

# Preparing to Manage Inflammatory Bowel Disease on My Own

You'll have a ton of questions about your disease, many now and many more as time goes on. Here are some tips and skills you can work on building to help you become an independent adult with IBD.

## + SKILLS:

- I am knowledgeable about my disease, the symptoms I can expect, and how the disease affects my body.

## At the Doctor

When you become an adult with IBD, knowing your medications and how much to take will come in handy, especially if there is ever an emergency. Also, other doctors you see for your health should know everything you are taking to avoid other medications that don't work well with your IBD medications.

There can be many common side effects and some risks to IBD medications. If you understand these, you will be better able to make the right decisions for your health in the future. Try asking your doctor about side effects next time!

## + SKILLS:

- I know the names of my medications and the doses.
- I understand why it is important to take my medications as prescribed by my doctor.
- I take my medications on my own.
- I know the possible side effects of my medications.

Throughout your journey with IBD, your doctor may order various routine tests, or other procedures when they are needed. Sometimes these tests require prepping so it's good to know what to expect. It's also important to get your results, so talk to your doctor!

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## + SKILLS:

- I understand what tests or procedures are being performed on me and why.
- I know how to follow instructions for preparations of any tests or procedures performed on me (if applicable).
- I follow up with my doctor to discuss results of any tests and procedures performed on me.

There may be a bump in the road when your disease might become more active, or your symptoms change. Talk to your healthcare team about what symptom changes you should be on the look-out for and when these changes require you to contact your doctor.

Call your doctor right away if it's an emergency.

## + SKILLS:

- I can recognize a flare or complication from my disease.
- I know when it is important to call my doctor.
- I know how to contact my doctor or healthcare team.
- I know when I should call 911.

## Be your own advocate!

If you are in middle school or high school, your parent or guardian may have set up a plan with your school to help with your needs as a patient (504 Accommodations Plan or Individualized Health Plan). But sometimes you may need to voice your concerns directly with your teachers, or school staff. That can happen at college too, and when you get there, you can contact Disability Support Services.

Any time there is a major change, whether you are moving to a new location, enrolling in a new health insurance plan, or if you are traveling abroad, make sure you know what medical services will be covered so you feel better prepared, and can make decisions about cost.

## + SKILLS:

- I feel confident speaking up about my needs in school, with other peers, and in social settings.

## + SKILLS:

- I carry a copy of my insurance card with me.
- I understand my medical insurance coverage.

## + SKILLS:

- I schedule my own medical appointments.
- I feel comfortable talking directly to my doctor during medical visits instead of my parent or guardian.
- I am searching for an adult gastroenterologist that works for me.

You are part of your healthcare team! Your doctor wants to hear from you, how you are feeling, changes, and other things that might be going on- good or bad.

If you don't feel comfortable, it may be best to find a doctor that is a better fit for your needs.

No matter what your next destination is along your journey with IBD, whether it is going to college, starting a new job, traveling or just doing what you love to do, know that CCFA is here to help.

If you ever have any questions about IBD or just need someone to point you in the right direction, contact CCFA at the information below:

(888) 694-8872  
or via Answer Chat: www.ccfa.org

My Next Destination

## + SKILLS:

- I am working with my pediatrician to make sure my care is completely transferred.
- I will continue advocating for my health.

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