

Audio guide 4: How to Describe Your Symptoms to Your Loved Ones

Corey Greenblatt 00:03

Welcome to audio guide four, 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. I'm Corey Greenblatt, Associate Director of Policy and Advocacy for the Global Healthy Living Foundation. And today we'll learn more about the symptoms of fistula and how to talk to your loved ones about them. Whether you or someone you know has a fistula, or even if you think you might, these audio guides are designed to help make sense of the symptoms and get you the care you need. Accurate information will help you work with your healthcare team to hopefully have fewer and less severe symptoms. Please remember that fistula is a medical issue and always talk to your healthcare team if you have symptoms that bother or worry you.

Corey Greenblatt 00:54

Finding out that you have a fistula can be overwhelming for both you and your loved ones. It may feel challenging or embarrassing to talk about your fistula symptoms, but sharing that information can help your loved ones appreciate the impact that Crohn's and fistula has on your everyday life, and it can also help them understand how best to support you. Remember, you only need to share details you are comfortable with. It is your healthcare journey, and it is up to you about when and how to tell your loved ones.

Corey Greenblatt 01:25

Here are a few tips for sharing with the people close to you. Educate, explain to them what fistula is and how it affects your life. Let them know when pain is affecting your ability to take part in activities. And if you need surgery, let them know when so they can help. Encourage open dialogue. Tell them it's okay to ask questions and that you will answer as best you can. Living with a chronic illness can be unpredictable and limiting. When the people you love don't understand or accept how your condition affects you, it can add to your stress. Express your needs. Don't leave them guessing as to what you want. Be clear on what you need from them whether it's something practical, or whether you just need some kind words or a hug. If you need them to just listen, let them know that their support can make a big difference in your journey. Be honest, don't try to hide your condition you are more likely to receive understanding and support if they know what you are going through. Share details wisely. You can explain your basic symptoms and share with others if you have pain or feel uncomfortable, but you don't have to let everybody know everything. Find a few safe people whom you can trust with your intimate details. Some people are better at handling your personal information than others. Don't make a big deal out of it. Fluid leakage, incontinence, or passing gas are all common with fistula. When it happens, be honest and take care of it but don't draw any unnecessary attention to it. And finally, find humor. Laughter relieves stress and puts yourself and others at ease.

Corey Greenblatt 02:57

Another aspect to consider is when. Finding the right time and place to talk about your health with your loved ones is also important. You don't want the conversation to be rushed or stressed. Here are some ways you can create an atmosphere of dialogue. Ask them when it's a good time to talk. Be courteous of their time and patient with interruptions. Set boundaries on the conversation and be aware of your listener. Stick to your own feelings and avoid judging others.

Corey Greenblatt 03:27

While there are no quick fixes when it comes to inflammatory bowel disease or fistula we hope this audio guide helps you feel more comfortable with sharing your health journey with your loved ones. Thank you for listening today to our audio guide on fistulas in Crohn's disease, I'm Corey Greenblatt, Associate Director of Policy and Advocacy for the Global Healthy Living Foundation. For more information about managing Crohn's disease and fistula please visit ghlf.org/fistula-support.

Narrator 04:00

Be inspired, supported and empowered. This is the Global Healthy Living Foundation Podcast Network.