

Quality of Life Discussion Guide

Below you'll find a summary of your answers. Print this sheet and take it with you to your next doctor appointment. It can show you and your doctor how IBD is affecting you, if you could be doing more to manage it, and what your next steps should be for seeking support and taking charge.

1. Do your IBD symptoms interfere with your daily responsibilities or tasks?

(e.g., frequent bathroom breaks or absences at work or school, distraction due to painful flare-ups)

Always

Often

Sometimes

Never

The best way to cope with IBD is to seek effective treatment. Work with your doctor to create a treatment plan that's right for you. If you're not satisfied with your current treatment, talk to your doctor about other options.

2. How does IBD make you feel emotionally/mentally?

Isolated

Sad

Stressed

Embarrassed

Depressed

Anxious

Helpless

Frustrated

Overwhelmed

Guilty

Angry

I don't let IBD get me down

None of the above

It's important to understand that these feelings are perfectly normal. And the better you can manage your IBD symptoms, the better you'll be able to cope with these feelings.

3. How does IBD affect your relationships?

I've distanced myself from family or friends.

I find myself avoiding coworkers, and even social and professional opportunities at work or school.

I can't be as intimate as I'd like to be with my loved one.

I have to miss out on some of my kids' activities.

My family feels helpless; they don't know how to support me.

Sometimes the pain and frustration of IBD is overwhelming, and I take it out on my family.

IBD has made my relationships stronger

None of the above

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4. To avoid public embarrassment and uncomfortable situations, you often:

- Avoid going out
- Skip meals to avoid symptoms
- Decline social invitations
- Plan an “escape” in case a flare hits
- Map out the nearest public restrooms
- Avoid traveling
- Carry an extra change of clothes
- I don't get embarrassed by my IBD
- None of the above

It's inevitable that at some point, you'll have flare-ups while you're away from home. But that doesn't have to stop you from living your life. Remember, an effective treatment plan that helps you manage IBD symptoms is key. So talk to your doctor about your treatment options. Also, for peace of mind, be prepared before heading out for the day or traveling.

5. Where have you turned to for support in coping with IBD?

- Doctor
 - Online support communities
 - Therapist
 - Family and friends
 - Local support groups
 - I'm not seeking support for coping with IBD
 - Other
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6. Starting today, what will you do to help control symptoms and take charge of IBD?

- Talk to my doctor about a treatment plan that helps me better manage my IBD symptoms
- Educate my family and friends about IBD so they better understand what I'm going through and how to support me
- Seek support from a therapist
- Join a local support group
- Join the CCFA Community to learn more about living well with IBD, and to connect with people like me
- Become an advocate for myself and others living with IBD