

Attention Deficit Hyperactive Disorder (ADHD)

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- ADHD is a brain condition found in children (usually primary school age) that can last into adulthood.
- ADHD is not a symptom of intellectual disabilities.
- Children with ADHD may have difficulties:
 - Paying attention
 - Controlling their behaviors (e.g. acting impulsively)
 - Being overly active (may or may not apply in 22q11.2DS)
- People with ADHD usually have difficulties with **executive functions**

Executive Functions

- Executive functions are the mental skills that allow us to respond to situations appropriately and complete tasks successfully.
- Executive functions include:
 - **Initiation** – Starting a task
 - **Mental flexibility** – Switching between tasks smoothly
 - **Planning** – Figuring out the different steps needed to solve a problem or complete a task
 - **Inhibition** – Stopping oneself from reacting automatically to a distraction or behaving a certain way
 - **Working memory** – Retaining information in the mind
- Individuals with ADHD may have difficulties with executive functions. Many **need guidance or step-by-step instructions**.

Diagnosing ADHD in Children with 22q11.2DS

Compared to those without 22q11.2DS, children with 22q11.2DS:

- Usually have the “inattentive type” of ADHD, i.e. “ADD”
- Have fewer oppositional symptoms
- Are much less likely to be hyperactive

Because of the low rate of hyperactivity in children with 22q11.2DS, **typical ADHD diagnostic strategies that focus on hyperactivity are unreliable for them**. Instead, ADHD diagnostic process for children with 22q11.2DS should **focus on attentional difficulties** and **include an evaluation of executive functions**. Also, an ADHD diagnosis needs to be distinguished from an anxiety disorder and from intellectual disability.

How Common is ADHD in Children?

General population: ~2 - 6%
22q11.2DS: ~40%
22q11.2DupS: ~18 - 40%

Some children may have attentional difficulties that may not fit all the diagnostic criteria of ADHD but are still significant enough to have a major impact on their daily functioning.

Impact of ADHD

Attentional skills and executive functions are important for academic success. However, ADHD reduces the person's ability to focus, remember instructions, and plan things step by step, **making it hard to do well at school**.

ADHD can also play a role in how the person interacts with peers, **impairing social life**.

As the child grows older, unmanaged ADHD can **affect the teenager's path to independence**.

After Getting Diagnosed

In a learning process called **psychoeducation**, healthcare providers help the child, as well as the parents and siblings, understand the child's diagnosis, symptoms, abilities, limits, the impact of ADHD, and potential treatments. This will likely increase the effectiveness of ADHD treatment.

Some attentional and organizational difficulties may persist into adulthood.

Attention Deficit Hyperactive Disorder (ADHD) – Continued

Manage ADHD – 3 Strategies

Treatments for ADHD are similar for individuals with and without 22q11.2 deletion or duplication.

1. Accommodations

- a) **Remove distractions** from work areas to help the child concentrate.
- b) **Schedule work sessions** that are suitable for the child's attention span.
- c) **Give simple instructions** rather than multi-step ones. Write down the instructions if needed.
- d) **Praise the child for good attitude or work**, even if it is a small step forward.

3. Medications

- In general, medications may be used for individuals aged 6+ with attention difficulties. It is highly recommended that the child also receive cognitive-behavioral therapy (CBT) and have accommodations and adapted environment/extra support.
- **Stimulants** are often the medication of choice.
 - A long-acting version (“extended release”) can be used to last throughout the school day.
 - A short-acting version can be used in the morning and/or to extend the effect into the late afternoon.
- **Nonstimulants** are less effective on their own, but can be used in combination with stimulants.
- Medications can help manage ADHD symptoms such as inattention and restlessness. When these symptoms are reduced, the individual may gain **self-confidence** and **independence**.
- Please check with your healthcare provider regarding the proper use of specific medications.
 - Ask about **side effects** and **medications that cannot be taken together**.
 - To find the right dose and minimize side effects, **start the medication at a low dose and increase by a small amount every 2 - 4 weeks**.
- Common side effects include a decrease in appetite, digestive discomforts, and sleep issues. These are frequent but typically mild. An **electrocardiogram (ECG)** is recommended to detect any changes in heart rhythm (very rare).
- If medications do not help with the ADHD, please consider seeking additional professional help, e.g., at a clinic specialized in 22q differences. [[USA](#) / [International](#)].

2. Cognitive-Behavioral Therapy (CBT)

Training individuals through tasks may help them with their attention span or executive functions. For children to apply the skills they learn, the training needs to be very similar to real life situations. There are multiple cognitive remediation programs (e.g. [ACTIVATE™](#)) for individuals with ADHD, but it is recommended to use them together with other approaches for the best chance to get results that are generalizable outside of the game. Children who are younger may not be able to regulate their behavior, but their [parents can be trained in behavioral therapy](#) to help them succeed.

References / Resources

- [Updated clinical practice recommendations for managing children with 22q11.2 deletion syndrome](#) – 2023
- [Updated clinical practice recommendations for managing adults with 22q11.2 deletion syndrome](#) – 2023
- [Cognitive Development And Mental Health](#) – Videos from 22q11 Europe. Videos 4 & 5 are on ADHD - 2022
- [22q11.2 duplications: Expanding the clinical presentation](#) – 2021
- [Attention Deficit Hyperactivity Disorder Symptoms and Psychosis in 22q11.2 Deletion Syndrome](#) – 2018
- [Attention-Deficit / Hyperactivity Disorder \(ADHD\)](#) – Center for Disease Control and Prevention, Atlanta, GA, USA
- [Attention Deficit Hyperactivity Disorder \(ADHD\)](#), Centre for Addiction and Mental Health (CAMH), Toronto, ON, Canada
- [ACTIVATE™](#) - A cognitive training and physical exercise program by C8 Sciences, New Haven, CT, USA