

Anxiety & Mood Problems in People with Williams Syndrome

At this summer's national convention, Dr. Karen Levine was quick to explain that anxiety is extremely common in people with Williams syndrome. In this session, Dr. Levine discussed anxiety in individuals of all ages in terms of how it manifests and how it can be treated.

Anxiety is thought to affect between 60-90% of individuals with Williams syndrome. Mood regulation problems are also very common and often occur with ADHD, anxiety and sensory modulation difficulties. They all involve difficulty "modulating" or "inhibiting" or controlling the intensity of one's response. All young children, including typical children, have mood difficulties but it is not considered a problem unless it is interfering with their well-being or the well-being of the caregivers. Medications are often appropriate, but it is not an issue of "either/or" with treatment and medication.

There may also be "executive functioning" difficulties: trouble organizing, inhibiting or planning one's response. The externalizing (acting out) component often gets better with age. Anxiety, however, persists with age although people develop increased tools to manage it. It also tends to ebb and flow in people with WS just as it does in people who do not have Williams syndrome. Big and small life changes can cause an increase in anxiety. The good news is that because anxiety, mood regulation and depression are so common in the general population, there are a wide variety of treatments.

In looking at the common course of anxiety in people with Williams syndrome, we see that, unlike the general population, phobias around specific concrete experiences may be more biologically triggered and may persist although generally, they improve somewhat as the child gets older. But as the child gets older, and also similar to the general population, more abstract fears can also kick in. Overall, there are more potential sources of anxiety in adults with

Williams syndrome than typical anxious adults. Although social anxiety (which is very common in the general public and can be quite painful) is very rare in individuals with Williams syndrome, specific phobias are very common. These phobias include those that are sound related (thunderstorms, fire alarms/drills), visual-spatial related (high places, etc), and worry related (about medical related procedures such as shots, seeing blood, etc). Also common are socially related fears (which are not to be confused with social fears). This includes worry about others being upset with the person or not liking them. Anticipatory anxiety is very often seen with individuals with Williams syndrome. This often shows up as repeated questions about an event (when is it going to happen, what is going to happen, is a certain person going to be there, etc). Individuals can be just as intense in this fashion before happy or feared events, often overlapping with other "obsessive" behavior.

In looking at strategies for dealing with anxiety across the ages, there is support for physical activity, high affect (lots of emotion – get them laughing) fun play, use of favorite music, relaxation music and relaxation videos. Physical activity is surprisingly helpful, but is increasingly difficult to incorporate as individuals get older. The goal is to strive for continual balance, but we often see the "peg and hole" dilemma. Do we work to make the person with WS able to cope with the world or do we create an environment in which the person with WS is able to function happily? In reality, one can do both. We can stretch the individual while adapting the environment. For example, WSA events are an opportunity for your children to both develop tools to cope with anxiety and also interact in an environment where they are comfortable.

When dealing with phobias, the use of "systematic desensitization" or gradual exposure in a tolerable amount and form is common. This includes photos, video clips (of a feared event such as fire truck,

birthday song, baby crying, person coughing) etc. Playing soothing music in the background can also help. When possible, try to video real situations (Uncle Frank coughing, the school's alarm, loud clapping, etc). The child can then study the situation, control it, watch it with or without sound, while listening to other music, etc.

Pretend play for younger children and role playing for older individuals can also help. Be sure to make re-enactments playful; get the child laughing! Youtube videos are a great (free) tool. The child can play around with the volume, starting and stopping the video, etc.

If your child is very young, practice dealing with anxiety (systematic desensitization) is important. Start small and distant, and then build up. Emotional reflection ("oh you're scared," etc rather than telling them not to be scared) and humor are critical tools as well.

For verbal children ages 10 to 12 years or so through adulthood, Cognitive Behavior Therapy should be used. The premise of this is looking at anxiety as a "cognitive perception error," typically enhancing self blame and/or bad outcomes. This process can be adapted within the fairly verbal child/adult across a range of levels. In general, it should be used with a therapist/counselor or other experienced adult. CBT is helpful for everyone even though it might not solve all issues.

1. Child learns relaxation or 'anti-anxiety' tools (e.g. deep breathing; visualization; meaningful personal thoughts) with help of therapist
2. Child learns to recognize where on the 'anxiety scale' they are. For instance 1 - 5; A - Z etc. - colors or personal metaphors etc. can also be used to create the scale
- 3 a. Child learns through practice to pair relaxation tool with anxiety build up
b - Child learns to recognize perceptual errors and fix them
4. Systematic desensitization; create close approximations of upsetting situations while practicing thought and

relaxation tools

It is important that parents and caregivers be aware of the power of suggestion. While anxiety is very real, it is very important for therapists/counselors to be aware that it can escalate with the power of suggestion. Empathy and help reframing and “shifting gears” are much more likely to help than empathy alone which can escalate. Saying “we aren’t going to talk about that anymore” is useful in these situations and helps individuals internalize their thoughts (rather than stating them out loud).

Individuals with Williams syndrome often experience mood regulation problems. They cry easily, are easily angered, easily frustrated, they shift mood quickly and often have problems with sadness and depression. In these cases, it is always important to look at the big picture. Is the person having enough successful social interactions? Is the person having enough school or work success? Do they have enough in their life that they feel they have control over?

Collaborative Problem Solving (CPS) is a useful tool for mood issues as it engages the individual in his or her own treatment. It is an approach used in between predictably difficult events or problems, one problem at a time. The premise of CPS is that children have reasons they are responding maladaptively (they are doing the best that they can) and getting the child involved as an active participant in working out a solution is more effective than imposing one’s will. When the child is not upset, an adult can point out: “I’ve noticed... what’s up?” in a non-judgmental opener to establish the topic. They can then help the child come up with possible reasons why and point out their own or someone else’s similar problem with the child’s current pattern. The adult should then invite the child to come up with solutions. Examples of situations where CPS can be affective are teeth brushing, getting ready in the morning, recess, not wanting to go to school etc.

Integrating approaches is often most successful and what works best is often very individualized.

**Please see page 34 to order mp3 recordings of Dr. Levine’s session on anxiety and all the convention sessions.*

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Resources for Treating Anxiety & Mood Regulation

While these resources are not WS specific they are easily adapted for individual’s with WS at all ages.. Many approaches can be used by parents, staff and/or teachers, but it is generally very helpful to work with an experienced therapist or clinician.

Books:

Aureen Pinto Wagner has written several books about treating children and teens with phobias, using adapted Cognitive Behavioral Therapy (CBT). Her books are very readable and useful. <http://www.lighthouse-press.com/LighthouseProducts.htm>. Individuals must have sufficient language and ‘metacognition’ to be able to talk about what upsets them and practice new ways of responding.

Levine, K. and Chedd, N. (2007) *Replays: Using Play to Enhance Emotional and Behavioral Development for Children with Autism Spectrum Disorders*, Jessica Kingsley Publishers, London UK. While the title specifies autism, many children with WS respond very well to this approach, especially for specific phobias. www.williams-syndrome.org/catalog/products/Books to order.

Greene, R. & Ablon, S. (2005) *Treating Explosive Kids; The Collaborative Problem Solving Approach*. This approach is a similar model to Replays but for children at a more advanced language and developmental level.

Websites

<http://www.thinkkids.org/> & <http://www.livesinthebalance.org/>

These websites explain a useful orientation and step by step video examples for working with verbal children who have challenges such as mood dysregulation/intense responding, anxiety and fears.

Articles

Levine, K., Chedd, N. and Bauch, D. (2009). *Social-Affective Diet*

This article provides ways to build positive social-emotional engagement with adults and/or peers into the IEP to help ‘reset’ or ‘re-regulate’ a child emotionally. *Autism Spectrum Quarterly*. Fall 2009

Other options

Music:

Music that an individual child, teen or adult finds relaxing can be very important. Listening to music is a very powerful relaxation tool especially for many people with WS. They often experience significant emotional responses to music.

Humor

For some individuals, humor has been found to be as effective as music to decrease phobic responses and increase a sense of well being. Having ‘private jokes’ that make an individual laugh, while not generally helpful in the ‘heat of the moment’ can help prevent escalating upset or anxiety, and can help an individual cope through predictably challenging experiences. Humorous audio tracks, audiobooks, recordings of favorite stories or TV show and funny DVDs can be used as well.

Relaxation DVDs: Music, Video Relaxation, Yoga

There are now many good relaxation DVDs. Yoga DVDs, which are often relaxing just to watch, as well as to follow along with, are available for both adults and children. Even preschool children with WS are able to engage in yoga and experience a relaxed state.

Physical Exercise

With doctor recommendations, exercise is often an especially helpful anxiety reducer or regulator. Accompanying exercise with music is often very effective., and swimming can be fun and relaxing at the same time. Exercise helps with many problems and can be a great social activity.