

Crohn's and Fistula Stigmas: Protecting Your Mental Health

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Welcome to Audio Guide Two: A Patient's Guide to Understanding Complex Perianal Fistula. This guide is produced by the Global Healthy Living Foundation and made possible with support from Takeda and Bristol Myers Squibb. I'm Corey Greenblatt, Senior Manager of Policy and Advocacy for the Global Healthy Living Foundation. And today we're talking about Crohn's and fistula stigmas and how to protect your mental health. Whether you or someone you know has a fistula, or even if you think they just might, these audio guides are designed to help you make sense of the symptoms and get the care that you need. Accurate information will help you work together with your healthcare professionals to hopefully have fewer and less severe symptoms. Please remember that a fistula is a medical issue, and always talk to your healthcare team if you have symptoms that bother worry you. In this audio guide, we discuss navigating the stigmas that may come along with a fistula diagnosis and how to support your mental health. Learning that your gastrointestinal symptoms may be more than your typical Crohn's disease symptoms may be confusing and scary. For many people, this information can be hard to process, even after hearing or reading about it more than once. Thinking about fistulas and the possible need for surgery can cause stress, worry and fear. However, a fistula diagnosis can also be reassuring. As you can finally start understanding how to manage, treat and live better with your symptoms. Part of that is caring for your emotional and mental health. The first important piece to remember is that there is a lot of stress that arises when living with a chronic condition like Crohn's disease, and the feelings of frustration and embarrassment are common and normal when it comes to dealing with fistula complications. It can be surprising and stressful to learn about complications like fistula when you already have a lot to deal with. So today we're confronting some of the common stigmas around inflammatory bowel disease and fistula with the truth. A common stigma for people living with inflammatory bowel disease is quote unquote, it's your fault. When it comes to gut health, patients often get blamed for eating poorly and not taking care of themselves. So, let's set the record straight. Crohn's disease is not your fault, and neither are its complications like fistulas. The truth is that inflammatory bowel disease is not caused by poor diet, stress or any other factors that you have total control over. While the exact cause remains unknown, many experts believe that it is due to a combination of your immune system, genetics, and environmental factors. Many people also minimize inflammatory bowel disease as "just a bathroom disease." While frequent and urgent restroom visits can be a hallmark symptom of the disease, it is certainly not the only one. Inflammatory bowel disease is a chronic autoimmune disease in which the immune system wrongly attacks itself causing inflammation in the gut. This has the potential to impact many parts of your life outside the bathroom, like keeping up with your job and social life. Inflammatory bowel disease can also cause problems in the joints, skin, bones, eyes, kidney and liver. And a third common myth, one that is more personal and often targeted at people with IBD, is that they hear that no one will love them or want to be intimate with them because of their disease. The truth is that you have a right to be loved, just like anyone else. And your life is just as valuable. And while it's up to you for when and how much of your disease you disclose, you should feel the support when you do.

So, how do you deal with all these? Knowing the facts is step one. Knowledge is power when it comes to chronic disease and dealing with your health. But it can be hard if you've been living with these stigmas and those around you are perpetuating them. Another thing that you can do is reconsider who is on your healthcare team and find the right providers for you. Whenever possible, it is good to have healthcare from a team from different areas of medicine who work together. Such a team may include a primary care provider, a gastroenterologist, a colorectal surgeon, and a social worker or psychologist. Building these relationships early also means that if and when surgery is needed, someone will be there for you. Additionally, seek out extra support. There are many online support groups for IBD. Making friends in these communities and talking about shared experiences may help relieve a lot of the stress that you may be holding on to. If you're having an especially hard time with your mental health, consider seeing a therapist. While any trained mental health professional can help with depression and anxiety, you may also benefit from working with one who specializes in gastroenterology known as a gastropsychologist. You can ask your doctor if they have one to recommend or search for an expert at romeegipsych.org. While there are no quick fixes when it comes to inflammatory bowel disease, fistula or mental health, know that there is a community out there ready to support you. Thanks for listening to our audio guide on fistulas in Crohn's disease. I'm Corey Greenblatt, Senior Manager of Policy and Advocacy for the Global Healthy Living Foundation. For more information about managing Crohn's disease and fistula symptoms, check out the show notes or visit ghlf.org