

Next Steps with CAH

WHAT THE
C@H?!™

MAKING THE MOVE TO AN ADULT ENDOCRINOLOGIST

Taking an active role in your care plan with congenital adrenal hyperplasia (CAH) is a big step and may feel overwhelming. Use this to help guide discussions and prepare you or your child for the move from a pediatric endocrinologist to an adult endocrinologist.

WHY IS MAKING THE MOVE TO AN ADULT ENDOCRINOLOGIST IMPORTANT?

As you or your child enter early adulthood, healthcare needs can evolve, potentially altering goals and priorities for treatment and CAH management.

The switch to an adult endocrinologist can happen at different times for people with CAH, but it's important to begin conversations early and often to help prepare for the future. Use this guide to help navigate and prepare you or your child to make the move to an adult endocrinologist.

Use the space below to list any questions for your doctor about the move to an adult endocrinologist.

Making the move to an adult endocrinologist means moving from a pediatric endocrinologist to an adult endocrinologist for CAH management.



Tip:

Moving into adult care doesn't mean you can't get help from your parents or care partner. If you need their support, ask them to come to your doctors' appointments with you until you feel confident.

UNDERSTANDING THE INS AND OUTS OF CAH



You might choose to use this checklist to help guide conversations with your child, doctors, parents or care partners. It is better to have these discussions early and often to help prepare.

Check **YES**, **NO**, or **SORT OF**

	YES	NO	SORT OF
I understand what CAH is and how it impacts my body.			
I understand how the medications I take help manage my CAH.			
I'm aware that there are symptoms of CAH and treatment side effects.			
I can communicate my CAH symptoms and treatment side effects to my care team.			
I know what a stress dose is and when to take one.			
I know what to do and who to go to when I'm not feeling well.			
I know the signs of adrenal crisis and what an emergency injection is.			
I know what to do if I have the signs of adrenal crisis.			
I am aware of what is needed when sleeping away from home or traveling.			
I can communicate my medical needs to someone new.			
I feel confident in managing my own care.			
Overall, I can be my own advocate.			



Start talking about making the move early, in advance of shifting care from a pediatric endocrinologist to an adult endocrinologist. This will give you plenty of time to ask questions and talk through any concerns (if you have them).

Watch videos and learn more about CAH at [WhatTheCAH.com](https://www.WhatTheCAH.com)



YOUR CARE TEAM



You or your child's care team may already involve various healthcare professionals who play a different role in your overall management of CAH. Some of those may include:

- An **endocrinologist** who specializes in the endocrine system, diagnosing and treating conditions related to hormone production and function
- A doctor who finds and treats urinary tract conditions, called a **urologist**
- 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 female reproductive system, called a **reproductive endocrinologist**
- A **nutritionist** who can help guide nutrition and offer advice on how to incorporate healthy food into you or your child's lifestyle
- A **dietician** who can translate nutrition science into personalized meal plans and provide clear guidance to help maintain sodium balance and manage weight



Use this space to write down all of the phone numbers for you or your child's care team members and pharmacy. Be sure to include additions and update phone numbers once the move takes place.

Join the CAH community for support.

Scan the QR code and we'll send videos and info about CAH straight to your inbox.

