

## 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 caring for your child living with CAH and how those around you can provide support.

### Explaining CAH

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

- When your child's CAH was diagnosed
- How CAH impacts your child and your family's day-to-day routines
- Daily medications that you need to give your child to help 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 doesn't produce hormones the same way your body does.
- Just like you may take medications for your health, my child 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 Your Child's School

**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

**It's important to help your child feel supported in their journey with CAH and celebrate the wins—big or small. Here are some suggestions on how you can encourage them to talk openly:**

- You can ask me any questions you have about your body or medicines.
- It's okay to feel frustrated or scared sometimes. We are here for you.
- Your body works a little differently than other kids' bodies, and that's okay.
- You are strong and brave for taking your medicines every day.
- I'm proud of how you handled that appointment today.
- You can always tell me when you're feeling down or sad because of how CAH makes you feel.
- CAH can't always be seen, but it doesn't mean you can't feel the impact, and that's okay.
- If you aren't feeling like yourself at school, talk to a teacher or nurse. You can ask them to call me when you're feeling this way.

## Adrenal Crisis: What to Know



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

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

- Adrenal crisis is a life-threatening complication of [child's 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 [child's 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 name] right away if something doesn't seem right.
- If you notice [child's name] is becoming dizzy, weak, confused, or nauseous, offer him/her fluids with electrolytes, call 911, and then contact [emergency contact name].
- Adrenal crisis is more likely to happen when physical stress is experienced, like when [child's name] is sick or injured.
- May I give you the pediatrician's and emergency contact's information in case of an emergency?
- [Child's name] has a medical alert ID on at all times. It's located \_\_\_\_\_. This ID has his/her disease, allergies, and medications on it. Please alert medical staff where it's located.
- There is an emergency steroid injection kit in \_\_\_\_\_ for when [child's 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.

Make sure your child's daycare or school knows if he/she gets injured to please call the emergency contact immediately.



### ADRENAL CRISIS TRIGGERS MAY INCLUDE:

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

### SYMPTOMS CAN PRESENT IN INFANTS AS:

Prolonged jaundice, poor weight gain, or recurring episodes of low blood sugar.

### SYMPTOMS CAN PRESENT IN CHILDREN AS:

Weakness, fatigue, high heart rate, low blood pressure, dizziness, nausea, vomiting, abdominal pain, sweating, and seizures related to profound low blood sugar.



### 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 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 other kids.



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