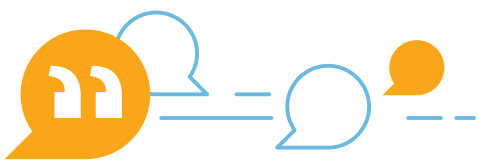


A conversation guide for friends and family

A trusted support system can help you manage your IBD and continue to live your life – on your terms. Thinking ahead about how to approach conversations with your friends and family about your Crohn’s disease, ulcerative colitis (UC) or inflammatory bowel disease (IBD) in general, can help you feel more prepared and comfortable.



This guide is intended to be used as a starting point for having these conversations. It’s important to know when you feel comfortable sharing details of your journey, and when you don’t, so that you can manage your disease in all settings.

You get to decide if, when and how you disclose your diagnosis. There is also no time limit on disclosing. So, take your time and share if and when it feels most comfortable for you.



“Although there are people who criticize me for being open about my condition and an advocate for the disease – there are far more people who praise and thank me for raising awareness and being open and honest about my experiences.”

Tina Aswani Omprakash,
patient living with Crohn’s
disease and health advocate for
the chronically ill and disabled

Start a conversation about IBD

Every person's experience with IBD is different, which means there is no one right way to share your diagnosis. You will naturally feel more comfortable sharing certain details with some people over others, and it's likely that each of your friends and family will react differently to your disease.

These conversation starters can help guide you through the process of sharing your journey. You can start by getting a sense of what the other person knows about IBD. For example:

- ▶ “What do you know about [ulcerative colitis/Crohn's disease]?”
- ▶ “My doctor has diagnosed me with Crohn's disease, do you know what that is?”
- ▶ “You've probably heard about people with IBS or irritable bowel syndrome, right? I've been diagnosed with a different condition, IBD or inflammatory bowel disease. It sounds similar to IBS, but it's different because...”



Tina's IBD Life

“Crohn's disease is very unpredictable. It's helpful for me to set expectations with my close friends and family ahead of time, so they know that if I cancel plans last minute, it's nothing against them.”

Tina Aswani Omprakash

Then, you can share more about what the diagnosis means for you and how they can support you. For example:

“Because of my IBD, I hesitate to [insert social activity], but I would love to [insert alternative.]”

Example: “Because of my Crohn's disease, I hesitate to go out to eat, but I would love to have you over for dinner.”

“[Insert routine] is really important to help manage my disease. Will that be available at [insert activity]? If not, I will plan to [alternative option].”

Example: “Sticking to my diet is really important to help manage my disease. Will there be gluten-free or vegan options at your party? If not, I'll bring something with me.”

“As I figure out my new norm with IBD, I would like...”

Example: “As I figure out my new norm with ulcerative colitis, I would like if we could eat at home for a couple of months.”

“Because of my IBD, I often experience [symptom]. Here's how you can help...”

Example 1: “Because of my IBD, I sometimes experience depression. If it seems like I'm being distant, I would love for you to check in on me.”

Example 2: “If I'm in a flare, I like to relax at home as much I can. It would mean a lot if we could do movie nights instead of going out.”

Find your support system

Positive and supportive relationships are critical to your health. However, no one person in your life is going to meet all of your needs. **It can be helpful to think about what specific roles different friends or family members can play as you face different challenges.** Think about each person in your life and how they tend to show love. Some may enjoy helping out with errands, while others may enjoy talking through a challenge you're facing at work or lending a supportive shoulder while you're in a flare-up. Understanding these preferences and strengths can help you feel more comfortable leaning on people.

You can also build meaningful connections through support groups. It can be refreshing to find people who understand your experience and can share tips for coping. However, there are some instances where non-moderated groups on social media can fuel negativity or misinformation about the disease and/or treatment options, so it's important to recognize whether these groups are serving you in a positive and productive way. Decide what works for you and take breaks if needed.

Tina's IBD Life

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Voice your boundaries

As someone living with IBD, you may find that friends and family ask invasive questions, pressure you to break your diet restrictions, or dismiss the seriousness of your disease altogether. Building confidence around voicing your needs and understanding who you can lean on for help will strengthen your relationships and ensure you're prioritizing your health.

Learning how to navigate uncomfortable situations with family and friends can be key to setting clear boundaries. In the end, helping your inner circle understand your condition, and become an advocate for and with you, can help you to feel more confident and comfortable in your everyday life.

These sample scenarios can help you navigate different kinds of situations:

Family member asks: "How was the doctor today?"

Sample response: "Thank you for asking. It wasn't so great. I need to get my mind off things so would prefer to talk about something else if you don't mind."

Friend asks: "Why did you cancel last minute?"

Sample response: "I'm sorry I missed you; I wasn't feeling up to it."

Scenario: Family member repeatedly adds spices to the family meal that you can't eat.

Sample response: "When you don't consider my diet restrictions, it makes me feel like you don't care about me."

Need additional resources to help navigate your journey with IBD? Visit [MyIBDLife.gastro.org](https://myIBDLife.gastro.org) to learn more.