

## Lowering Your Steroid Dose:

# A BIG STEP FORWARD

If you and your doctor are planning to lower your high steroid (glucocorticoid) dose, it's important to know what to expect and how this change might affect your CAH management and overall health.

High steroid doses are associated with risks like:

■ Bone loss (osteoporosis) ■ Weight gain (obesity) ■ High blood pressure ■ Diabetes

So reducing your steroid dose may help reduce your risk of these conditions. But after years of treatment, taking less of them can feel scary, too. That's why knowing what to expect can help make the path ahead easier to manage.

## Lowering Your Dose? Here's What to Know

A certain amount of steroids will always be necessary to replace missing cortisol as part of your CAH treatment plan. Once you and your doctor have decided to lower your steroid dose, it's helpful to prepare for what you may experience as you make that shift. Symptoms associated with these changes are known as **steroid withdrawal symptoms**, and they can happen to anyone reducing their steroid dose, not just to people with CAH.

The good news is that **these symptoms are temporary** and tend to improve—and they **don't** mean you need to abandon your new treatment plan. As your body adjusts to the new dose, your care team will be there to help you every step of the way.

## Temporary symptoms of lowering your steroid dose may include:

- Fatigue or low energy
- Muscle or joint aches
- Mood changes (feeling off or irritable)
- Nausea
- Sleep issues
- Simply not "feeling well"

Withdrawal symptoms are often tied to the amount and speed of the reductions. So if symptoms become hard to manage or last longer than expected, your doctor may slow down the steroid dose reduction or briefly increase your dose before continuing to cut back more gradually.



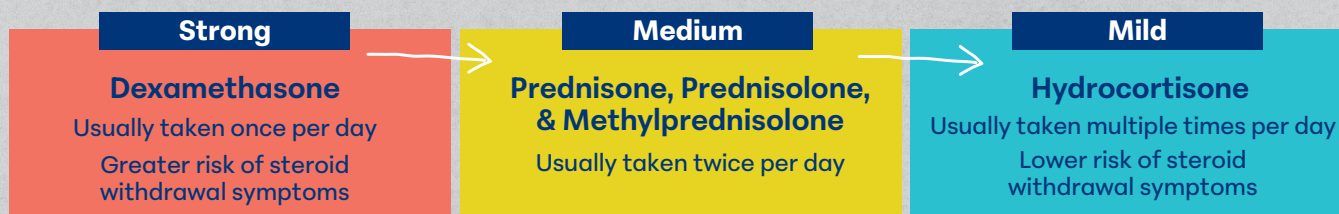
As you begin this next step on your treatment journey, remember to talk to your doctor about what to expect and let them know if you notice any withdrawal symptoms.



## Lowering or changing type—what's the difference?!

Beyond lowering the amount of steroid you take, your doctor may recommend switching to milder types of steroids to manage your CAH. For example, if you take dexamethasone and hydrocortisone, your doctor may switch you to hydrocortisone only.

### Here's a quick overview of common steroid types:



If you currently take a steroid other than hydrocortisone, talk to your doctor about whether a milder type could be right for you.

## Wait, what about my stress dosing plan?

When your everyday steroid dose goes down, your **stress dosing plan**—the extra steroid you add during illness, injury, or surgery—might need a refresh too. For example, it may no longer be sufficient to simply double or triple your dose. This is because you'll still need the same *amount* of total steroid during stress. So with a lower everyday dose, you will need to add a larger amount to get to your typical target "stress dose."

- Your doctor will do the math and tell you if you need to adjust your dose. For example:
  - If your everyday steroid dose was 30 mg and your stress dose was 60 mg, to get your stress dose you would double your daily amount
  - However, if you reduce your daily dose to 20 mg, that means you'll need to triple your new daily dose to have the same 60 mg stress dose you need
- If you're taking fewer daily doses of steroids, you may also need to take them more often when you are sick or injured

Talk to your doctor about the amount and timing of stress doses so you can be prepared when the need arises.

## As always, communication is key

If you and your doctor decide that lowering your dose is right for you, your doctor will then provide guidance on how and when to adjust your treatment plan. During this process, your doctor can also help you:

- Track how your body is responding
- Tell you when you've reached your new everyday dose (yay!)
- Stay focused on your big-picture goals—such as fertility, bone health, and quality of life

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