

Following an IBD Diagnosis, Knowledge Is Power

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Hearing that IBD diagnosis can cause a whirlwind of emotions.

If you've recently been diagnosed, you might initially feel anxious due to the reality and uncertainty of living with a chronic disease. At the same time, you likely feel relief in finally naming the affliction, the distributor of life, and in being one step closer to regaining some control.

After the shock has worn off and you've gone through the next five stages of grief — denial, anger, bargaining, depression, and testing — you're ready for the last stage: acceptance. Accepting your new normal involves educating yourself about your disease and what to expect from your medical care so that you can advocate for the best quality of life possible while living with a chronic illness.

Education begins with learning disease causes and triggers, the symptoms to look for, and possible treatments and tests necessary to keeping your disease under control and to prevent it from worsening. If you are like me, you probably stopped listening to the doctor after you were diagnosed, as you processed the news, or because you were overwhelmed with information. But even if you were listening, you may want to learn more about your disease.

An excellent IBD resource I discovered a few years ago is the Crohn's and Colitis Foundation. This nonprofit organization was founded more than 50 years ago and is dedicated to working with medical professionals, healthcare providers, and the government to fund and perform scientific research to find a cure for IBD and to advocate for IBD patients. Both patients and

caregivers will find the comprehensive website helpful for finding basic information, such as what IBD is, and for researching more serious topics, such as [managing the cost of IBD](#) and [participating in clinical trials](#). The site also offers resources for [finding support groups](#) and has a [community forum](#) to discuss your disease with others who can relate.

The [Mayo Clinic](#) is another credible resource I've found helpful over the years, especially to check my symptoms and to gain a better understanding of certain tests and procedures associated with IBD. You can also follow the [Mayo Clinic IBD Newsfeed](#) for the latest IBD news and research.

And of course, [IBD News Today](#) covers the latest in IBD research and news, along with publishing columns like this one.

Asking questions is another way to educate yourself and to become a better advocate for your healthcare. Don't be shy about asking your doctor, nurse, or other providers questions about your treatment plan. In fact, bringing a list of questions and a notepad to your appointments should become a regular habit.

The more you understand about your disease, the more you'll be able to work along with your healthcare providers to find the best solutions to fit your individual needs. When the doctor orders a test or procedure, don't just ask how to prepare and what is involved. Have the doctor explain what the purpose is so that you'll be able to comprehend the results and how they may affect your overall health or continuing care.

If you're prescribed a new medication, have your doctor or pharmacist go through the side effects along with what the medication is supposed to do, so that you can determine if it is improving or worsening your condition. Also, don't be afraid to ask if tests or treatments are absolutely necessary or if other options are available.

By asking my doctor questions over the years, he got to know me as a person and not just as a patient. I believe that some of the decisions he made for my medical treatment were based on my personality and lifestyle rather than a one-size-fits-all regimen.

Take note: There's a huge difference between asking questions and questioning your doctor. The former involves taking an active role in your healthcare and developing a respectful relationship with your healthcare team. The latter discounts your doctor's experience and knowledge, which can cause a sense of distrust and puts your health in the middle of a tug of war.

Finally, if your provider refuses to answer questions or if you don't feel your questions or concerns are being addressed or heard, don't be afraid to get a second opinion or change doctors altogether. You and your IBD team will be together for a long time, and you want to be able to trust and work with them.

With continuous research and scientific discoveries, you'll never be able to learn everything there is about IBD. However, staying well informed will help you advocate for your best care and provide a sense of control over your disease and your life.

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