CF and Mental Health: Thriving With ADHD

A Guide for People Living With CF

What Is Attention-Deficit/Hyperactivity Disorder?

Attention-deficit/hyperactivity disorder (ADHD) is a common condition that begins in childhood and affects behavior and thinking throughout a person's lifespan.

People with ADHD have difficulty functioning as expected for their age and stage of development at home and at school or at work because of challenges in the following areas:

Inattention

- Has a hard time focusing and keeping attention
- Is easily distracted
- Misses details
- "Zones out" during conversations
- Has trouble following instructions
- Procrastinates or avoids complex tasks
- Has trouble managing time
- Is forgetful in daily activities
- Often loses important items

Hyperactivity and Impulsivity

- Is "always" moving
- · Fidgets and squirms
- Has trouble staying seated when expected
- Often in other people's physical space
- Has trouble doing activities quietly
- Talks excessively and/or interrupts
- Talks or acts without thinking first
- Has trouble waiting
- Takes risks without planning ahead

Some people with ADHD also experience learning challenges or struggle in social relationships. They may have trouble with sleep, managing frustration, regulating emotions, and learning from consequences. Untreated ADHD can lead to challenges in daily functioning and increase the risk of anxiety, depression, substance misuse, and worsening health when CF is not well managed.

How Can ADHD Affect People Living With CF?

Symptoms of ADHD may be more common in people with CF compared with the general population. Living with CF often means there are extra tasks to juggle every day, and ADHD can make these demands more challenging to complete. ADHD often runs in families.

When a person with CF or a family caregiver has ADHD, it can be more challenging to:

- Manage regular routines around eating, sleeping, and exercise
- · Complete daily CF care consistently
- Organize medical appointments and prescriptions
- · Remember the questions you want to ask during CF visits and plans for next steps
- Navigate tasks related to health care like completing insurance paperwork or paying bills



How Is ADHD Diagnosed?

If you or your child is having difficulty with any symptoms listed previously you can talk about your concerns with your CF care team. Your care team can help you determine next steps for an evaluation, if needed. ADHD evaluations may be conducted by a psychiatrist, psychologist, or another qualified health care provider.

ADHD evaluations may include gathering information from clinical interviews, standardized rating scales completed by people with CF, teachers and parents, academic testing, and sometimes neuropsychological testing to evaluate thinking, memory, and attention.

Coordination between your CF care team and the provider doing the ADHD evaluation is important when considering other medical or mental health issues that could possibly explain your symptoms, and how ADHD symptoms can affect your physical health and sustaining daily CF care.

How Is ADHD Treated?

ADHD is often best managed with a combination of therapy support and medication. Most people with CF can safely use ADHD medications, and there are a variety of effective options available. Benefits of medication often include improved focus and ability to organize and complete tasks. If side effects (e.g., decreased appetite, mood changes) are experienced, they can usually be managed by working with your prescribing provider to make changes to your medication treatment.

Getting support through behavior therapy can be very helpful for people with ADHD of all ages. Families and educators can also learn ways to support people with ADHD by providing structure for learning and building skills to improve concentration, organize, prioritize, and complete complex tasks. People with ADHD may qualify for accommodations to help them thrive at school and work.

Strategies to Support Thriving With ADHD During CF Care Visits

Your CF care team can work with you to identify ways to help you get the most out of your CF clinic visits and develop treatment plans that work for you.

- Create a list of questions or concerns you have before your CF clinic visit to remind you of what you want to discuss with your team. Take notes about the answers and information you receive.
- Bring activities, such as books or music, to clinic visits that will make waiting easier.
- Children may benefit from a checklist of what to expect during the visit, such as which team members they will see.
- Use technology wisely. Cell phones and tablets can be useful for taking notes and making voice memos. They can also be distracting, making it harder to focus during important conversations.

- Work with your CF care team to make your treatment plan more manageable. Are there ways to simplify tasks or break them down into smaller steps? What will help you stay organized?
- Ask health care providers to repeat or explain information if you don't understand something.
- Before you leave your appointment, review the recommendations and your treatment plans.
- When you get home, look at your patient portal for an after-visit summary or copies of medical notes to review your treatment plans.
- Contact your CF care team if you have questions or need support to complete your daily CF care.

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