

MANAGING ATTENTION DEFICIT HYPERACTIVITY BEHAVIORS IN CHILDREN WITH FRAGILE X SYNDROME

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Children with fragile X syndrome are often friendly, social, active children who are quick to learn by watching others. They have strong visual problem-solving abilities and are often very verbal and outgoing. Children with fragile X syndrome also present with a number of challenging characteristics. We know of cognitive deficits ranging from learning disabilities to severe mental retardation, communication difficulties, a hypersensitivity to visual, auditory, and tactile stimuli, and attention problems including hyperactivity and impulsivity.

Approximately 80% of children diagnosed with fragile X syndrome also carry a diagnosis of attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD). These diagnoses are characterized by symptoms of inattention, impulsivity, or hyperactivity. Symptoms of inattention may include difficulty sustaining attention in tasks or in play, difficulty organizing, seeming "not to listen" when spoken to directly, and often being easily distracted by events going on around them. Symptoms of hyperactivity may include excessive talking and moving, fidgeting, and difficulty remaining seated. Symptoms of impulsivity may include difficulty waiting, blurting out answers before questions have been completed, and interrupting others in conversation or play.

Improving ADD or ADHD behavior is often one of the greatest psycho-educational needs identified for children with fragile X syndrome. We do know of treatment and management strategies that can be helpful at home and in a classroom setting.

Medical management is beneficial to a great majority of children with fragile X syndrome. Medication is effective in managing the ADHD behaviors as well as the anxiety and obsessive-compulsive behaviors frequently seen. Counseling for the child and/or the family can also be supportive in monitoring growth and change of behaviors as well as in understanding and coping with some very difficult situations.

Occupational therapy with a therapist trained in sensory integrative techniques such as brushing, deep pressure and calming can be a great support in managing the ADHD behaviors, as well as the hypersensitivity's that often drive them.

Environmental accommodations and behavior management can be done at home and in the school environment. It is important that expectations be consistent and appropriate for the developmental level of the child. Some accommodations to promote attention, especially in a school environment, may include seating the child in a more quiet area of the classroom near a good role model. We know most children with fragile X are very good imitators. Keeping enough distance between desks to avoid distractions by others is also relatively easy to do. Keep in mind that windows, pencil sharpeners and doorways are very distracting so avoid seating the child near them. Use timers to help with task completion or shorten assignments to allow more time if needed. Try to involve the child in lesson presentation. Let him use manipulatives and materials of interest to pull him in. Try using a private visual signal to cue him to stay on task. This can be set up with the teacher, a peer, and parents. Always give clear concise instructions and use visual materials to outline expectations. A picture schedule of the day is an excellent way for children to understand what is expected and when. It is also helpful to model appropriate behaviors when too much is going on. Demonstrate to the child how to ask for help or quiet time. Also, allow the child to move some if he needs to. He does not need to be sitting quietly to be attending.

Impulsivity can be a great problem for many children with fragile X syndrome. Transitions can be a time of behavior outburst and impulsive reaction. Supervising the child closely during transitions and providing him with an object to carry or transitional song can be helpful. Using positive redirection of impulsive behavior is also effective. Telling the child what he can do as opposed to what he cannot or should not do is more positive and educational. Instead of telling the child not to grab the person in front of him tell him to use his words, wave or stamp his feet, etc. It is also effective to attend to and notice positive behaviors frequently. Acknowledging positive behaviors and responses of the child as well as others near by may encourage thinking before acting.

Many children with fragile X are very active and seem to "need to move" all the time. Allowing them the opportunity to move or stand while working is often helpful. Sometimes using a rocking chair, therapy ball, or beanbag chair for at least part of the day gives the child some variety in seating. Allow for seat breaks during the day. Being the messenger, running errands, and passing out materials all allow for appropriate movement. Give the child the opportunity for oral input such as gum to chew, hard candy to suck or tubing to chew on to meet some of their needs. Using occupational therapy techniques such as joint compression, deep pressure and brushing before requiring the child to sit for long periods of time can also promote internal organization.

All behavior management strategies need to be positive and redirective to be most effective. Teaching positive, meaningful responses is often necessary as many children have difficulty generalizing from one situation to another. Setting short-term goals with visual checklists and schedules can also encourage independence and promote self-esteem.

There are many modifications that can help promote more appropriate behaviors in children with fragile X syndrome. It takes careful thought and planning to individualize the supportive services and management techniques. Ongoing communication between parents, teachers, and therapists is essential for any plan to be most effective.