving behavior begins at the bottom of the PWS Intervention Pyramid.



ENVIRONMENTAL INTERVENTIONS

The components of environmental interventions for most people with PWS include food control, FOOD SECURITY, calorie management, mandatory exercise, opportunities for sensory motor stimulation, a daily plan with a schedule of activities suitable for developmental age, and caregiver attributes of consistency, predictability, and communication style. These environmental elements are further described in a tool called the TRAIN which is available on the Pittsburgh Partnership website (www.pittsburghpartnership.com). These domains require effort and maintenance, but we have found that families who are more structured and consistent with the daily plan experience less stress.

Behaviors often occur when environmental security, consistency, and predictability change. First, evaluate the environment at home, school, or work, and firm up any areas that have relaxed over time. Staff turnovers can mean unexpected challenges for the person with PWS. Changes do not have to be recent to be the source of a new behavior problem.

For example:

- The start of a new school year is always a source of stress because there is no guarantee that the previously established plan that was working well will be carried over.
- The move from elementary to middle school is especially problematic due to the increased number of transitions during the day.
- The move from middle school to senior high school is usually associated with increased independence, which increases opportunities for food theft and more social stress.
- Good weight control should not lead to the removal of locks or more access to food.
- Old activities ending may lead to increased down time and social isolation; plan to add new meaningful activities.
- Increased independence should include scheduled, planned activities, increased accountability and possibly more 1:1 supervision.
- New staff is hired with excessively high expectations. Harsh punitive attitudes have no role in managing PWS!

COPING STRATEGIES

Everyone has built-in, “hard wired” strategies to cope with stress. It is important to identify what these strategies are for each person. For example, avoidance can work well, but it causes problems for the parent or caregiver when the person refuses to make a transition to avoid what they perceive to be a stressful situation. Distraction through watching YouTube, TV, or DVDs or engaging in repetitive activities (playing video games, assembling puzzles, or doing crafts) can be stress relieving, but may

occupy too much time during the day. Although these preferred activities can be scheduled more frequently through the day, they must be time limited, and sometimes stopping them can be upsetting. There are other coping strategies that can be taught to the person with PWS, but due to their learning style, the intervention must be scripted, cued, rehearsed, and done together with the caregiver. It is highly unlikely that the person with PWS will be able to consistently implement these strategies independently.

For example:

- Teach children to identify and name their feelings, then identify and discuss how they are feeling
- Help them identify when they are upset, and provide appropriate choices of what to do next, such as taking a break.
- Relaxation training (progressive muscle relaxation; rhythmic breathing: blowing a pin wheel or blowing into a balloon; visual imaging: put worries on a cloud; stretching putting arms up reaching over the head)
- Anger management training (there are many components to this, and it is usually done with a counselor)
- Social skills training (emphasize empathy for hurting other people's feelings and the emotional significance of an apology...never blame PWS!)
- Social stories are always helpful, especially using animals, but people with PWS have difficulty adapting these concepts to their own current situation; the caregiver can help by saying, "remember when Sammy the Shark became angry?"

Using a cue like a "flexibility card" can signal when a change in daily schedule is about to occur. If you print coping and relaxation strategies on the back of the card, it can be used to prompt use of these to deal with the stress.

INCENTIVES

Positive reinforcement can be a very powerful tool to increase a desirable behavior. Verbal praise with positive tone of voice is the easiest form of reinforcement. "You are doing a great job" is very helpful but saying "You must be proud of yourself for doing a good job" shifts the locus of control onto the adolescent and fosters independence and self-esteem. The use of incentives should be explained to the child or adolescent as a way for everyone to work together to improve behavior. Keep the incentives small, frequent, and integrated into the daily schedule. Remember that consistency is essential. For example:

- Verbal praise for completing ordinary tasks like setting the table or putting the clean silverware away.
- A sticker every day for being ready to go to school or work.
- Earning more time to do a preferred activity (playing video games, watching YouTube or Netflix) for completing homework after school.

- Selecting the family movie on the weekend for folding the laundry.
- Earning time with a parent after picking up their room.

BEHAVIOR PLANS

These interventions should be developed with the help of a teacher, mental health provider, behavior specialist or the family crisis counselors at PWSA | USA. Behavior plans are developed to decrease problematic or unwanted behaviors. They work well in tandem with incentives because we are always trying to replace an undesirable behavior with an appropriate one. The essential components of any behavior plan are a list of positively phrased rules or desirable behaviors and the consequences that will occur if the rule is broken. Ideally, the behavior plan will be developed with the participation and cooperation of the person, like a contract.

For example:

- For an adolescent with repeated theft, the behavior plan might state: I will respect other's belongings. If I steal, I will return the item or pay for it out of my own money, and I will write a note of apology.

The behavior plan might also include the use of incentives and rewards, when they can be earned, and what caregiver is responsible for overseeing this.

For example:

- An older child is recording too many shows on DVR, using up the entire digital space for the family. The behavior plan states: I will record only 25% of the space on the DVR. My mom will check the percentage each day, and if I stay at 25%, she will watch a program with me that evening. If I go over that amount during the week, my dad will erase the shows I have taped back to 25%.

Rewards can be postponed (until they are earned) but they are never lost, e.g., "When you get a happy face (incentive) from school 3 days in a row, we will go to the Dollar Store (reward)." Rewards can't be too special though, because postponing or not achieving them can cause disappointment, and that makes behavior worse.

Punishments are ineffective in PWS and often worsen behaviors. Offering rewards on the spur of the moment to stop an undesirable activity is called bribery. This can never be sustained and can make the behavior worse.

The behavior plan may require a change of daily schedule or a change in the behavior of the caregiver. Caregivers are urged to make the effort to help and enable the person to follow the rules and achieve desirable behaviors. In addition to rewards, caregiver actions such as selective ignoring, differential reinforcement of other (appropriate) behavior, or time out might be recommended. There are printed resources and a video on the PWSA | USA website under "Family Support". On the Pittsburgh Partnership website, you can download and read about The Anatomy of a Tantrum or The Hyper-reactive Child or The Art of Communication.

MEDICATIONS

Even when all the layers of the PWS Intervention Pyramid have been followed correctly, some individuals may benefit from short-term or long-term medications. When behavior challenges escalate, see a doctor promptly. Early intervention is crucial before individual behaviors and caregiver reactions form a perpetuating cycle. Delineating the nature of behavioral symptoms, the duration of symptoms, and the level of impairment of function is the work of a psychiatrist or a mental health therapist. Psychiatric medications are used to treat an underlying disorder (antidepressants, mood stabilizers or antipsychotics); to modulate the interaction between the person and their environment (stimulants, adrenergic agonists, or tranquilizers); and to stabilize a crisis that might result in a change of placement or hospitalization.

There is not one specific medication used to treat problem behaviors or psychiatric illness for persons with PWS. But having a correct psychiatric diagnosis is an essential step to choosing the right medication. PWSA | USA has resources for psychiatrists which includes the advice to start with the lowest dose and raise doses or add additional medications with caution. Psychiatrists can call PWSA | USA and request printed information or a consultation with an expert member of our Clinical Advisory Board.

The information provided in this publication is intended for your general knowledge only and is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this publication.

Permission is granted to reproduce this article in its entirety, but it may not be reused without the following credit line: Reprinted with permission from Prader-Willi Syndrome Association | USA.