

# Braden on Behavior



## Anxiety – Just how bad is it?

Many clinicians who see individuals with fragile X syndrome hear from parents on a daily basis about how anxiety affects their child's behavior. It is not uncommon for a child to throw a tantrum before going on a trip to a favorite play spot, activity or recreational facility. Adolescents and adults may retreat to a bedroom and refuse to come out. It is hard to understand how these kinds of events can trigger such a negative reaction.

Like many things about individuals with fragile X, this scenario doesn't fit a logical pattern. When an activity or experience has been fun one would expect the child to be excited and recall positive feelings about the experience. There are several important factors to consider in order to better understand this phenomenon.

A person with fragile X has difficulty modulating incoming stimuli. We know from a variety of research venues that too much sensory input and a pervasive discomfort from excitation can promote hyperarousal resulting in "behavioral meltdowns". The mere fact that the child enjoyed the activity at another time isn't enough to override the initial feeling of being overwhelmed.

Anxiety is usually accompanied by physical symptoms such as a racing heart, blushing (red ears or neck), sweating and nausea. Experiencing those physical changes can also create more fear, followed by panic.

The person with fragile X may also be impacted by an executive function deficit that interferes with his ability to remember the past experience in a way that would provide reassurance and motivation to try again. When confronted with the excitement, the person with fragile X may first become anxious followed by an inability to regulate his arousal level and properly manage his behavior. An attempt to avoid the situation may occur in order to endure the anticipated stress. This cycle feeds the pathology causing the behavior to escalate.

It is counter therapeutic to avoid these family outings and recreational experiences, even though it is at times very tempting. In order for the child to become desensitized he must experience repeated exposure to the event. This takes a lot of patience with the understanding that if the time and energy is spent early it will become less difficult and disruptive later.

There are a number of ways parents and caregivers can prepare the child for the activity. Some parents report reading a bedtime story the night before with pictures taken of a fun experience. If the child has a tendency to obsess and worry about the future it may be better to discuss it right before leaving with time built in to employ a sensory menu. The preparation time includes utilization of calming strategies and an emergency kit of chewing gum, water bottles, audio tapes, fidget toys and other self calming supplies to take to use on the way to the activity.

It is well known that anxiety can have biological roots. Fearfulness is associated with irregularities in neurotransmitters such as dopamine and serotonin. Studies in the general population show that high levels of the stress hormone cortisol release when one is anxious. Belser and Sudhalter have also researched the affect of arousal on individuals with fragile X and found similar results.

Anxiety can have far reaching effects on the life of one with fragile X. Each experience can virtually shut down adaptive behavior. The fear can be so intense that the individual with fragile X may revert to a primal reaction of flight or fight and become unable to access an appropriate behavioral response.

The best remedy to all of this is the gift of time. Building in enough preparation time to allow for a sensory diet, behavioral story and use of the emergency kit can slow down the process and allow a "slow motion" effect to take hold. This will also give the parents and caregivers sufficient time to react in a calm and supportive way, adding less stress to the mix.

With the holidays ahead and higher probability of novel experiences attached to celebration, take time now to create a specific plan that will allow you to be successful and create the ultimate PEACE ON EARTH.

*EDITOR'S NOTE: Marcia Braden, PhD, is a psychologist and a longtime advisor to the National Fragile X Foundation. She is also the author of the acclaimed book, "Fragile, Handle With Care", and a nationally known lecturer on fragile X. Her sessions at the NFXF's International Conferences are always "standing room only".*