

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 more confidently. Use this resource to help guide your next conversation about CAH and how those around you can best support you or your family's needs.

Explaining CAH

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

- When your child or teen's CAH was diagnosed
- Daily impact of CAH
- Daily medications to manage CAH
- What you wish other people knew about CAH

Here are some phrases you could use to explain CAH:

- My son/daughter was diagnosed with CAH, which is a genetic condition he/she will have for the rest of his/her life.
- All babies born in the US receive newborn screening, which is when my child was diagnosed with CAH.
- CAH affects the adrenal glands, which are located at the top of the kidneys. Because of this, my child or teen doesn't produce hormones the same way your body does.
- Just like you may take medications for your health, my child or teen takes medications to replace his/her hormones and help his/her body function.

If you feel comfortable, you could share some of your child's CAH symptoms. Symptoms may include rapid growth, early puberty, acne, and/or facial hair.

Explaining CAH to Your Child

Explaining CAH to your child requires sensitivity and age-appropriate language. Here are some ideas on how to approach it:

- You have had CAH since you were born, and your body doesn't work and grow the same way as someone who doesn't have CAH.
- You don't have CAH because of something you did. It's just part of who you are, and that's okay.
- The medicine you take is to help your body stay healthy and grow the way it should. We need to see your doctor often to make sure your medicine is working the way it should.
- CAH will make you feel unwell sometimes, and it's important for you to let me know when you aren't feeling like yourself.
- I am here to help support you. You can always come to me if you aren't feeling well or if you want to talk about something.

Talking About CAH With Different People

Here are some ways you can discuss your child's needs with a principal, teacher, coach, or school nurse:

- I want to let you know that [child's name] has a condition called CAH, which affects his/her hormone levels. I will provide a list of medications he/she takes daily and will go through the protocol on what to do in an emergency and who to contact if you have questions or concerns.
- It is important that he/she is well-hydrated and fed regular snacks throughout the school day. This is because the hormones that regulate blood sugar and body fluid may be insufficient due to CAH.
- CAH can affect how he/she handles stress, manages salt levels, and responds to sickness.
- It's important that he/she avoids excessive physical exertion, as this can lead to dehydration and physical stress, which may cause a medical emergency due to the body's inability to manage stress properly.

Supporting Your Child or Teen

Supporting a child or teen with CAH involves fostering their independence and encouraging active involvement in understanding CAH and managing their condition. Here are some ways to encourage their involvement:

- I want to make sure you understand what CAH is and how it affects your body. Let's go over it together so you can start to learn more about CAH.
- Remember, it's good to know the symptoms to watch for and when to reach out to the doctor. I'll help you recognize what's important to pay attention to.
- Let's talk about your medication. I'll show you how to take it properly so you can start to get comfortable, for when you start doing it on your own.
- At your next doctor appointment, feel free to ask any questions you have. It's important for you to be involved in your CAH management.
- As you become more familiar with managing your condition, we'll gradually give you more responsibility.
- I want to make sure I'm supporting you in the best way possible. Do you have any questions for me about your CAH or your CAH medicine?



Adrenal Crisis: What to Know

It is important to have someone in different areas of your child or teen's life, such as at home, school, and social events, who is informed about what an adrenal crisis can look like and how to take action.

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

- Adrenal crisis is a life-threatening complication of [name]'s CAH. It can be caused if my child doesn't take his/her medication or if he/she has an increased need for more cortisol when his/her body is stressed.
- If [name] says things like: "I don't feel good," he/she may be in the initial stages of an adrenal crisis. Reach out to [emergency contact] right away if [name] doesn't seem like himself/herself.
- If you notice [name] is becoming dizzy, weak, sweaty, confused, or nauseous, offer fluids with electrolytes, call 911, and then contact [emergency contact].
- Adrenal crisis is more likely to happen when physical stress is experienced, like when [name] is sick or injured.
- May I give you our doctor's information and emergency contact in case of an emergency?
- [Name] has a medical alert ID on at all times. It's located _____. This ID has his/her disease, allergies, and medication information on it. Please alert medical staff where it's located.
- There is an emergency steroid injection kit in _____ for use when [name] is having an adrenal crisis. I'd like to show you where it is and how to use it in case of an emergency.

No two people with CAH experience the same symptoms or triggers of an adrenal crisis. During adolescence, crisis education should be discussed frequently with the child or teen to ensure understanding and empowerment.

ADRENAL CRISIS TRIGGERS MAY INCLUDE:

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

SYMPTOMS CAN PRESENT AS:

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



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



Notes

Use this section below to jot down any notes that will help you guide your conversations about CAH, or let your child use it to write down how they would like to explain CAH to their friends.



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This document is intended to provide general information only. It is not a substitute for professional advice that may be needed based on individual needs. Always consult your doctor about what you are experiencing.