

Sex, Intimacy and IBD

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The slides have been reviewed for off label information by Ferring Pharmaceuticals

@ibdpassport

Disclosures

Herewith declare the following paid or unpaid consultancies, business interests or sources of honoraria payments for the past three years, and

anything else which could potentially be viewed as a conflict of interest:

- Galapagos UK: Consultancy work
- Takeda Pharmaceuticals: Consultancy work
- Sandoz: Paid Lecturing

Question to the audience!

Do you proactively bring up the topic of sex with your patients?

1. Yes



2. No, I would always wait for them to bring it up

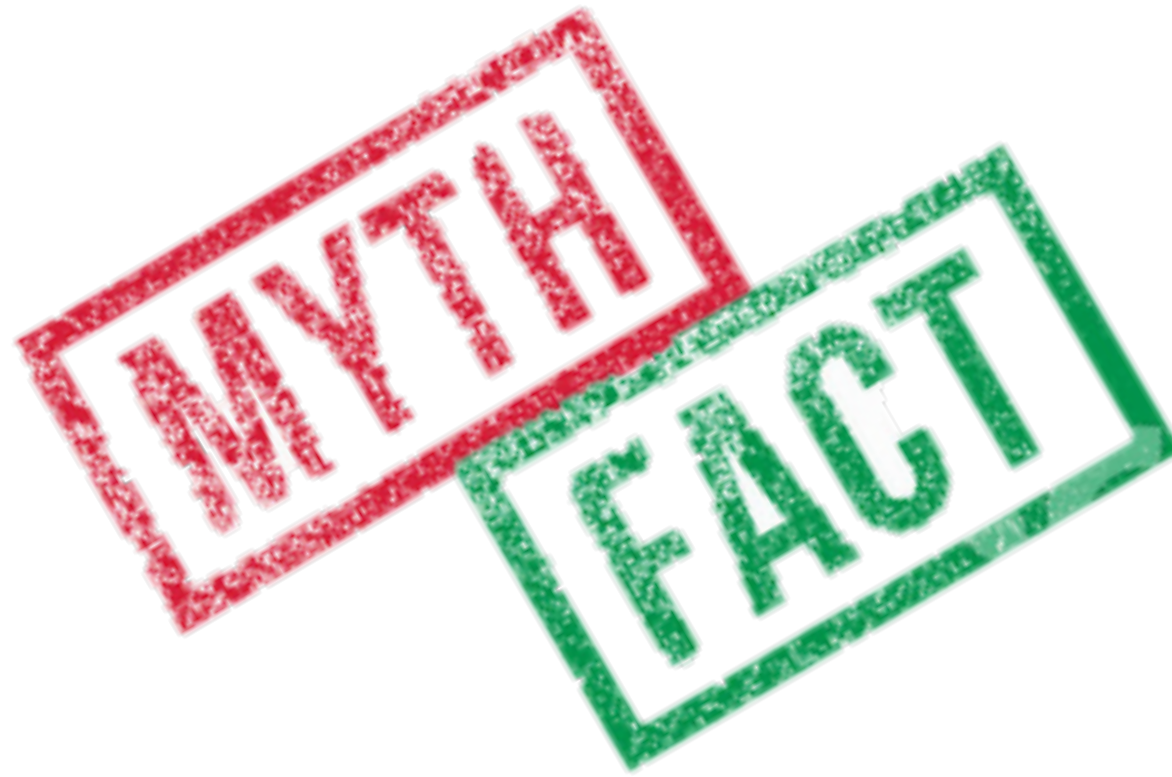


3. Sometimes

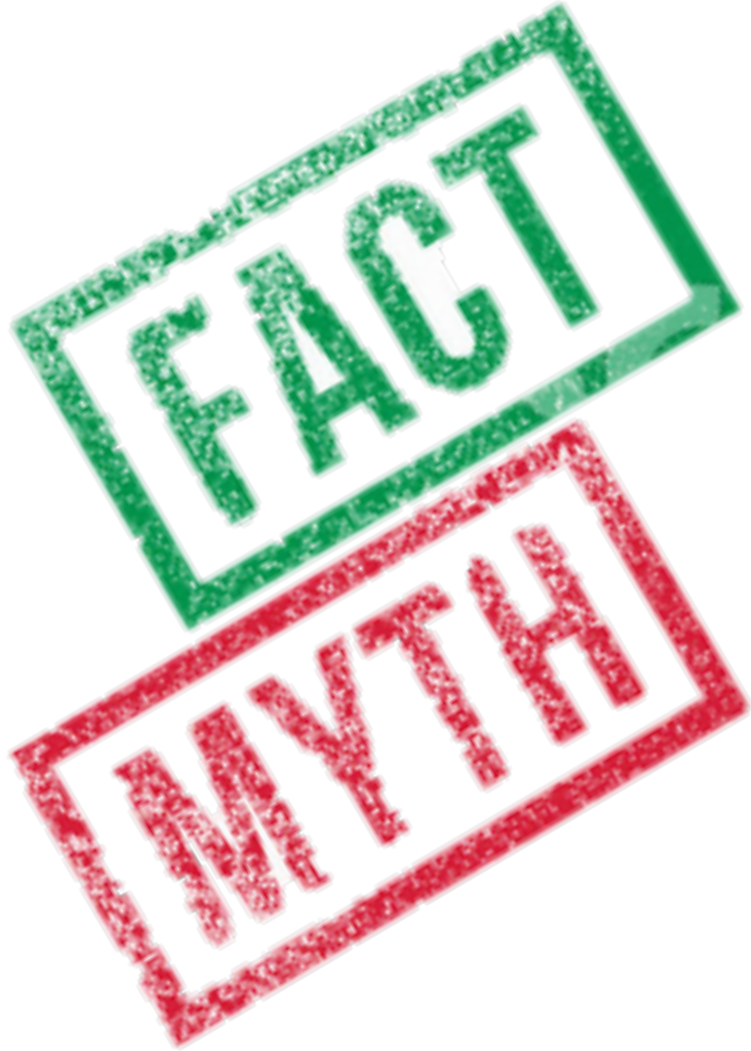


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IBD impacts the
body image of ~50%
of patients



IBD impacts the body image of ~50% of patients



- A survey of >200 patients with IBD found that 51% of men reported impaired body image...
- ...but this figure rose to 75% in women surveyed.

Patients will bring up the
topic of *sex* with their HCP if
it's important to them



Patients will bring up the topic if it's important..



- <1 in 5 patients or HCPs* report having discussions on the impact of IBD on sex^{1,2}
- In a recent qualitative survey, patients with IBD reported sexual issues can be ignored by HCPs or handled badly³
- The study also highlighted the need for holistic patient care...
- **....this includes talking about sex!**³

Therapies for IBD can impact sex



Therapies for IBD can impact sex



- These are a few different ways that IBD therapies can impact sex:
- Steroids can affect sexual satisfaction, libido and body image
- Surgeries may mean certain sexual positions are painful or even impossible (sometimes in the long-term)
- Other therapies may impact fertility

All gay men
have anal sex



All gay men have anal sex



- In a US study of gay and bisexual men, **only 37.2% reported anal sex during their most sexual encounter¹**
 - 72.7% reported oral sex and 68.4% reported partnered masturbation¹
- Another US study found that >20% of heterosexual men (25–49 yo) or women (20–39 yo) reported anal sex in the last year²

**Patients with a stoma always
have more difficulty with sex**



Patients with a stoma always have more difficulty



- Research has found that patients with a stoma report higher levels of libido and sexual satisfaction after surgery
- This may be because they no longer have many of the symptoms that previously troubled them
- **HOWEVER**, there are some specific sexual issues relating to surgery, which we will be discussing in the next session...

Ice breakers



Question to the audience!

If you do raise the topic of intimacy in clinic,
how do you start the conversation?

Ice breakers

Top tips:

- Patients are asking these questions
- Normalise the conversation
- You don't need to be an expert!
- Extensive sexual function questionnaires¹
- Symptoms can be a opportunity to discuss

1. Grover & Shouan (2020), Journal of psychosexual Health, 2, 2, 121-138



crohns_colitis_questions



Is it safe to have anal sex with Crohns?



Crohn's & Colitis UK Forum

Kerry Watkins · 27 Jul 2018 ·

I know this probably isn't the place for this, but I feel too embarrassed to talk to my friends and family..

I'm feeling really low and sad, just had an argument with my boyfriend about our sex life! He says it's got boring and we don't do it enough! I do agree we don't have it a lot but I'm always so tired I can never be bothered! My energy levels are always scraping just above empty I swear!

@ibdpassport

Fatigue

Top tips for patients:

- Arousal is harder when you are tired: give yourself permission to dedicate time to rest and recovery¹
- Make time to connect¹
 - Think about what time in the day works best for you and your partner
- Explore different kinds of intimacy and self pleasure¹
 - Sensate focus is a type of therapy comprising exercises that refocus thoughts on intimacy rather than sex (this is usually facilitated by a sex therapist)^{1,2}
- Consider sex toys¹
- Consider other sources of stress in your life and introduce exercise¹
- There are some useful resources online³

1. Weiner et al. *Sexual and relationship therapy*. 2014;29:307–19. 2. Fatigue in IBD. Available at: <https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/fatigue-ibd..> 3. Fatigue in IBD. Available at: <http://www.fatigueinibd.co.uk/questionnaire>



The first ever fatigue rating scale for IBD

In-depth qualitative interviews with our study volunteers confirmed that fatigue is a big issue with a severe impact on many areas of life. They also confirmed a need for a tool to measure fatigue, to enable people with IBD to discuss fatigue with their health care professionals and test interventions and treatments.

Fatigue scales have been used in many other conditions to help patients and doctors measure levels of fatigue. Before this research study there had been no fatigue scale for people with IBD.

Our fatigue scale – which can be accessed and scored below – will enable people living with IBD to:

- self-assess their fatigue and the impact it has on their lives
- more easily raise their fatigue symptoms with healthcare professionals

Give now

Join us

Fatigue & IBD

10 Tips for Managing Fatigue

It's like being hit in the face with a wave of heaviness.

@ibdpasport

Man problems

A man in a dark shirt is seen from the back, looking out at a vast, blue mountain range under a clear sky. The image is part of a presentation header.

Important info:

- There is a variety of treatments available for men with erectile dysfunction – these include vacuums, creams, pills and injections
- Ask about relationship status
- There is often a psychosexual component, due to low self-esteem or relationship status, that should be addressed – this adds many layers to an already complex issue...

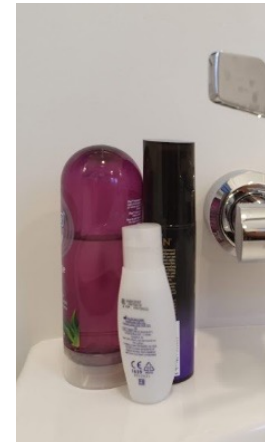
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Woman problems



Top tips for patients:

- Lube can make some positions more comfortable
- Consider R/V fistula
- 80% of women orgasm from clitoral stimulation, so self-pleasure and activities that aren't penetrative should be considered
- For leakage consider using:
 - Menstrual pads
 - A towel on the bed
 - Using wipes to freshen beforehand



Relationship impact: useful resources



Sex and the Single Ostomate

So You Have an Ostomy

Individuals with ostomies have proven that they can achieve anything they desire. An ostomy alone is not a deterrent to any activities you are otherwise capable of and that includes your social life.

Whether a person desires companionship, active participation in sex, or a serious romance leading to marriage, how one's surgery will be accepted by a potential partner or friend is a normal concern.

Body image is the way we see ourselves in the mirror and like to imagine our appearance. Although the change seems so great to oneself, most others do not see the ostomy as changing in any major way the person they love. Harmony within oneself precedes harmony in a relationship.

Sharing the News

1. **Whom.** You can choose whom you want to tell. Sexual partners will naturally have to be told because, covered or uncovered, the stoma or pouch will be apparent during intimate moments. You should tell a prospective marriage partner, because being open and honest is important to the success of any marriage. In addition, the reaction to your disclosure gives a good indication of the person's feelings about the whole you.
2. **When.** You can pick your time to tell but it seems better to tell early in a relationship. This not only relieves your anxiety, but also if there is an adverse reaction the letdown is not as harsh as it might be later. Most people prefer to tell at a time when there is a calm and understanding mood with their partner. Do not wait until "discovery is imminent."
3. **What.** When you explain the surgery, do it clearly and confidently, with self-assurance. Start with a simple explanation. You need not be too detailed and technical at this point. Emphasize that this type of surgery was necessary and that managing your ostomy does not interfere with your activities and enjoyment of life.

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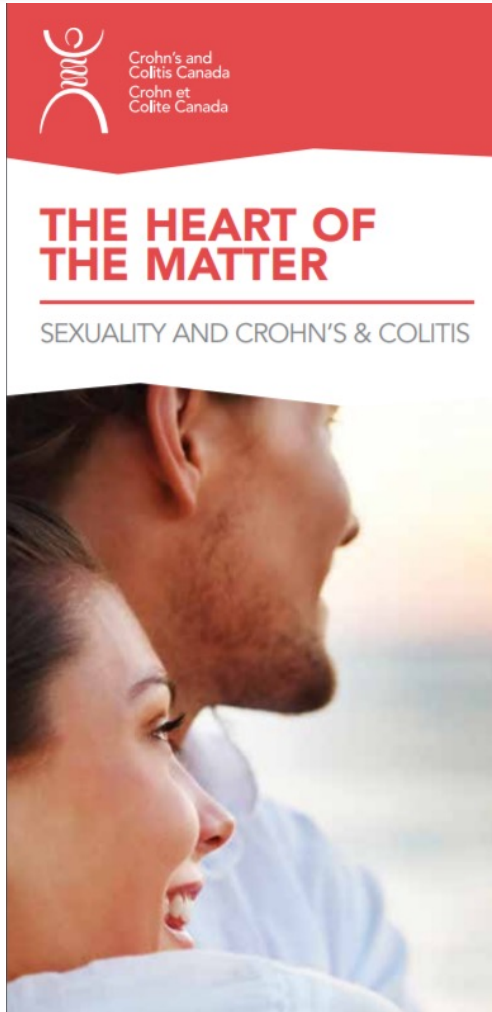
Improving health services

Healthcare Professionals

Sexual Relationships and IBD



Home > About Crohn's and Colitis > Our publications > Sexual Relationships and IBD



DIGESTIVE HEALTH > INFLAMMATORY BOWEL DISEASE > SUPPORT & COPING

Advice for Partners of People With IBD

✓ Medically reviewed by [Carly Snyder, MD](#) on November 06, 2019 | Written by [Amber J. Tresca](#)



More in Inflammatory Bowel Disease

Support & Coping

Diagnosis

Living With

Being married to someone who has [inflammatory bowel disease \(IBD\)](#) is going to have a certain amount of ups and downs. This is no different than any other relationship, but [Crohn's disease](#) and [ulcerative colitis](#) can bring some unusual situations. Here is some advice on how you can work together to have a loving, rewarding relationship, despite the IBD.

Telling Others About Your Spouse's IBD



When Your Partner Has Crohn's Disease



As the partner of someone who has a long-term condition like Crohn's, you'll see their ups and downs with the disease. You want to be there for them, but also respect their decisions about how they handle it.

The physical symptoms they may get include bouts of cramping, [mouth sores](#), [fatigue](#), [fever](#), and [diarrhea](#). It can also trigger emotions like fear, embarrassment, or feeling like the condition is a burden for you, too.

Of course, [Crohn's](#) isn't contagious. You can't catch it from your partner. But it can affect you and your relationship. Whether your partner's in an active phase

- Sex and the single ostomate. Available at: <http://www.ostomyinternational.org/Facts/Sex%20and%20the%20Single%20Ostomate.pdf>. 2. Sexual relationships and IBD. Available at: <https://www.crohnsandcolitis.org.uk/about-crohns-and-colitis/publications/sexual-relationships-and-ibd> 3. The heart of the matter. Available at: http://crohnsandcolitis.ca/Crohns_and_Colitis/documents/english-brochures/2017-Heart-Matter-EN-LR.pdf. 4. Advice for Partners of People with IBD. <https://www.verywellhealth.com/staying-married-to-someone-with-ibd-194253> 5. When your partner has Crohn's disease. Available at: <https://www.webmd.com/ibd-crohns-disease/crohns-disease/crohns-disease-and-relationship>

Summary

- Bring up the topic and normalize the conversation
- Signpost patients to resources that can help them



9,656
Posts

18.6 k
Followers

1,675
Following

Crohn's and Colitis Q&A

Community

Send me your questions through DM and I will anonymously post them. Click on the link below to share your IBD story! #IBDWarriors 💪💜
docs.google.com/forms/d/1JSyV1tXJr95CQsx_WgJ...
Followed by juliempalumbo, shithappensIdn and 87 others

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About Crohn's & Colitis Support for You Living with Crohn's & Colitis Research Ways to Give Get Involved

There will be some concerns to discuss and issues that may require adjustment. Those issues may include symptoms, treatment approaches, medication and surgery – as well as how Crohn's or colitis might impact such psychological factors as self-esteem, fatigue and depression.

Get Started

IN THIS SECTION

Mind-Body Connection

Medications and
Intimacy

Surgery and Intimacy

Feelings: Yours And
Your Partner's

Starting A New
Relationship

Tips to Help with
Intimacy

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Now for the patient perspective...

15th National IBD
Nurse Forum 2021

EVER INCREASING CIRCLES THE EVOLUTION OF THE IBD NURSING ROLE

FERRING

PHARMACEUTICALS

