
When to Talk About Crohn's Disease

Sharing information about your Crohn's disease with people you're close to can make life easier — find out how.

By Connie Brichford

Medically reviewed by Lindsey Marcellin MD, MPH

Crohn's disease affects the digestive system, and living with Crohn's disease can mean frequent trips to the bathroom. But discussing bathroom functions are somewhat of a social taboo, and for some people, Crohn's disease symptoms can be a source of embarrassment.

There are a number of reasons, however, why people with Crohn's disease might want to consider sharing information about their illness with family, friends, teachers, and even co-workers and bosses. Frank J. Sileo, PhD, a New Jersey-based psychologist, says, "Telling someone about your Crohn's is a personal choice." While you don't have to tell anyone about your experiences with Crohn's disease, you may find that it is in your best interest to do so.

Some reasons for explaining your Crohn's disease to others include:

Easing the Way at School

Students at publicly funded schools, from kindergarten through graduate school, are covered by Section 504 of the Rehabilitation Act of 1973 and other non-discrimination laws. "As a person with Crohn's, you are entitled to certain accommodations under the law," Sileo says. "If you are a student and have Crohn's, you may have a 504, which allows students certain privileges and accommodations in school."

In general, students may find that good communication with teachers makes their time at school easier. Students with Crohn's disease may have to leave class often, either to visit the bathroom or get their medications from the school nurse. The more teachers know about this in advance, the less likely they are to question a student when he or she needs to leave class.

Additionally, missed class time and extended absences due to flare-ups of Crohn's disease symptoms can sometimes result in students falling behind. If teachers are aware a child's illness, they will be better able to help in getting them back up to speed and in making up any missed schoolwork.

On-The-Job Understanding

"In the workplace, you are also covered under the law," Sileo says. The Americans with Disabilities Act of 1990 prohibits workplace discrimination and also requires that reasonable accommodations be made for applicants and employees with disabilities. You may choose to tell your managers about your Crohn's disease so that they can make arrangements that will help you succeed at your job. This could include moving your workstation to an area that's closer to the bathroom or allowing you to work from home

when your symptoms flare.

And remember, you have the law on your side. If you ever feel that you are being discriminated against at work or school, there are places to get help. Many organizations provide free or low-cost legal services, advice, and advocacy to people with disabilities.

Finding Support Among Friends

"I believe in educating others about Crohn's disease — what it is and what it isn't," Sileo says. "Many people think that it's just about diarrhea. While diarrhea is a huge part of some individuals' Crohn's pain, nausea, fever, joint pain, etcetera, are also part of it."

If your friends or family don't know about the wide range of symptoms you experience with Crohn's, they may not understand when you have to decline invitations because of an attack or sudden flare of your symptoms. Plus, with knowledge comes increased understanding. "With friends, telling them about the Crohn's will help with the support factor," Sileo says. "Explaining the disease to them keeps them from thinking, 'Oh, you're just stressed out,' or, 'It's all in your head.'" As with teachers and bosses, the more your friends learn about the nature of Crohn's disease, the better able they will be to support and help you in useful ways.

The Bottom Line: It can be difficult to strike the right balance between maintaining your privacy and revealing enough to get the support and help you need for Crohn's disease. But ultimately, deciding who to tell, and when to tell them, is completely up to you. You don't have to tell everyone all at once. Consider starting with closer friends and family so that you can get comfortable approaching the conversation and sharing information about your disease with others.



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