



A New Role, Not A Smaller One

Helping your young adult take the lead, without going it alone.

Part of the
**IBD In Real
Life series.**

It's not just your son or daughter who's been managing a lot with IBD – you have been, too. But as college, work, or greater independence approaches, it's time to share the responsibility.

This guide provides general educational information and is not a substitute for individualized medical advice. Families should work with their young adult's healthcare team to develop appropriate treatment, transition and emergency plans.

NATIONAL ASSOCIATION



FOR CONTINENCE



When your child has Crohn's disease or ulcerative colitis, you've probably spent years doing more than most parents realize. Scheduling appointments. Tracking medications. Coordinating treatment. Watching for symptoms. Calling providers. Managing insurance. And knowing when something just doesn't seem right.

But now your child is becoming a young adult. Maybe they're leaving for college, starting a job or simply taking on more responsibility for their own healthcare. That means your role is changing, too.

The goal isn't to step away completely. It's to help your young adult develop the skills and confidence to manage their condition while knowing you're still there when they need support.

Start with a gradual handoff

Independence doesn't have to happen all at once. Begin by identifying the responsibilities your young adult can take on now, those they can learn with support, and those that may require continued help.

Responsibility

What the handoff might look like

Medications

They manage reminders and take medications as prescribed. You help establish a reliable routine.

Refills

They request refills and track delivery dates. You're available if there's an insurance or pharmacy problem.

Appointments

They schedule visits and manage their calendar. You help with logistics when needed.

Provider conversations

They describe symptoms and ask questions. You help them prepare beforehand.

Symptom tracking

They monitor changes and communicate concerns. You help them recognize when to contact their care team.

Insurance and paperwork

They learn where to find information and whom to contact. You help explain unfamiliar processes.

A simple way to begin

Ask your young adult: ***"What's one thing you're ready to handle yourself, and one thing you'd still like help with?"***

Start there. Build on what's working, and revisit responsibilities as their confidence and circumstances change.



COACH, DON'T TAKE OVER

Sometimes the most helpful thing you can do is ask a question

When you've spent years anticipating problems, it's natural to want to jump in with a solution. But giving your son or daughter room to think through a situation – and helping them find their own answer – can build confidence that lasts well into adulthood.

That doesn't mean leaving them to struggle. It means being available without automatically taking control.



A new approach to old challenges

Instead of: “Did you remember to refill your prescription?”

Try: “What’s your plan for keeping track of refills?”

Instead of: “I’ll call your doctor and find out what’s going on.”

Try: “Would it help to make a list of questions before you call?”

Instead of: “You shouldn’t eat that. It’ll make you sick.”

Try: “How have you been feeling with different foods lately? Is there anything you want to discuss with your care team?”

Instead of: “You need to tell your roommate about your condition.”

Try: “Have you thought about what you’d want your roommate to know?”

*The difference may seem small, but the message changes from **I’ll handle this** to **I believe you can handle this, and I’m here if you need me.***

Remember to make room for privacy

As your child becomes an adult, they may want more control over who knows about their health, including you. That can be difficult, particularly when you’ve been closely involved in their care.

Try agreeing on a few expectations together:

- What health information do they want to share with you?
- When would they like you to check in?
- What kinds of situations would they want help managing?
- When would they prefer to handle things privately?

Remember that healthcare providers generally need an adult patient’s permission to share protected medical information with family members, subject to applicable legal exceptions.

Respecting privacy doesn’t mean caring less. It means allowing your relationship to evolve.

HELP THEM FIND THE WORDS

Managing IBD means having conversations beyond the doctor's office

Your young adult may need to explain an unexpected absence, ask for bathroom access, discuss treatment scheduling or tell a friend why plans have changed.

Those conversations can feel uncomfortable, especially when they're trying to fit in, make a good impression or avoid drawing attention to their condition. You can help by practicing simple, practical language together.



With a roommate

"I have a medical condition that sometimes means I need the bathroom urgently. I just wanted to let you know in case it comes up."

With a professor or campus support office

"I have a chronic medical condition that can affect my attendance and sometimes requires urgent bathroom access. I'd like to understand what accommodations may be available."

With an employer

"I have a medical condition that occasionally requires appointments or some flexibility. Could you explain the process for requesting support if I need it?"

With friends

"I'm not feeling great today, so I may need to change our plans. It's nothing personal."

With a healthcare provider

"My symptoms have been worse lately, and they're starting to interfere with classes and sleep. I'd like to talk about what might be happening."



You don't need to speak for them to help them find their voice.

Your role: help them prepare, then let them speak.

Before an appointment or difficult conversation, you might ask:

- "What do you want the other person to understand?"
- "What would make the situation easier for you?"
- "Is there anything you're worried about saying?"
- "Would you like to practice the conversation?"

Encourage them to speak directly with their healthcare team and campus accessibility or disability services office support contacts whenever possible.

KNOW WHEN TO STEP BACK AND WHEN TO STEP IN

Independence doesn't mean ignoring problems

Learning to manage IBD includes making decisions, asking questions and occasionally making mistakes. But there's an important difference between giving your young adult room to learn and overlooking signs that they may need help.



When to step back

Give them room to manage routine responsibilities, make everyday decisions and handle conversations they're prepared for. You can remain available without checking every detail.

When to offer support

Reach out when they seem overwhelmed, are struggling to manage appointments or medications, or ask for help navigating a problem.

How to go about it

A good way to build their independence while still remaining available to them is to put the ball in their court. Try asking, "Do you want me to listen, help you think it through, or help you take care of something?" That question gives them a choice while making it clear you're there when they need you.

When to take symptoms seriously

Encourage your young adult to contact their healthcare team when symptoms are new, worsening or interfering with everyday life. That includes changes in bowel habits, increasing pain, persistent fatigue, difficulty eating or drinking, or problems keeping up with treatment.

And while it might seem obvious to you, they may not realize that severe abdominal pain, significant bleeding, fainting or signs of serious dehydration are serious and may require emergency medical attention. Make sure they know not to ignore these signs.

Work with their healthcare team to establish a personalized flare and emergency plan, including when they should seek urgent care and how you can help if they're unable to manage the situation independently.

The goal is to support their judgment – not replace it.

Before they leave home, talk through these questions

You don't need to settle everything in one conversation, but discussing these issues ahead of time can help everyone feel more prepared.

1. Who will schedule appointments, request refills and track treatment dates?
2. Does your young adult know how to reach their GI provider, including after hours?
3. What should they do if symptoms worsen or a medication is delayed?
4. Do they know where to find their insurance information and pharmacy contacts?
5. Have they considered what support they might need at school or work?
6. Who can they turn to locally if they need help?
7. How often would they like you to check in?
8. Under what circumstances would they want you to become more involved?



One last thing

Your young adult doesn't need to manage IBD perfectly to become more independent. There will be things they handle confidently and others they'll still need help figuring out. There may be setbacks, difficult conversations and unexpected challenges along the way.

What matters is that they're developing the skills, confidence and support system to take a more active role in their health.

You're not stepping out of their life.
You're helping them take the next
step in their own.



More resources from NAFC

Explore the **IBD In Real Life video series** and companion resources, including

- Young Adult Guide to Talking About IBD
- My IBD Backup Plan: College + Independent Living

Visit **NAFC.org** to learn more.



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