

Breaking Down CAH

A GUIDE TO EXPLAINING CONGENITAL ADRENAL HYPERPLASIA

Talking about congenital adrenal hyperplasia (CAH) may seem daunting, but with the tips below, you may be able to start the conversation confidently. Use this resource to help guide your next conversation about living with CAH and how those around you can provide support.

Explaining CAH

Friends, partners, family, coworkers, and other acquaintances may be curious about CAH and what it means for you. It's important to set boundaries for yourself and only share what you're comfortable with, such as:

- When you were diagnosed
- How CAH impacts your daily life
- Your daily medications to help manage CAH
- What you wish other people knew about CAH

Here are some phrases you could use to explain CAH:

- I was diagnosed with CAH, which is a genetic condition that I will have for the rest of my life.
- CAH affects the adrenal glands, which are located at the top of my kidneys. Because of this, my body doesn't produce hormones the same way your body does.
- Just like you may take medications for your health, I take medications to replace my missing hormones and help my body function.

If you feel comfortable, you could share some of your CAH symptoms. Symptoms may include acne, facial hair, anxiety, and/or depression.

Talking About CAH With Different People

Here are some topics that may arise and how you could discuss them with a partner or close friend:

- I have a hormonal condition called CAH. I'd love to tell you more about it so you know what's going on.
- There are several online resources to help understand CAH. Would you like me to share some with you?
- It's common for people with long-term health conditions like CAH to have anxiety and depression. Can we talk about this and how it can impact me?
- If you have any questions about CAH, you can ask me. I'll share as much as I am comfortable with.
- Having support during doctor's appointments is important for people with CAH. I would appreciate it if you would come with me to my appointments.
- Since my condition is genetic, we might need to see a fertility or genetics specialist if we decide to have children. I'd love to talk more about this if we choose to take that step.

Here are some topics that may arise and how you could discuss them with colleagues or other acquaintances:

- I'm comfortable sharing some details about CAH, but I would prefer that you keep those details between us.

Try using symptoms specific to your life to help guide conversations.

- I need to take medication at specific times, so I might need to adjust my work schedule slightly to ensure I have time to take my medication.
- Sometimes, CAH can make me more tired, so I might need to take breaks more frequently some days.
- Physical stress may affect symptoms of CAH. I have methods of relaxation that I use, but sometimes I could use reminders to take a deep breath or partner together to complete a task.
- Managing CAH requires consistent lab tests and doctor appointments. Having flexibility in my schedule is very important.

Asking for Support

Asking for help can be hard, but strong relationships are built on support. This is especially true when you're dealing with CAH. Figure out what kind of help you need, whether it be a pep talk, a hand with daily activities, or simply someone to vent to.

Here are some tips on how to ask for support in a way that feels easy:

- Occasionally, I might need assistance with picking up a prescription or getting a ride to a doctor appointment. Would it be possible for me to reach out to you for help when needed?
- There are certain activities that I try to limit to ensure my physical health is supported, such as ____.
- There might be days when I need to adjust my schedule a bit due to medication or fatigue. Would you be okay if we communicated openly if something comes up and I need to make a change?
- I've been feeling overwhelmed lately, and I was hoping I could talk about it with you.
- Sometimes, I just need someone to vent to. Would you be up for listening?
- When we're out, I'll need to have snacks and drinks with electrolytes with me. Could you remind me to stay hydrated and nourished?
- When we are out or traveling together, it is important that you know about my condition and what an adrenal crisis can look like. Can I talk with you about what to expect and what I might need if an adrenal crisis does happen?

Adrenal Crisis: What to Know

It is important to have someone in different areas of your life, such as at home, school, work, and social gatherings, who is informed about what an adrenal crisis might look like and how to take action.

Here are a few ways to explain what adrenal crisis is and how to prepare those around you if an emergency situation occurs:

- Adrenal crisis is a life-threatening complication of my CAH. It can be caused if I don't take my medication or if I have an increased need for more cortisol when my body is stressed.
- If I say things like: "I don't feel good," "I feel terrible," or "something feels wrong," I may be in the initial stages of an adrenal crisis. Reach out to my emergency contact right away if I don't seem like myself.
- If you notice I'm becoming dizzy, weak, confused, or nauseous, offer me fluids with electrolytes, call 911, and then contact my emergency contact.
- Adrenal crisis is more likely to happen when I experience physical stress, like when I'm sick or injured.
- May I give you my doctor's information and my emergency contact in case of an emergency?
- I have a medical alert ID on me at all times. It's located _____. This ID has my disease, allergies, and medications on it. In case of an emergency, please alert medical staff where it's located.
- I carry an emergency steroid injection kit in my bag for use when I'm having an adrenal crisis. I'd like to show you where it is and how to use it in case of an emergency.

As a teen or young adult, social gatherings are typically more frequent. Having CAH will likely not prevent you from enjoying these experiences. Being mindful of your needs will help support your well-being while making memories. It might be helpful to have a friend with you who knows about your CAH.

No two people with CAH experience the same symptoms or triggers of an adrenal crisis.

TRIGGERS MAY INCLUDE:

Infection, illness, severe physical stress, excessive physical activity, dehydration, recent surgery, or not taking medications as prescribed.

SYMPTOMS CAN PRESENT AS:

Extreme fatigue, confusion, dizziness, feeling cold, nausea, headache, vomiting, lower body or abdominal pain, and complaints of feeling terrible or not feeling well.

Sign up for the **WHAT THE C@H?! newsletter.**

Join our community by scanning the QR code. We'll send videos and info about CAH straight to your inbox.



Notes

Use the section below to jot down your own thoughts on how to prepare for conversations about CAH.



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