

# **Fact Sheet**

## Sex, Intimacy, and IBD

For people with inflammatory bowel disease (IBD), sex and intimacy can be a difficult subject to discuss. Here are some of the frequently asked questions from patients about sex, intimacy, and IBD.

#### What is the different between sex and intimacy?

Although these words are often used interchangeably, sex is the physical act of intercourse whereas intimacy is the emotional connection you have with someone close to you.

#### How can having IBD affect one's intimate or sexual relationship?

Not only can IBD impact your physical and emotional health, but it can impact one's sexuality and relationships as well. Although most IBD patients are physically capable of being intimate, the disease course, medication, surgery, and symptoms can sometimes hinder one's desire to have sex. Certain medications, surgeries and disease symptoms can affect your sexual drive and potentially cause erectile dysfunction in men. However, through proper disease treatment and open communication with your partner and your healthcare providers, IBD patients can engage in healthy, intimate, thriving relationships.

#### What does the research say?

Unfortunately, sexual activity and IBD have not been thoroughly researched to date and there is a need for more research to understand how IBD can impact sex, intimacy, and sexuality (a person's behaviors, desires, and attitudes related to sex and physical intimacy with others.). Here's what we know from research so far:

- Approximately 40% of IBD patients say that their disease has prevented them from pursuing intimate relationships.<sup>1</sup>
- Almost 70% of IBD patients report impaired body image. This is more prevalent in women (75%) than men (51%). This is also more prevalent in patients who have had surgery (81%) versus non-surgical patients (51%).<sup>2</sup>
- Sexual dysfunction rates in patients with IBD are higher than the general population. In IBD patients, about 52% of women and 20% of men report experiencing sexual dysfunction, as compared to 30% and 5% of the general population respectively. 3
- Overall, IBD patients report a decreased sexual quality of life as compared to their healthy counterparts. 3

#### How can I talk to my partner about sex?

One of the issues IBD patients face most is not being able to be as spontaneous in their sexual activity as their partners. Having IBD may require more planning and communication before engaging in sex. Talking to your partner about sex can feel challenging, but it can help you both feel more comfortable. If you don't know how to bring it up in conversation,

find something you can use for a conversation starter like an article, this <u>facebook live</u>, or a book. Remember that, although it's important to keep an open forum for discussion with you partner, when it comes to your IBD, you only have to share what you are comfortable sharing.

#### How do I bring up sex with my healthcare provider?

You may have some specific concerns about sex and IBD, and it can be hard to discuss everything going on with your IBD in a short visit. Talk to your healthcare provider or ask to be referred to a psychologist, sex therapist, or another provider than has expertise in this area. If your healthcare provider is not familiar with any experts in this field, you can search for a provider using the <a href="ROME Foundation GastroPsych Directory">ROME Foundation GastroPsych Directory</a>.

#### Is it okay to have sex when flaring?

This can depend on several factors as every IBD patient experiences flares differently. There are no written rules, but for patients with significant symptoms, such as abdominal pain, bloody diarrhea, or currently taking certain medications, specifically medications that are used rectally, participating in sexual activity can be more challenging. For many patients, symptoms, like pain and fatigue, can be a barrier to engaging in sex. If you aren't feeling great, this can have an effect on your mood. Don't be afraid to bring up your concerns with your healthcare provider. Perhaps one of your desires is to be more intimate with you partner, or to feel well enough to do things you enjoy. This is an important consideration for your healthcare team as your work together to establish an approach to treatment that allows you to achieve all your goals.

#### Is it okay for IBD patients to engage in anal sex?

When engaging in anal sex, IBD patients in remission should consider the same precautions that would apply to any other sexual intercourse. For patients who have severe disease, flaring proctitis (inflammation in the rectum), bloody diarrhea, or currently using rectal therapies (such as an enema or suppository), you may want to avoid anal intercourse temporarily. Remember that being informed about what is going on in your body and open communication allows you to make the best decision for your care.

#### Is it okay for patients to engage in sexual activity pre- or post-surgery?

Your healthcare provider will discuss how your upcoming or past surgery might affect your body. Prior to surgery, speak with your healthcare provider about any concerns such as sexual function or fertility. If you are recently recovering from surgery or planning to undergo a procedure, such as j-pouch construction or others, have an open discussion with your surgeon about when your body may be ready for sexual activity. If you have a partner, you may wish to include the conversation to help them understand what you can or cannot do. Becoming as well-informed as possible will make you feel better about your upcoming operation.

You might find it helpful to connect with other patients who have undergone similar procedures and their experiences with sexual activity after recovery. The Crohn's & Colitis Foundation offers many support resources including the <a href="Power of Two program">Power of Two program</a>, and patient support groups.

### What if I don't feel comfortable with my body?

There may be moments when you are not able to be as physically active and are feeling uncomfortable with the way your body looks. That is completely normal! It's important to take some time to reflect and decide what activities you are comfortable participating in based on how you feel. Seeking help in the form of counseling or talking to other IBD patients can help you feel better about your body image.

#### **References:**

- 1.LeenhardtR, Rivière P, Papazian P, et al. Sexual health and fertility for individuals with inflammatory bowel disease. *World J Gastroenterol*. 2019;25(36):5423-5433. doi:10.3748/wjg.v25.i36.5423
- 2. Rosenblatt E, Kane S. Sex-Specific Issues in Inflammatory Bowel Disease. *Gastroenterol Hepatol (N Y)*. 2015;11(9):592-601
- 3. Sexual Quality of Life in Inflammatory Bowel Disease: A Multicenter, National-Level Study" published in the August 2019 issue of Inflammatory Bowel Diseases by Joana Roseira, MD, Fernando Magro, PhD, MD, Samuel Fernandes, MD, Carolina Simões, MD, Francisco Portela, MD, Ana Isabel Vieira, MD, Marta Patita, MD, Carina Leal, MD, Paula Lago, MD, Paulo Caldeira, MD, Tânia Gago, MD, Pedro Currais, MD, Cláudia Camila Dias, PhD, Mafalda Santiago, Sandra Dias, and Helena Tavares de Sousa, MD; on behalf of GEDII.
- 4. Crohn's & Colitis Foundation Facebook Live- Sex, Intimacy and IBD

#### Other resources:

- United Ostomy Associations of America: <a href="https://www.ostomy.org/sexuality/">https://www.ostomy.org/sexuality/</a>
- Sex Ed for Social Change: <a href="https://siecus.org/">https://siecus.org/</a>
- American Association of Sex Educator, Counselors and Therapists: <a href="https://www.aasect.org/">https://www.aasect.org/</a>
- American Association for Marriage and Family Therapy: www.aamft.org
- Rome Foundation GastroPsych Directory: https://theromefoundation.org/rome-gi-psych-committee/

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May 2021