

## How Does a Person with PWS Think?

By: Kim Tula, MS

Individuals with PWS are generally concrete thinkers; they often take things literally. Being a concrete thinker makes it difficult for individuals with PWS to understand metaphors, idioms, abstract concepts, and sarcasm. Being a concrete thinker can also make it difficult for individuals with PWS to understand humor. Below are tips for communicating with someone with PWS.

### Avoid:

- Phrases like, “Hop to it!” (meaning “begin the task now”) may be misunderstood and result in a communication breakdown causing confusion, increased anxiety, and result in an unwanted behavior.
- The use of sarcasm, and at times, humor can also create confusion and increased anxiety. Unless you know the person understands sarcasm and humor, do not use them.
- Never use sarcasm or humor when a person is upset. It is likely they will not process what you are saying or will misunderstand your intentions.

### Use:

- Clear, concrete, concise statements. Say exactly what you mean. For example, if you want someone to begin a task, say “Please, sit down and start your worksheet” vs using the phrase “hop to it” or “get going”.
- Provide 1-2 step directions at a time.
- Communicate in a calm, neutral tone.
- Use pictures to assist with directions for task completing.

### Delay in Processing:

Many individuals with PWS have a delay in processing information. This delay in processing can lead to confusion, misunderstandings, increased anxiety, and unwanted behaviors, especially if the person with PWS is feeling rushed. Sometimes parents and/or caregivers may see the delay between what is said and the individual beginning to act as defiance. However, it is important to remember to give them time to process the request before you determine they are ignoring you or being defiant.

- Always give the individual time to process what has been said. Most individuals with PWS will take between 3-5 seconds to understand what you said, some people may take longer.
- Keep instructions simple, give 1-2 step instructions/directions at a time. If too many instructions are given, they will likely miss the middle part of what is said, resulting in confusion and misunderstandings.
- Ensure instructions are short and specific. If instructions are generalized or vague, the individual may not be able to break the task down into smaller steps causing a misunderstanding. For example, instead of saying “go get ready for bed”, break the request down into steps; it is time to brush your teeth, wait 5-7 seconds before repeating

the request. If after the second request they do not comply, perform the task with them before asking that they do the next step.

- Always start your message with a positive, then follow with the negative if needed. People with PWS tend to have a more difficult time processing information when they hear something negative. For example, “We are going to have so much fun at the zoo today and you will get to see your favorite animal. So, I am sorry, going over to Jonny’s will have to happen another day”
- Keep it simple and be patient. If you push for an answer to a question too quickly, the individual may impulsively give an answer that is not what he/she wanted, leading to confusion, frustration, and unwanted behaviors

### **Cognitive Challenges:**

Many individuals with PWS face cognitive challenges; however, they can and do excel in some areas of learning. It is important to remember; everyone has different strengths and challenges.

- It is possible for some deficits to be masked by other areas that one excels in. For example, an individual may have severe deficits in the ability to learn academics yet excel in communication skills; making it appear as though they have very little or no deficits.
- Individuals with PWS do better with concrete concepts rather than abstract (as previously mentioned, they are concrete thinkers). So, math is likely to be learned better if it is hands on i.e., objects they can touch and work with. Another example is when an individual with PWS is asked to write, they become focused on making the letters instead of what the letter represents.
- Some individuals with PWS do better academically, if they learn to type at a young age and use this as much as possible for schoolwork.
- It is common for individuals with PWS to have short-term memory issues. This can make teaching new skills a challenge and this process may take longer. However, their long-term memory is usually excellent; thus, once something is learned it is remembered forever.
- Most individuals with PWS struggle to sort items in sequence. This makes problem solving a challenge, as well as completing multi-step tasks without support or guidance. They can become easily frustrated and anxious trying to do what is asked of them; not knowing what to do first or what the task entails. Teaching sequential tasks takes repetition. Teaching problem solving skills takes practice and often support when new problems arise; individuals with PWS often lack the ability to generalize skills across situations.

### **Sensory Integration (SI):**

It is common for individuals with PWS to have sensory integration impairments. Sensory integration impairment or sensory processing disorder is a neurological disorder characterized by a neurological sensory integration deficit.

- Sensory integration impairment or sensory processing disorder cause a person to have difficulties interacting with the environment; often resulting in unwanted or challenging behaviors. Individuals with sensory integration impairments struggle to organize and respond to stimulation in the environment. If the environment is loud, they may cover

their ears, begin to cry, become anxious or agitated, or “shut down” due to their inability to tolerate the level of noise.

- Individuals with PWS also struggle with sensory integration related to internal stimulation. This can be seen when an individual’s engine is running too slow or too fast (i.e., the individual is too lethargic or hyperactive). The individual may need sensory integration to regulate their own body.
- There are activities that can be done at home to help improve SI. These activities help the child to interact with their environment, regulate emotions and to be calmer.
- Occupational Therapists and Physical Therapists can help design a program for your child. The national office of PWSA | USA also has information on SI.

## Anxiety:

For individuals with PWS, a lack of emotional regulation produces anxiety.

- Individuals with PWS generally have great difficulty managing their emotions. They typically feel high levels of anxiety – all the time. This high level of anxiety can be related to food, sensory integration impairments, and/or change.
- What is felt, emotionally, tends to be felt with great intensity. This labile affect is caused in part by a defect in the hypothalamic and pituitary systems.
- Maladaptive or unwanted behaviors are often attempting to reduce the level of anxiety the individual with PWS is feeling. Examples of behaviors one may see questions, excessive talking, and controlling, oppositional or argumentative behavior.
- Offering sensory integration items or techniques and providing empathy and support can be beneficial in helping one manage their anxiety and/or emotions.
- **Rigid Thoughts and Inflexible Behavior** are very common in people with PWS. Rigid thoughts and inflexible behavior can interfere with the flow of the day and cause tremendous upset for the individual with PWS and those around them.
- Increased anxiety can lead to rigid thoughts and inflexible behavior to understand the situation and reduce their anxiety. Suggestions to help with reduce rigid thoughts and inflexible behavior related to anxiety:
  - Slowing the environment down (e.g., lower the noise level, reduce stimulation in the immediate area)
  - Encourage everyone to communicate in the same manner; allow for 3-5 sec. processing time and use the same words to communicate. If it is snack time, ensure everyone calls it snack time. If one person calls it break time the individual will likely begin to feel anxious because of the change in words – resulting in unwanted behaviors.
  - Break tasks down into small, more manageable steps.
  - Do not get into a power struggle over things that do not truly matter. If the individual says the sky is purple today, it is okay to go with it. For example, “Really, you see the sky as purple today?” I kind of see it as blue, but I like purple. The sky sure is pretty today.”
- Pre-setting or using lead time before transitions or changes in activities can also be beneficial in working with rigid thoughts and inflexible behaviors.
- Offering two preferred choices to someone demonstrating inflexibility can also be beneficial by allowing them to have a sense of control. You want Maddie to take a jacket to school; offer her the choice of jacket she would like to take. “
- Reducing or eliminating the cause of the anxiety, can reduce or eliminate the behavior problem!

- Medications are also helpful in reducing anxiety of individuals with PWS when the anxiety is impeding daily life activities.

*Rebranded November 2022*