

A guide to help navigate conversations with your health care providers

For someone living with Crohn's disease, ulcerative colitis (UC) or inflammatory bowel disease (IBD) in general, establishing a good relationship with your care team can help ensure you're managing your disease well and put your mind at ease.

That's why we created this guide – to help you navigate your interactions with providers and make the most out of your visits.

Keep your medical team informed

Knowing that IBD can affect other parts of your body beyond the gut, you will likely see many different providers to help manage your condition and to address other medical needs. They are your medical team, and it is important to keep them informed so they know how to best treat you and your specific symptoms. See the cheat sheet on page 4, which includes a list of health care providers you may see and what they specialize in.



Tip for Provider Visits

“To make it easier to coordinate care among specialists, it can be helpful to find providers that work in the same center or have a shared health records or patient portal system so that you can have a shared medical record.

The one exception is surgeons, who don't need to be at the same center or location as your GI provider because typically the long-term relationship stays with the GI. So, in the case of surgery, I tell my patients to prioritize choosing the best surgeon for them.”

Dr. Laurie Keefer, psychologist at Mount Sinai who specializes in chronic digestive diseases

Prepare your medical story

“I always tell my patients to write out an ‘elevator pitch’ for anytime they see a non-GI provider. It should go something like this:

‘I have X condition, I was diagnosed X years ago, this is how it’s treated, and this is how it affects me.’

It’s a good starting point of disease history that doesn’t need to go too far into the weeds. Then the patient can share what they’d like to focus on during that specific visit.

For example, ‘Today I’m here because my GI doctor is concerned my hip pain might be IBD-related arthritis.’ I tell my patients to practice this elevator speech in the mirror before a visit, so they can best communicate their needs.”

Dr. Laurie Keefer



Define and share your short and long-term goals

Tell your provider about your short and long-term life goals. This can include milestones like starting a family, getting promoted at work, or taking a vacation; or everyday actions like incorporating different foods into your diet, or being able to take walks without wearing protective underwear.

In addition to your medical story, consider sharing other personal information with your providers, such as:



Preferred gender and sexual orientation.



Whether you’re struggling with depression and/or anxiety.



If you have experienced medical trauma.

While these topics may be hard to talk about or not seem relevant to the specific medical issue you are having, they can help inform your care and provide context to your provider. Similar to your medical story, it can be helpful to write down and practice what you’re going to say ahead of time.

Sharing your personal goals with your health care provider can help pave a clear path forward.

Here are some sample conversation starters:

- ▶ “I have been in remission for [insert here]. How can I begin to incorporate...”
- ▶ “My goal is to [insert goal]. What are the steps to achieve this goal?”
- ▶ “I would like to try [insert activity]. Is now the best time to start? If not, what can I do in the meantime?”
- ▶ “I usually [insert routine], but I would like to transition to [insert plan]. What are steps I can take to get there?”

Make the most of your appointments

It's crucial to be open, honest and proactive with your care team so they can provide the best possible care.

Bring a list of questions to help you make the most of your appointments. You can schedule another appointment to discuss something further if time runs out.



Consider asking these questions, if relevant, to keep your appointments on track:

Communication

- ▶ When is it most appropriate to reach out to you; your nurse; or use an online portal?
- ▶ What is the best way to reach out?
- ▶ When should I schedule a telehealth appointment vs. an in-person appointment?
- ▶ How do I get in touch with you in an emergency

Managing Symptoms

- ▶ Should I take dietary supplements?
- ▶ Are there other medicines I can take to help manage my symptoms?
- ▶ How can I best manage my symptoms through my diet?
- ▶ How can I best manage my symptoms through exercise?
- ▶ What can make my IBD flare?
- ▶ How do I manage stressors that may cause an IBD flare?
- ▶ What symptoms indicate an emergency?

Treatment

- ▶ How can I create a routine around the medicine I take in a day/week?
- ▶ Will I need surgery at some point?
- ▶ Is there an alternative treatment plan for me if I don't want surgery?
- ▶ How do I best prepare for an upcoming procedure?
- ▶ How will you know if my new treatment program is working?
- ▶ When should I expect to feel better?
- ▶ How much better should I expect to feel?
- ▶ What are the benefits and risks of the treatment program I'm following?
- ▶ If you can't get insurance approval, is there a way to appeal? What is the next best treatment? What concerns do you have about it?

Additional Resources

- ▶ Where can I find emotional support for my condition?
- ▶ Do you have additional resources you can share (such as resources related to mental health, nutrition, conception and pregnancy, risks of medications, surgery, etc.)?

Health care provider cheat sheet

Clinical pharmacist: Many IBD centers and clinics have pharmacists who specialize in IBD treatments. They can help you work with your insurance company, understand how medications do or don't work together (interactions), explain side-effects, and suggest other possible treatments.

Dentist: This doctor specializes in treating the diseases and conditions that affect the teeth and gums.

Dermatologist: This doctor diagnoses and treats skin disorders and can help with skin-related complications from your IBD or IBD medicines. You should also get regular skin checks to prevent cancer.

Registered dietitian: These specialists have special training in diet and nutrition and how the body uses food. They can help you find the correct diet to prevent malnutrition and manage your IBD symptoms, both in remission and during flare-ups.

Endocrinologist: This is a medical provider qualified to diagnose and treat disorders of the endocrine glands and hormones. You may see an endocrinologist to help with side effects of taking steroids as a part of your IBD treatment.

Gastroenterologist (GI): This doctor specializes in disorders and diseases that affect the digestive system. This will be the main provider you see to diagnose, treat and manage your IBD. Some gastroenterologists have additional specialized training in IBD and its medications.

Nurse/nurse practitioner (NP): These providers focus on patient education, symptom management, surveillance and preventative care and monitoring of disease markers over time. NPs are permitted to prescribe treatments, order tests and diagnose patients. In addition to your GI, you may have a regular nurse or nurse practitioner that helps you navigate your IBD journey.

Obstetrician (OB) or maternal-fetal medicine (MFM) subspecialist: These are doctors who specialize in female reproductive health. If

Here is a list, in alphabetical order, of some providers you may see in your health journey. Remember to keep them informed of your medical story and other personal information that may be important for your care.

4

you become pregnant, it will be important to work with your maternal-fetal medicine (MFM) subspecialist and/or obstetric provider to lead your pregnancy-related care. Learn more about pregnancy and IBD [here](#).

Ophthalmologist: This doctor diagnoses and treats eye diseases and vision problems. You may see an ophthalmologist if you experience issues with your vision, which could be due to inflammation, or swelling, from IBD or develop side effects from medications (e.g. cataracts).

Physician assistant (PA): This provider is qualified to assist a physician and carry out routine clinical procedures under the supervision of a physician. You may see a PA as a part of your care team.

Primary care provider (PCP): A PCP provides, coordinates and helps patients access a range of health care services. It's a good idea to have a PCP for regular check-ups and things like your annual flu shot and other essential vaccinations.

Rheumatologists: This doctor specializes in the diagnosis and treatment of diseases that affect the muscles, bones, joints, ligaments and tendons. You may see this specialist for joint pain and/or inflammation which can be due to IBD itself or the medications used to treat IBD.

Surgeon(s): Some IBD patients may require surgery. Surgery for IBD removes part of the bowel (large or small intestine) which is damaged and/or inflamed and/or local IBD complications such as perianal abscesses or fistula. You can work with your medical team to find the best surgeon in your area.

Psychologist/therapist: These providers are licensed mental health professionals who specialize in helping clients cope with various life challenges. They can help you develop skills to manage the emotional and social aspects of IBD. For best results, look for someone who has experience with chronic illness populations and who is willing to work with your other providers.