

Behavior Problems and WAGR syndrome

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“All behavior is communication”

~Paul Watzlawick, American-Austrian psychologist

Many children and adults with WAGR syndrome have challenging behaviors. These behaviors can make everyday life difficult for the person and their family, and may also interfere with family dynamics, school, work, and participating in the community.

Some examples of common challenging behaviors are: frequent tantrums; intense reactions to certain sights, sounds, or situations; self-harm such as head-banging or biting; meltdowns; and/or aggression toward others.

These behaviors can be incredibly stressful, and parents often feel embarrassed, guilty, frustrated, and helpless. It's important to know that you are not to blame nor is your child the only one exhibiting challenging and unwanted behaviors. These behaviors are likely the result of conditions associated with WAGR syndrome. The good news is that there are strategies that can help, and life can become easier and more enjoyable for both you and your child.

Steps to Take

1. Learn

You have already taken the first step: you've begun to learn. There are many possible causes for challenging behaviors in people with WAGR syndrome. Some causes are:

- Developmental delay
- Speech delay and communication disorders
- Sensory Integration Disorder
- Differences in the structure of the brain
- Intellectual disability
- Autism Spectrum Disorders
- Central Auditory Processing Disorder
- Obsessive/Compulsive Disorder
- Attention Deficit Hyperactivity Disorder (ADD/ADHD)

The more you know about challenging behavior, the easier it will be for you to help your child. Check out the Resources at the end of this article to learn more.

2. Observe

Start keeping a **Behavior Notebook**. Every day, make notes about your child's behavior. Over time, these notes will help you and your child's doctor to determine whether the behaviors you are seeing are typical or not, and will also help identify the causes and possible solutions.

Make notes about:

- The time the behavior began
- Describe the behavior (screaming, crying, hitting, flailing on the floor)
- Where did the behavior occur? (at home, in the car, at a store)
- Describe the circumstances right before the behavior started (you or your spouse just got home from work, you told the child no, the child argued with a sibling)
- Describe your response to the behavior (talking to him, holding him, giving him what he wants, time out, ignoring her, offering her music or a special toy)
- How long did the behavior last?
- If your child goes to daycare or school, have them keep a notebook too

Your Child's Behavior Log



Behavior Log for: _____

Medications: _____

Log begun (month, day, and year): _____

Date	What happened or what was the behavior?	Where and when did the behavior take place? (Example: At school, during recess, while doing homework.)	What was taking place right before the behavior happened? (Example: Change in family plans, child told "no" about something he wanted, argument with sibling.)	Other comments, details, or factors involved? (Meds change? Illness? Event in family?)	What happened after the behavior? (Action you, others, or the child took.)

(courtesy of autismspeaks.org)

Detailed records of your child's behavior can be an *extremely valuable* tool. It will help your child's doctor to understand your concerns and can also help you to identify patterns of behavior that weren't obvious before.

3. Get help

Discuss your child's behavior with their doctor. Show them your child's behavior notebook. Ask if referral to a specialist is needed. A comprehensive evaluation by a psychologist, a behavioral therapist, or an early intervention or school assessment team can help with diagnosis and treatment. You are an important partner in this process, and your behavior notebook will help the specialists to understand your child and his needs.

4. Make a Plan

After careful observation and evaluation, you and your child's doctor or team will discuss things to try that might help. Depending on the type of behavior, the plan may involve changes in the child's environment, changing the way caregivers respond to the child's behavior, teaching the child new coping strategies, medication, or a combination or all of these.

Improving challenging behaviors usually takes time and determination. Some interventions or medications may be more effective than others. Keep making notes in your Behavior Notebook. Your notes will help you and your doctor to chart whether a strategy or medication is working, and they will help you and your child to build on your successes.

Adolescents

Diagnosis

Adolescents with complex chronic medical disorders like WAGR syndrome may develop gradual or sudden changes in behavior or reactions to certain situations. The conditions associated with WAGR syndrome can be stigmatizing, potentially life-threatening, may require frequent clinic visits or hospitalizations, and may limit a teenager's ability to participate in the same activities as their peers or family members.

Common behaviors in response to these issues may include meltdowns, difficulty interacting with peers, social isolation, poor self esteem, and declining successes in an educational setting.

Many factors may increase the risk for these behaviors, including but not limited to:

- Poor coping skills
- Lack of control over illness
- Frightening symptoms
- Limited options for extracurricular activities

- Peer rejection
- Treatment side effects
- Effects of illness on brain function

It is important to recognize that changes in behavior in adolescents may also indicate the development of one of the following psychiatric conditions:

- Anxiety
- Depression
- Dysthymia
- Attention Deficit Hyperactivity Disorder
- Oppositional Defiant Disorder
- Conduct Disorder
- Disruptive Mood Dysregulation Disorder

In addition to these specific diagnoses, the following are more common among all children with chronic illnesses:

- Negative mood
- Argumentativeness
- Non-compliance with medical treatment
- Self-esteem issues
- Difficulty with self-image
- Social Isolation

The range of medical conditions and degree of sensory and intellectual impairment varies widely among individuals with WAGR syndrome. This variability can make identifying the factor(s) underlying behavior problems in adolescents very difficult. It is therefore recommended that parents seek help soon after the onset of new or increasingly difficult behaviors.

Treatment

A collaborative approach is preferred, with a team consisting of the adolescent, parents, the primary care provider, subspecialists, educators, psychologists, and educational advocates when necessary.

When seeing adolescents with WAGR syndrome, primary care providers are encouraged to use well established screening tools to conduct surveillance and screening for the common psychiatric conditions listed above, and to refer patients to psychology/psychiatry as appropriate.

Parents observations can be extremely valuable to the team. Keeping detailed notes such as those recommended in the Behavior Notebook above can help to form the basis for timely diagnosis and effective treatment.

Resources

The Resources below will help you to **Learn** more about challenging behavior, teach you how and what to **Observe**, show you where to **Get Help**, and give you some great ideas and useful tips as you **Make a Plan** to help your child.

Challenging Behaviors Toolkit

The Challenging Behaviors Toolkit is a tremendous resource, but it should be noted that while autistic-like behavior is common in people with WAGR syndrome, most do not meet the criteria for a diagnosis of Autism. In addition, 90% of people with WAGR syndrome have some degree of auditory processing disorder, as well as other conditions that may impact their behavior. Careful evaluation is necessary to ensure accurate diagnosis and appropriate interventions.

<https://www.autismspeaks.org/tool-kit/challenging-behaviors-tool-kit>

Behavioral Issues in Children with Visual Impairments and Blindness: A Guide for Parents

http://www.familyconnect.org/info/browse-by-age/preschoolers/growth-anddevelopment-preschoolers/behavioral-issues-in-children-with-visual-impairments-andblindness-a-guide-for-parents/1234?fbclid=IwAR3qbl7qTmMPRtLDxZn9mS9AUoBb6cieUdXrMwxD_JQSXL_RkC0ZgNg41k

What is a Meltdown?

<https://www.autism.org.uk/about/behaviour/meltdowns.aspx>

The Difference Between Tantrums and Sensory Meltdowns

<https://www.understood.org/en/learning-attention-issues/child-learning-disabilities/sensory-processing-issues/the-difference-between-tantrums-and-sensorymeltdowns>

Is it Behavior? Or is it Sensory? <https://www.growinghandsonkids.com/behavior-sensory-subscriberprintable.html?fbclid=IwAR1rweG30LA2z5FvajAiI2aLqR9FhYOqRzR1jnzfminGn2orgGeMMiiVDk>

How Anxiety Leads to Disruptive Behavior

https://childmind.org/article/how-anxiety-leads-to-disruptive-behavior/?fbclid=IwAR2CQMG4E9WUtL0CoKMEyiaz4ruDab1mALcZrZuBzaKn8oNzPJ_aTy6rL8Qo#.Vq1BPzcUQ4R.facebook

“Should My Child Take Medicine for Challenging Behavior?”

A Decision Aid for Parents

<https://www.autismspeaks.org/sites/default/files/201808/Medication%20Decision%20Aid.pdf>