

Your Top 10 Crohn's Disease Questions, Answered!

You've got worries, we've got solutions. Download this cheat sheet to all your pressing Crohn's concerns and take it with you to your next gastro appointment.

This spring, HealthCentral hosted two hour-long live events, asking some of the country's top inflammatory bowel disease experts to field questions about successful treatment for Crohn's disease. Our team of gastroenterologists talked about topics ranging from inflammation to invisible symptoms, broaching the subject of Crohn's treatments in ways everyone can understand. If you missed our event (or just have more Crohn's questions), you'll want to read the advice shared below.

Our all-star panel of pros tackling tough Crohn's questions includes Bo Shen, M.D., medical director of the Inflammatory Bowel Disease Center at NewYork Presbyterian Hospital/Columbia University Irving Medical Center in New York City, gastroenterologist Sheila Rustgi, M.D., also from NewYork Presbyterian, Reezwana Chowdhury, M.D., a gastroenterologist at Johns Hopkins Medicine in Baltimore, and Julia J. Liu, M.D., professor of medicine and chief of the division of gastroenterology at Morehouse School of Medicine in Atlanta.

For the bottom line on your top questions about treatment for Crohn's disease, check out what our experts have to say.

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What Does Treatment Success Look Like With Crohn's?

Dr. Chowdhury: Basically, our goal is to reduce the inflammatory burden to allow patients with Crohn's disease as much of a normal life as possible. Inflammation can affect the entire lining of the colon wall—all the different layers—and different parts of the GI tract as well. And prolonged inflammation can also lead to cancer down the road. Inflammation can also lead to micro-perforations or a fistula in the colon; you can also have fistulas or abscesses outside of the anus. Regardless, the goal is trying to get patients back to living a normal life so that we can try to avoid surgery.

2

Why Is Early Treatment So Important With Crohn's?

Dr. Rustgi: There's evidence that shows patients who have inflammation from Crohn's that's been uncontrolled for a long time can have scarring, and it can be harder for them to respond to medications. It's really important, when you're trying to manage your symptoms, that you're talking to your doctors about "Why do I still have diarrhea?" and "When should I expect that my medications will help me start to feel better?" Patients who have better early control over their disease are also better off in the long-term in managing their Crohn's.

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How Do You Define Remission With Crohn's?

Dr. Chowdhury: We use various factors, including clinical symptoms and a clinical disease activity index. The index is a scoring system in terms of number of bowel movements, abdominal pain, and general wellbeing. We also look at someone's inflammatory markers, such as their CRP levels, and we do a colonoscopy with biopsy. We'll do an endoscopy to see if they have ulcers or severe inflammation and check whether their colon looks improved from before—meaning there are no more ulcerations. We consider that endoscopic remission. If someone has small bowel disease, we would do an MRI to see if there's still inflammation in that area. All of those together would indicate endoscopic and clinical remission.

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Does the Amount of Inflammation Determine the Treatment Path?

Dr. Shen: The patient who has a high burden of inflammation is also at highest risk for surgical intervention. But Crohn's disease is unlike other diseases in that after Crohn's disease surgery, 80% to 90% of patients still have disease recurrence. Also, with Crohn's you have a high risk for surgical complications. So patients should try to do whatever they can to postpone or even ideally avoid surgery. There are medical therapies—very potent biologic agents and small molecule medicines. Some of the biological agents work better for Crohn's disease in the large bowel, some work better for Crohn's disease in the small bowel. With small molecule agents, disease location is also very important.

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What Should You Expect on Crohn's Medication?

Dr. Rustgi: Once you're talking to the doctor about starting the medication, I think that's a great time to talk about, "When do you think I should expect to start feeling better?" and "At what point should I contact you if I'm not feeling better?" You want to know, is it days or weeks? Certainly if you're not feeling better or at least seeing some improvement within a few weeks, you should not be shy about reaching out to your doctor. This is a case where early intervention to help control the inflammation and control your symptoms is important.

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What Are Side Effects of Crohn's Medications?

Dr. Chowdhury: Various biologics can have various side effects. Infliximab and adalimumab, anti-TNF agents, can give patients infusion-site or injection-site reactions. There is a slightly higher risk of infections with these biologics because they are suppressing your immune system in order to get this disease under control. And there's a slightly higher risk of lymphoma with our anti-TNFs. In terms of other side effects, some patients on biologics feel more tired initially right after an infusion, but then they'll feel better once it's been a day or so later. There's a psoriasis-type of reaction that can happen with infliximab as well. But overall, if the medication is working, it's usually a positive response that we hear from our patients.

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How Can People With Crohn's Help Doctors Understand What They're Going Through?

Dr. Rustgi: Doctors like to hear data. So when you're talking with your doctor, it can be helpful to say, I'm still having eight bowel movements a day or I'm still not able to go to work this many days of the month. Can we talk about what my blood work is showing? Can we talk about what my colonoscopy findings are? Using objective data to quantify your symptoms while also looking at your blood work and looking at your colonoscopy findings together is a really helpful way for you and the doctor to get on the same page about whether you're making progress on a treatment.

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How Do You Choose a Medication?

Dr. Shen: It used to be what we called step-up therapy: You tried mesalamine first, then a biologic or immunosuppressing agent, then surgery. But now, the paradigm has changed: If you have very severe disease to begin with you may go right to a disease-modifying agent like a biologic. It's interesting—usually when you choose a biologic or small molecule agent, the first one you try always works the best. But even so, about 40% of people don't respond to it. It's not your fault or the doctor's fault—you just need to keep monitoring symptoms and try another approach.

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What Do You Tell Your Patients With Crohn's?

Dr. Liu: I tell them that this is a disease. You have to take your treatment just like you would for high blood pressure. Even if you're not feeling any illness—even if you feel better—you still have to take the medicine because it has been shown repeatedly that if you stop, Crohn's will come back. I have a physician's assistant who works with me to educate patients and then also calls them the next day or the following week after their appointment to make sure they understand the medications they're taking—how to inject themselves or that they need to go and get their biologic at an infusion appointment. People think they understand or maybe they're not sure, but they won't call. So it's up to us to make sure they're doing the right thing.

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Any Advice for Patients Who Are Nervous Seeing a Gastro?

Dr. Liu: I mean, we're poop doctors. Let's face it. I look at poop every day and patients even show me their poop. That's what we do. I let my patients know, these are the things you need to keep track of in terms of your diarrhea, in terms of bleeding, in terms of pain. I explain to them: This is what you have and these are the things we need to do to get you better. You want to find a doctor who actually cares about you and you're comfortable with, but there are always patients who just don't click with me and I completely understand that. That's why I say, please find a doctor who works for you, you know?