



Let's Talk About IBD.

A Young Adult's Guide to Talking About Symptoms, Needs and Everyday Life

You don't have to explain everything. You just need to know how to say what matters.

What and when to share about your condition with friends, roommates, professors, employers and healthcare providers.

Part of the
IBD In Real Life series.

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This guide provides general educational information and is not a substitute for medical advice. Work with your healthcare team to develop a plan appropriate for your condition and individual needs.



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FOR CONTINENCE

YOU GET TO DECIDE WHAT TO SHARE

Living with IBD is personal. Talking about it should be, too.

College is full of new experiences, new people and new responsibilities. And when you're living with inflammatory bowel disease (IBD), it can also mean having conversations you've never had to manage on your own before.

Maybe you're worried about explaining why you need to leave class unexpectedly. Or why you're not feeling up to going out. Or why you need time away for medical appointments.

Sometimes the hardest part isn't managing the symptoms themselves. It's figuring out what to say about them.

Here's something worth remembering: You don't owe everyone your complete medical history.

You get to decide who you tell, what you share and how much detail you're comfortable providing. Some people may need to understand your condition. Others may only need to know how it affects your plans or what kind of help you might need.

And it's okay if those conversations feel awkward at first. Like anything else that comes with becoming more independent, talking about your health takes practice.

Start with what matters.

A helpful way to approach almost any conversation is to think about three things:

1. What do they need to know? Maybe it's that you have a chronic medical condition. Maybe it's simply that you occasionally need to step away or change plans.
2. What do you need from them? Understanding? Privacy? Flexibility? A little practical help?
3. How much do you want to share?

That's your decision. You can always explain more later if you choose.

A few ways to get started:

"I have a medical condition that sometimes affects my energy and digestion."

"My symptoms can be unpredictable, so I sometimes need a little flexibility."

"I'm doing okay, but I need to be thoughtful about how I plan things."

"I'd rather not get into the details, but I appreciate your understanding."

You don't need to have the perfect words. You just need words that work for you.

ROOMMATES, FRIENDS AND THE PEOPLE CLOSE TO YOU

Sharing a room doesn't mean sharing everything.

Living with a roommate can take some getting used to, even without IBD. You're sharing space, routines and possibly a bathroom with someone who may know very little about your health.

You don't have to tell your roommate everything. But explaining a few practical things early on can make daily life easier for both of you.



Some helpful phrasing to consider

If you're talking with a roommate:

"I have Crohn's disease, which sometimes means I need the bathroom pretty urgently. I'm managing it, but I wanted to mention it so you understand if I need to get in there quickly."

If you'd rather keep things more general:

"I have a digestive condition that sometimes affects my bathroom routine. It's something I'm managing, but I wanted to give you a heads up."

If you need privacy:

"I keep some medical supplies here, and I'd appreciate it if we could keep that private."

If you need help:

"I'm not feeling great today. Would you mind picking something up for me while you're out?"

You don't have to make a big announcement. Often, a quick conversation is enough.

What about friends?

Friends may not understand why you're sometimes tired, why you check for bathrooms or why you hesitate before agreeing to plans. They

don't necessarily need a detailed explanation, but giving them a little context can prevent misunderstandings.

If someone asks why you're always checking for bathrooms:

"I have a digestive condition, so knowing where the bathrooms are helps me relax and enjoy myself."

If you're feeling exhausted:

"My IBD can make me really tired, even when I look fine. I think I need to take it easy tonight."

If you want someone to understand without making it a big deal:

"Sometimes my symptoms get in the way of things. I don't need you to do anything special. Just know that if I need to change plans, it's not because I don't want to be there."

The goal isn't to make IBD the center of your friendships. It's to help the people you care about understand you a little better.

WHEN PLANS CHANGE

Sometimes the answer is “I’d love to, but...”

A spontaneous road trip. Dinner somewhere new. A concert. A party. These are the kinds of experiences that make college memorable. But when you have IBD, even simple plans can come with questions.

Will there be bathrooms? What can I eat? How long will we be gone? What if I start feeling sick? You don’t necessarily have to say no. Sometimes you just need to make a few adjustments.



If you’re going on a long drive:

“I’m definitely interested. Could we plan a stop about halfway through? That would make the trip a lot easier for me.”

If you’re unsure about the restaurant:

“Can we check the menu first? I have some dietary restrictions and want to make sure there’s something that works for me.”

If you need to leave early:

“I’m starting to feel a little off, so I think I’m going to head back. I had a great time, though.”

If you need to cancel:

“I’m sorry for the late change, but my symptoms are acting up today. Could we reschedule?”

If someone keeps pushing for an explanation:

“It’s a health thing, but I’d rather not get into the details right now. Thanks for understanding.”

What if people think you’re unreliable?

It’s understandable to worry about disappointing people, especially when your symptoms can change without much warning. But being honest about what you can manage is better than constantly pushing yourself to meet expectations that may not be realistic.

And remember, plans don’t always have to be all-or-nothing. You can suggest a shorter outing, a different restaurant, a later start time or something closer to home.

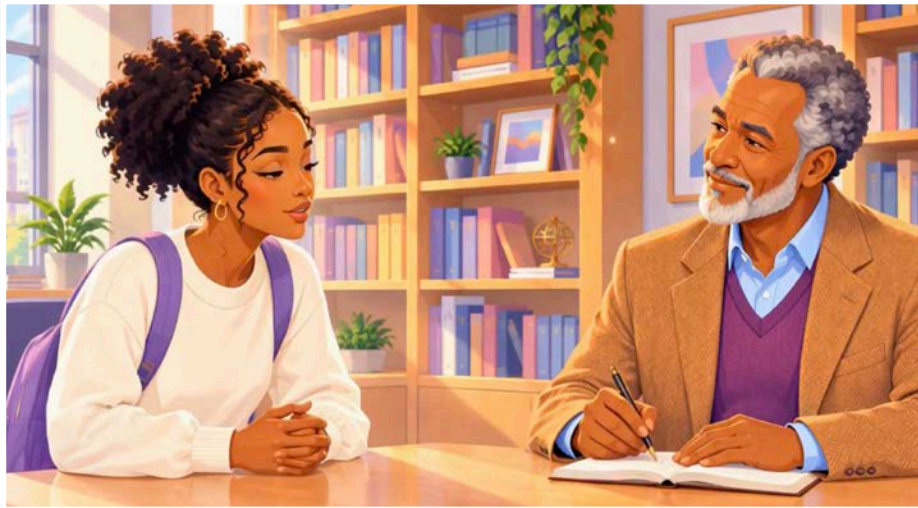
Being flexible with your plans doesn’t mean missing out on life. It means finding ways to participate that work for you.

TALKING TO PROFESSORS AND CAMPUS SUPPORT SERVICES

Asking for support is part of being independent.

IBD doesn't always fit neatly into a class schedule. You may need unexpected bathroom breaks, miss class because of a flare, or have medical appointments that conflict with lectures or exams.

The good news is that colleges generally have offices dedicated to helping students with disabilities and chronic medical conditions access appropriate accommodations. You don't have to wait until you're struggling academically to ask what support may be available.



Start with your school's disability or accessibility services office.

You might say: "I have inflammatory bowel disease, a chronic medical condition that can affect my attendance and sometimes requires urgent bathroom access. I'd like to understand what accommodations might be available and what documentation you need."

Depending on your situation and your school's policies, accommodations may include:

- Bathroom breaks during class or exams.
- Flexibility related to medically necessary absences.
- Adjustments to testing arrangements.
- Housing or dining accommodations.
- Scheduling considerations related to treatment.

Your school's accessibility office can explain the process and help determine what is appropriate for your situation.

Talking to a professor

Once accommodations are arranged, you may need to discuss how they'll work in a particular class. Don't wait until you're actually having an issue before mentioning anything to a professor. Instead, have the conversation early in the semester to establish an understanding well in advance.

First, set expectations:

"I wanted to let you know that I have a medical accommodation that sometimes requires me to step out during class. I just want to make sure you're aware. I try to be discreet about it, so if I ever do have to leave, there won't be any disruption."

If you have upcoming medical appointments:

"I have recurring/occasional doctor's appointments that may cause a scheduling conflict every once in a while. Could we discuss how to handle those dates?"

If you're going to miss class:

"I'm dealing with a medical issue and won't be able to attend today. Could you let me know the best way to keep up with the material?"

You don't have to convince someone that your symptoms are real. The goal is to communicate what you need and work through the appropriate support process.

TALKING TO YOUR HEALTHCARE TEAM

Your provider needs the full picture. Even the awkward parts.



Be specific about what's happening.

Instead of: “My stomach has been bothering me.”

Try: “I’ve been having more abdominal pain over the past two weeks, especially after eating. I’ve also had more frequent diarrhea and urgency than usual.”

Instead of: “I’m really tired.”

Try: “I’m exhausted most afternoons, even when I’ve slept enough. It’s making it difficult to concentrate in class and keep up with my usual activities.”

The more clearly you describe what’s happening, the easier it is for your provider to understand how IBD is affecting you.

There may be times when you want to downplay your symptoms. Maybe you’re embarrassed, or maybe you’ve gotten so used to feeling a certain way that you don’t think it’s worth mentioning.

But your healthcare team can only work with the information you give them. And as you become more independent, learning to describe your symptoms and ask questions is one of the most important skills you can develop.

It can also help to remember that your healthcare team is used to talking about symptoms like diarrhea, urgency, pain, bleeding and fatigue. What feels embarrassing to you is an important part of the information they need to understand how you’re doing. What feels embarrassing to you is routine to them.

Before an appointment, think about:

Symptoms: What’s happening? How often? How severe?

Changes: Is anything new or getting worse?

Timing: When did the symptoms begin? Are there patterns?

Daily life: Are symptoms affecting sleep, school, work or social activities?

Treatment: Are you having trouble with medications, refills, side effects or appointments?

Questions: What do you want to understand before you leave?

You can keep notes on your phone so you don’t forget anything important.

Don’t worry about knowing all the medical terminology – just be honest about what you’re experiencing.

Questions worth asking:

“How can I tell whether my symptoms might be a flare?”

“What should I do if my symptoms suddenly get worse?”

“Who should I contact if I have a problem with a medication or refill?”

“What symptoms mean I should seek urgent medical attention?”

“Can we talk about how my fatigue is affecting my daily life?”

And if something doesn’t make sense, say so.

“Could you explain that another way?”

“I’m not sure I understand what I should do next.”

“Can we go over the plan one more time?”

WHEN YOU NEED HELP, FLEXIBILITY OR A LITTLE SPACE

You can ask for what you need without all the details.

Sometimes the hardest conversations are the shortest ones. You may need a break, a schedule change, help with something practical or simply a little understanding. And you may not want to turn every request into a discussion about your condition. **That's okay.**



If you need a little space:

"I'm dealing with some symptoms today and need a little time to myself."

If you need flexibility:

"My condition can be unpredictable. Would it be possible to make an adjustment if I'm having a difficult day?"

If you need someone to help:

"I'm not feeling well enough to handle everything today. Could you help me with one thing?"

If you don't want to explain further:

"I appreciate you asking, but I'd rather keep the details private."

If you're starting a job or internship:

"I have a chronic medical condition that occasionally requires appointments or some flexibility. I'd like to understand the process for requesting support if I need it."

For formal workplace accommodations, you may need to work with HR or another designated contact and provide appropriate documentation. You can ask about that process without sharing your entire medical history with coworkers.

When it's time to speak up about your symptoms

It's one thing to manage a difficult day. It's another to keep minimizing symptoms that are getting worse or interfering with your life. Contact your healthcare team if you notice changes such as:

- More frequent or severe diarrhea, urgency or abdominal pain.
- New or increasing blood in your stool.
- Persistent or worsening fatigue.
- Difficulty eating, drinking or maintaining your usual activities.
- Symptoms that interfere with classes, work, sleep or daily life.
- Problems taking medications or keeping up with your treatment plan.

Don't wait for a scheduled appointment if you're concerned about worsening symptoms. Ask your care team what to do and how quickly you should be evaluated.

Seek urgent medical attention for severe symptoms such as intense abdominal pain, significant bleeding, fainting, or signs of serious dehydration.

And remember: You don't have to decide on your own whether a symptom is serious enough to mention. If something concerns you, it's worth asking.

YOUR WORDS. YOUR HEALTH. YOUR LIFE.

You don't have to figure everything out at once.



Becoming more independent with IBD doesn't happen overnight. You'll learn which conversations feel comfortable, which people you trust and how to explain your needs in ways that feel natural to you.

Some days you'll have everything organized. Other days, you may need to ask for help, change plans or make a few adjustments.

That's part of learning to manage a chronic condition while building a life of your own.

Four key things to remember

1. You decide what to share.

You can be honest about your needs without telling everyone every single thing.

2. It's okay to ask for support.

Friends, roommates, professors, healthcare providers and others may be able to help in different ways.

3. Speak up when something changes.

If your symptoms are worsening or affecting your life, contact your healthcare team.

4. Keep practicing.

The more you communicate about your health, the easier it can become to find the words that work for you.

A conversation starter you can make your own:

"I have _____, which sometimes affects _____.

When that happens, it helps if _____.
I appreciate your understanding."

You can use this with a friend, roommate, professor, employer or anyone else who may need to understand what you're managing.

IBD is part of your life. It doesn't have to be your whole story.

More resources from NAFC

Explore the **IBD In Real Life video series** and download additional tools to help you plan for college, manage your care and build independence.

Visit [URL TO COME] to learn more.

