



## FREQUENTLY ASKED QUESTIONS FROM THE 2021 IBD INSIDER PROGRAM

### Treatments

**Question: I've been on a biologic for a couple of years and although my inflammation and my symptoms have improved there is still evidence of mild inflammation. Is this a good target? Or is deep/total remission the actual target and should I be switching my medication?**

Targets for each patient will be different based on the type, severity, and progression of disease as well as age, symptoms, co-existing and/or pre-existing conditions, and other social and emotional factors. Total remission may be a long-term goal that you and your provider set to achieve, but in the meantime, reducing inflammation is an excellent short-term goal.

It is important to share with your provider, at every visit, your personal preferences, short, and long-term goals to ensure that the medication and treatments are best for you. [Click here](#) to learn more about partnering with your doctor and goal setting.

### Working with healthcare team

**Question: What can a patient do when the insurance won't cover the treatment plan the doctor has put together? How do I work with my doctor to get the coverage I need?**

Before starting a new treatment, or switching treatments, it is always a good idea to share with your healthcare provider your current insurance to see if your plan will cover the treatment. If your insurance doesn't cover the treatment, and your provider feels this is the best possible treatment, you have a couple of options. You can appeal the denial from your insurance company and the Foundation has several helpful tips and appeal letter templates to help support your claim. [Click here](#) for more information on appealing claims. Additionally, many pharmaceutical companies provide assistance in the form of co-pay programs or direct financial assistance. [Click here](#) to search for financial assistance programs that are currently available for IBD patients.

**Sometimes my labs come back normal, yet I still don't feel well at all. What can we do as patients to comfortably share with our provider that even though I may not have inflammation, I'm feeling terrible and want to consider changing my treatment?**

It is possible for your lab tests to indicate that your IBD is showing no evidence of inflammation while at the same time still have bothersome symptoms. It may be possible that you may need a change in dose or frequency, a lifestyle change, or an additional medication to keep your symptoms in check. Keeping a record of your symptoms at home and honestly sharing how you are feeling at every visit is extremely important and will help guide you and your physician in the event you do need to make a treatment adjustment. [Click here](#) to access the Foundation's symptom tracker and be sure to bring this with you at every visit.

**Question: When I was first diagnosed, years ago, I was physically examined every time I visited the doctor. Now, my doctor, who is an excellent doctor, only seems to examine me when I have a procedure. Is that the standard now?**

As a patient, you are the ultimate driver of your own healthcare. Though it isn't always easy, it's important to be upfront about your symptoms, personal preferences, and your expectations at each visit. If you do not feel that you are getting the most thorough exam when you visit with your provider – it's important to speak up and share your thoughts and concerns. Shared-decision making is a process where you are actively involved in making decisions around your healthcare along with your provider – this not only includes your treatment plan but all aspects of your healthcare. [Click here](#) to learn more about communicating with your doctor so you can feel confident in advocating for your needs.

## Diet

**Although my doctor continually tells me there is no special IBD diet that works for all patients, is it recommended to consult with a dietitian? If so – how do I go about finding a dietitian who specializes in IBD?**

If you are diagnosed with vitamin and mineral deficiencies or if you struggle with eating or the thought of eating, it can help to speak with a registered dietitian. Your GI or primary care provider may be a good resource to help you locate a registered dietitian in your area. Local/virtual support groups, local Foundation chapter staff/volunteers, and mental health professionals may also be able to connect you as well. You can always connect with the [IBD Help Center](#). The Crohn's & Colitis Foundation's information specialists are available to answer your Crohn's and ulcerative colitis questions Monday through Friday, 9 AM to 5 PM EST. Specialists are available by phone, [email](#), or chat. Call a specialist at 888-MY-GUT-PAIN (888-694-8872).

**How much fiber is recommended for patients with IBD?**

Dietary fiber is essential for health and digestion and can be found in plant-based foods, such as fruits, vegetables, nuts, grains, legumes, and seeds. For some people with IBD, consuming fiber during times when your disease is active may cause abdominal cramping, bloating, and worsening diarrhea. For others, some sources of fiber may actually help with IBD symptoms. It's important to understand the two different sources of fiber: soluble and insoluble. Soluble fiber (found in canned fruit, peeled fruit, bananas, cooked oats, lentils, beans, peas, potatoes, and squash) dissolves in water, forms a gel in your intestines, and can add consistency and formation to your stools. Insoluble fiber (found in fruit with seeds, fruit and vegetable skins, whole nuts and seeds, wheat bran, whole grains, brown rice, quinoa, corn, and green leafy

vegetables) does not dissolve in water, is coarse, and more difficult to digest. Depending on your symptoms, talk to your doctor or a registered dietitian about what types of fiber and the amount of fiber is recommended. For more information on diet and nutrition visit:

[www.crohnscolitisfoundation.org/diet-and-nutrition](http://www.crohnscolitisfoundation.org/diet-and-nutrition)

**Question: Is there any evidence that fermented foods are beneficial for IBD patients?**

Fermented foods have a range of microorganisms that may be beneficial to our intestine and help us digest foods. Common fermented foods like yogurt, kefir (a drinkable yogurt), kimchi, miso, or sauerkraut have beneficial probiotics [healthy bacteria] that can hopefully help reduce gastrointestinal symptoms, such as gas, bloating, and discomfort. Studies on probiotics are limited. In ulcerative colitis, studies suggest there may be a benefit at inducing and maintaining remission. In Crohn's disease, studies are also limited, but prevention and remission has not been associated with taking probiotics. In pouchitis (inflammation of a pouch created using small intestine), studies suggest there may be a benefit in preventing and maintaining remission.

For more information on probiotics visit: [www.crohnscolitisfoundation.org/complementary-medicine](http://www.crohnscolitisfoundation.org/complementary-medicine).

**Question: The Mediterranean diet was discussed as being potentially helpful for patients with IBD. Can raw food like salads be consumed safely? How safe are raw fruits and vegetables for IBD patients?**

Always keep in mind that diets, such as the Mediterranean Diet, are individual and may not work for every patient. However, fruit and vegetables are important sources of many nutrients and IBD patients are encouraged to try a variety of them. Tolerance for eating raw fruit and vegetables may vary. If you do experience discomfort, there are a few things to keep in mind. Removing the skin and seeds and cooking them until tender may help you tolerate them better. If you have trouble tolerating high fiber fruits, low fiber fruit options include bananas, cantaloupe, honeydew, or cooked fruit. As for vegetables, if eating them raw is troublesome, try fully cooked, seedless, skinless, and non-cruciferous vegetables. Good options include asparagus tips, potatoes, cucumbers, and squash. For more information on IBD diets and nutrition, visit:

[www.crohnscolitisfoundation.org/diet-and-nutrition](http://www.crohnscolitisfoundation.org/diet-and-nutrition)

## Pediatric patients and caregivers

**If there is a history of IBD in my family, what is the likelihood of it being passed down to future generations?**

Studies have shown that between 5% and 20% of people with IBD have a first-degree relative, such as a parent, child, or sibling, who also has one of the diseases.<sup>1</sup> The genetic risk is greater with Crohn's disease than ulcerative colitis. The risk of Crohn's disease or ulcerative colitis is substantially higher when both parents have IBD.

1. Reference: Russell RK, Satsangi J. Does IBD run in families? *Inflamm Bowel Dis.* 2008;14(S2):S20-S21.

## **How do you involve your family to build support to help patients with IBD and what is not helpful?**

For kids and teens with IBD, it can be very helpful to have close people, whether they are family or friends that you are comfortable enough with to talk about your IBD. Remember, you only have to share with others what you want to; never feel pressured to share more than you would like to. Your close family and friends are most likely the people you will spend most of your time around, so they will see your highs and your lows. Learn more about talking to family and friends about your IBD [here](#).

### **Question: What would you tell newly diagnosed pediatric patients and their caregivers?**

When your child is diagnosed with [Crohn's disease](#) or [ulcerative colitis](#), you may have a lot of questions, including, "How can I help my child?". It's important to remember that your child can live a full and successful life with inflammatory bowel disease (IBD). Our education resources can help you and your child learn to manage all aspects of their illness. Find them [here](#).

### **Question: What resources do you recommend for teens with IBD who are planning for life after high school, or college? Any tips for dealing with transitioning care, flares, studying abroad, stress of school etc.? Are there support groups, blogs, or young adults who write on this topic?**

There are many topics that teens and college students with IBD will need to be aware of during the transition to young adulthood. [Campus Connection](#) is a place for prospective and current students to find answers to all of their questions about navigating young adulthood with IBD. Topics include [disability services](#), [studying abroad](#), [managing care](#), [coping with stress](#), [preparing for adult care](#) and more. Students can also connect to our online college community by adding themselves to the map and starting discussions with other students who are also affected by IBD. You can check out the map, and other college resources [here](#).

### **Question: How important is it for my child to meet with a dietitian during their treatment journey?**

IBD tends to increase the body's need for calories, nutrients, and energy. Children with IBD may find it hard to maintain adequate nutrition. It can be helpful to speak with your healthcare provider or a dietitian to ensure that your child is getting those nutrients from another source, such as a vitamin or supplement. To learn more about how to help your child manage their diet and nutrition, [see our youth and parent resources](#).

### **Question: When I was a pediatric patient, I had to fight for autonomy. My parents had to tell my doctors that they could speak to me and not them (I was 15). As an advocate, how can I push for shared decision-making in pediatric care?**

While there are many differences between pediatrics and adult care from a clinical perspective, many issues that young adult IBD patients may face are ones that revolve around skills such as independence, and communication. Intentionally preparing for this transition can alleviate anxiety and can get you the care you need sooner. Teens and college students can find more information and tips on transitioning to adult care at our [justlikemeibd](#) and [Campus Connection](#) websites.