

## Discussing CAH



# A GUIDE TO OPEN COMMUNICATION WITH YOUR DOCTOR

Being prepared for your next visit will help you get the most out of your appointment. Use this guide to help plan your conversations with your doctor, and talk openly about how you are feeling.

Symptoms of CAH can be hard to tell apart from high-dose steroid side effects.

### Common symptoms of excess androgens include:

- Rapid initial growth
- Early puberty
- Excessive hair growth
- Acne

### Common side effects of high-dose steroids may include:

- Short stature
- Weight gain
- Diabetes
- Reduced bone density

List any symptoms you or your child have had, and for how long.

Print or email yourself this list so that it is handy to take to your appointment.



Jot down key medical information, like current medications and allergies, and prepare questions you may want to ask during your next appointment.



Use these questions to guide conversations about CAH with your doctor, including understanding the condition, treatment options, and management.

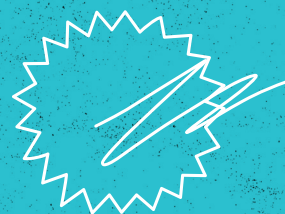
### Understanding CAH

- Are there different types of CAH?
- What type of CAH have I or my child been diagnosed with?
- How can CAH be explained to family, friends, and caregivers?
- What is likely to cause the symptoms that are being experienced?
- What factors impact my cortisol levels?
- What causes high androgen levels?

### Treatment and Management of CAH

- What tests are needed to monitor CAH and how often should these tests be done?
- How often should an endocrinologist be seen?
- What are the options for treatment?
- What are the risks and benefits of each of the treatment options?
- What is realistic to expect with treatment goals?
- What is the difference between symptoms and side effects?
- With CAH, how is health monitored over time?
- What is the risk of long-term medical problems relating to treatment?
- What are the symptoms of an adrenal crisis, and what steps should be taken if one occurs?
- Is mental health counseling recommended?
- Is it possible to travel safely and manage CAH needs while on the go?

It's a good idea to wear a medical identification bracelet or necklace that says you have CAH, lists your medications, and your emergency contact. It can help to provide information to people around you in case of an emergency.



Use the space below to add your notes:



Learn more at **WhatTheCAH.com**



Use these questions based on your or your child's stage in life to help guide discussions with your doctor.

### Child

- There was an abnormal newborn (17-OHP level) screening result. What now?
- How will CAH affect growth and development?
- What needs to be done before starting school?
- What is the current medication dose, and will it change?
- When is the emergency injection needed?
- What is a "stress dose" and when would it be needed?
- Are there possible treatment side effects?

### Teen/Adolescent

- How often should an endocrinologist be seen?
- Should sports and other activities be limited?
- How can CAH be explained to friends?
- Are there treatment side effects to be aware of?
- At what age should transition of care from a pediatric endocrinologist to an adult endocrinologist happen?

### Young Adult

- How often should an endocrinologist be seen?
- Should an adult endocrinologist be seen?
- What steps need to be taken when managing CAH and moving to a new city?
- What should be considered when family planning?
- How can a CAH medical history be shared with a new doctor?
- What are some strategies for effectively communicating CAH needs to doctors, roommates, work friends, or partners?
- What resources are available to best advocate for healthcare needs?

Mental health support is key for pre-teens with CAH. It can help with the social and emotional parts of the condition. Look for a psychologist who has experience helping people with CAH.



For more information on the transfer of care process, please reference the Patient Adult Endocrinologist Checklist located on [WhatTheCAH.com](http://WhatTheCAH.com).



Use these questions relevant to your or your child's age range to help guide discussions with your doctor.

### Adult

- Is osteoporosis a concern due to CAH treatment?
- Will CAH affect fertility or ability to have children?
- What are the risks of passing CAH on to children?
- With CAH, are there any special considerations for pregnancy?
- With lifestyle changes at home or work, how is it best to manage CAH and a medication schedule?

If you have questions about fertility, see a reproductive endocrinologist and/or fertility specialist. If there is a known family history of CAH, prenatal diagnosis may be possible through genetic testing.



## YOUR HEALTHCARE TEAM ALSO MAY INCLUDE SEVERAL HEALTHCARE PROFESSIONALS, SUCH AS:



- An **endocrinologist** who specializes in the endocrine system, diagnosing and treating conditions related to hormone production and function
- A mental health professional called a **psychologist** who can provide coping strategies and other emotional support
- A doctor who finds and treats conditions of the reproductive system, called a **reproductive endocrinologist**
- A doctor who finds and treats urinary tract conditions, called a **urologist**
- An expert in the study of genes, called a **geneticist**, who can confirm an accurate CAH diagnosis and inform family planning decisions
- A **dietician** who can help guide nutrition and offer advice on how to incorporate healthy food into your or your child's lifestyle



### Let's get to know each other

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

