

How Does a Person With PWS Think?

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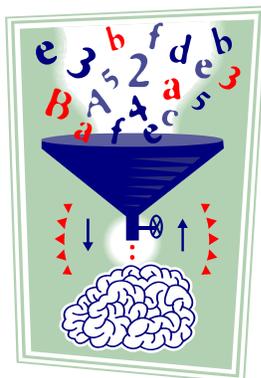
- Persons with PWS are generally concrete thinkers. Terms like, “Hop to it!” may not be understood to mean “Begin the task immediately” and may cause confusion, anxiety, and result in an unwanted behavior.
- Persons with PWS have a delay in processing the information you give them. Most children will take between 3-5 seconds to understand what you say. If too many instructions are given, or the instructions are generalized, they can miss the middle part of what you said and misunderstandings occur. Instead of saying “go get ready for bed”, try breaking the process down into steps; It’s time to brush your teeth. Wait 3-5 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.
- Problem-solving skills are often impaired. This is in part due to the processing problem, and an inability to sort items in sequence for completion. This also creates anxiety. Children become frustrated and anxious trying to do what you ask of them without knowing what to do first and what the task entails.
- Short-term memory is often poor.
- Long-term memory is usually excellent. Once something is learned, it’s remembered forever.

PWS is All About Anxiety

Persons with Prader-Willi syndrome typically feel high levels of anxiety – all the time.

Maladaptive, unwanted behaviors are often attempts to reduce the level of anxiety the individual with PWS is feeling. Examples of this behavior are skin picking (also done when feeling bored), repeated questions, excessive talking, and controlling, oppositional or argumentative behavior.

If you can reduce or eliminate the cause of the anxiety, you’ll reduce or eliminate the behavior problem! The best start is to remember they have a processing delay and they want to please you.



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Emotional Regulation is a Brain Thing Producing Anxiety

- People with PWS generally have great difficulty managing their emotions. Whatever is felt tends to be felt with great intensity. This labile affect is caused in part by a defect in the hypothalamic and pituitary systems.
 - **Cognitive challenges**, impaired sensory-integration, slower processing speed, etc. make understanding the environment more difficult and raises the level of anxiety.
 - **Cognitive challenges**-Children with PWS can and do excel in some areas of learning. It's more like they have spotty deficits. They are better with concrete concepts than abstract. So math is learned better if it is hands on; ie., money they can touch and work with. Another example to help with education is that our children have poor fine motor skills. When they are given paper and pencil, the motor skill is lost and they perseverate on the making of the letters instead of what the letters are representing. Children with PWS do better if they learn to type at a young age and use this as much as possible for school work. Continuing with therapy to develop fine motor skills is very important.
 - **Sensory Integration (SI)**- Impaired sensory integration- Sensory integration dysfunction is a neurological disorder characterized by a neurological sensory integration deficit. The more current diagnostic nosology (Miller et al., 2007) uses the term sensory processing disorder to describe this condition. There are activities that can be done at home to help improve SI. These activities help the child to integrate 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.
- **Slower processing speed**- Again, this is where our children take longer to process what is being said to them. Breaking down requests into small steps and allowing 3-5 seconds for them to process each step can give them the time to process and decreases anxiety.
- **Increased anxiety** leads to the need for rigid thoughts in an attempt to understand the situation and reduce anxiety. Slowing the environment down, having everyone communicate in the same manner (3-5 sec. processing time), and using the same words to communicate can help decrease anxiety.
- **Rigid thoughts** lead to inflexible behavior in an attempt to control a situation and reduce anxiety.
- **Inflexible behavior** can interfere with the flow of the day and cause tremendous upset for the individual with PWS and those around him.

**Remember-We can't change the brain in our loved one, with Prader-Willi syndrome.
But, We CAN change our own behavior which DOES change the behavior of our loved one with PWS.**