

THE HEART OF THE MATTER

SEXUALITY AND CROHN'S & COLITIS



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Human beings are sexual beings. We live, we love, we have intimate relationships and some of us will have children. Our spirits are nurtured through our relationships, and that includes relationships of a sexual nature.

This doesn't automatically change now that you or someone you care about has been diagnosed with Crohn's disease or ulcerative colitis. 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.

Crohn's and Colitis Canada is here to help.

WHAT IS NATURAL?



When dealing with a chronic condition such as inflammatory bowel disease (IBD), which includes both Crohn's disease and ulcerative colitis, it is quite common to experience ups and downs over the course of your life. Before we discuss specific issues related to Crohn's and colitis, it's important to keep in mind that many people who don't have lifelong conditions see natural changes in their levels of desire and sexual activity over the course of their life.

How you feel is natural for you at this point in time. Yet many things affecting your level of desire can be managed – as can effects on self-esteem. Learning more about your disease is an empowering process that can give you a sense of control over your health.

In specific terms, physical intimacy could be affected by; how long you've lived with Crohn's or colitis, the treatment(s) you are on, whether you are experiencing a flare-up, and/or your specific symptoms. Here we will discuss what you can do to manage such occurrences.

SEX IS GOOD FOR YOU

TACKLING THE ISSUES

Sex has many health benefits. Research into the mindbody connection shows that what we feel emotionally can impact us physically and vice-versa. The positive emotions experienced in intimate sexual relationships could help us feel good physically as well.

In addition to the positive effects of intimacy in a caring relationship, research has shown that the benefits of regular sex include:

- Mood improvement
- Relief of depression
- Stress relief
- Increased self-esteem and sense of well-being
- Higher levels of the hormone oxytocin, which is linked to increased feelings of happiness and improved sleep
- Increased levels of endorphins, which help reduce overall sensations of pain

How Your Feelings Are Affected

The physical symptoms of Crohn's and colitis may impact your emotional state, causing fatigue, apathy and potentially even depression. Depression can reduce feelings of self-worth or desirability. The good news is that some of these issues can be treated, both independently and with your health care team.

Being in the moment can change the way you look at situations, helping to create a more positive mindset. Pay attention to what you say to yourself about your diagnosis: are you kind to your body or do you criticize it? Do you demand more from yourself than you are physically able to do? Just as you would to a good friend, celebrate what your body does despite Crohn's or colitis. When you see your body in a positive way, you will feel good about your body, and this will create opportunity for intimacy.

It is said that comparison is the thief of happiness: don't compare yourself to others, instead focus on the things you can do and the positive relationships you have with others, including your intimate partner.



Feelings - Yours and Your Partner's

Your physical and emotional feelings are important, but it's critical to remember they aren't the only reality. You may begin to feel unattractive, especially if you have experienced a lot of pain, fatigue or several trips to the bathroom due to your Crohn's or colitis today. However, your partner's desire to be with you may not be impacted by the things you experience as unattractive. While you focus on a negative concern, your partner is focusing on the incredible things that make you YOU.

Don't discount his or her desires or need to be intimate with you. Their emotions and desires are important as well, and deserve recognition just as your own do. By respecting each other's feelings and experiences, you build rapport and trust while creating a nonjudgmental relationship that encourages communication and honesty. Physically, you may feel you cannot do a specific act, but emotionally, you may be able to be intimate in a way that meets many of your partner's needs.



Physical Complications of Crohn's and Colitis

Many people are familiar with the nausea, diarrhea, abdominal cramping and vomiting that are often part of living with Crohn's or colitis. Long-term partners will be familiar with them too. Another physical symptom of Crohn's or colitis are fistulas, which are "tunnels" of infection that can develop in the intestine and burrow their way to the skin or a neighboring organ. If the fistula is in the vaginal or anal areas it could cause pain during sex due to tearing.

Depending on your physical symptoms, it might be something you and your partner – and your doctor – can manage together over the short and/or long term. Speak openly and honestly with your physician when you meet, and take the time to describe how the symptoms affect intimate acts in detail. Your doctor may have some suggestions.

In the short term, on a romantic date with your partner, assess what you feel you can do and discuss with him or her. You may suspect that your partner will settle for nothing less than sexual intercourse, but your partner may be open to adapting to what you can do at that time. Discuss sexual activities openly and honestly and invite him or her to share their thoughts and desires with you too. Sitting and touching can help the conversation.

Also, don't forgo intimacy completely; activities such as kissing, hugging, caressing each other and body massage could help you feel better physically. Get that mind-body connection working for you! There is a lot you could do with your partner outside of sexual intercourse (penetrative sex). Being willing to explore and engage in other types of physical intimacy could increase your desire and improve your self-esteem, making you less hesitant to be intimate.



Medications

Steroids are a valuable tool in treating Crohn's and colitis flare-ups. Unfortunately, they may also have a dampening effect on sexual drive as well as sexual function in some people. In addition, the weight gain associated with steroids may affect the way you feel about your image.

Fortunately, most people are not on steroids for prolonged periods of time and steroid-related decrease in desire is temporary. If you are on steroids for long periods of time, talk to your doctor about the dose and the effect on your desires.

Sometimes antibiotics are prescribed for Crohn's or colitis treatment and occasionally these cause a vaginal discharge in women. Most often, the discharge is normal and will not pose a risk to anyone or a deterrent to sex. Occasionally, antibiotics cause a yeast infection: if you suspect you have one, treat it early.

Surgery

Surgery is sometimes necessary to treat certain conditions of Crohn's disease or ulcerative colitis.

Some surgical procedures could result in an ostomy (an opening of the large intestine onto the skin of the abdominal wall) and an ostomy bag for the collection of feces. Please see our booklet "The Cutting Edge" for more specific information on Crohn's disease, ulcerative colitis and surgery.

You may see your body differently if you have an ostomy bag. Some people experience self-consciousness and embarrassment. You may experience feeling less "sexy" or fear that the bag may dislodge or leak during sex. These feelings are normal at first, but manageable.

We know that for many people sexual activity actually increases after they have had an ostomy because their health is greatly improved after surgery. With better health comes increased sexual drive. For many couples, the presence of an ostomy is not a deterrent to a fulfilling sex life at all!

For women, the removal of the large bowel and rectum (known as a total colectomy) can sometimes result in pain during intercourse (known as dyspareunia) because the removal of the rectum causes organs to re-position. Fortunately, this is a temporary condition and pain will usually fade. Some people also find that emptying the ostomy bag prior to sex helps decrease the pain.

TALKING WITH NEW PARTNERS

So far in this booklet, we have assumed that you have known your partner for a while. But what happens if you are starting a new relationship? When do you tell someone about your condition and about the challenges you face? How do you tell them about your ostomy or your fistula?

Two old adages come to mind: "Timing is everything" and "Honesty is the best policy".

Trust your instincts as to the "when" – some people lead with this information and others wait until they've established a connection to share health information. Choose the approach that works for you but don't wait too long or, as your emotional connection builds, your fear of rejection may also increase and become a source of anxiety.

Whenever you do decide to share your condition with someone, be straightforward. Discuss the facts surrounding your diagnosis and your current health status. Answer their questions simply and honestly. While many of us know that most long-term relationships will include health challenges in at least one partner at some point, some people may not be ready at this stage in their life to consider that element in a relationship.

If you pursue a sexual relationship after explaining your health situation, appreciate the shared values that helped form your relationship (again, positive mind-body connection!). If, however, the person you are getting to know has a negative reaction to your condition, accept that it is better to find out earlier in the relationship rather than later. Don't let his or her decision impact your self-esteem: you simply met someone with whom you were incompatible.

YOUR BRAIN IS THE MOST IMPORTANT SEXUAL ORGAN

All of the above factors can play a role in your selfimage and your sex drive. Yet your own thoughts and emotions play a much bigger role in how you perceive yourself and how you feel physically, as well as your capacity for sexual arousal and desire.

Skin is the largest sexual organ – touch is beautiful. But your brain is the most important sexual organ. Your sense of humour and your passion for life could make you as sexy as a Hollywood star. Discuss with your partner what each of you finds arousing and what your enjoy, individually and together. How you think about yourself, with or without the challenges of Crohn's or colitis, is more important than your body's physical condition. Your feel-good thoughts can help stimulate feel-good emotions, leading to positive sexual experiences that again stimulate your thoughts and emotions.



TIPS FOR INCREASING SHARED PLEASURE

You and your partner would like your intimate times to be as pleasurable as possible. Here are some suggestions to consider:

- If intercourse is not on the agenda at this time, try alternatives. Hugging, cuddling, kissing, caressing, massage - these stimulants provide ways of expressing your love for your partner without actually having sexual intercourse.
- Ensure you are well-rested, eat well and exercise regularly. A healthy and active lifestyle contributes to a positive frame of mind as well as a healthier body.
- Try a lubricant to enhance sexual experience and reduce the possibility of anal or vaginal tearing. This is particularly important if you have fistulas. Lubricants come in different formulations that include water-based, oil-based and silicone-based. Be careful as oil-based gels may cause an allergic reaction in some people and make latex-based condoms ineffective. Read the labels carefully and be sure to try a test spot before you use one.

- If you have an ostomy, empty the bag before intercourse. This minimizes the possibility of leakage, giving you peace of mind and leaving you free to be in the moment.
- Although it may not be spontaneous, try to plan your intimate moments for a time of day when you know you are feeling the best. For example, if the evening is your most energetic and most symptom-free time of day, schedule time with your partner then.
- Experiment with different sexual positions. Some positions will be more comfortable and therefore more pleasurable than others. Communicate honestly about what works for you (and your partner) and what does not.
- Avoid alcohol and tobacco. Both of these substances can affect your sexual performance and, in some cases, aggravate your symptoms.



COMMUNICATE!

We encourage you to communicate! With your partner, your doctor, your health care team, your friends, your family, your support network – talk to them authentically and honestly about what is on your mind.

Genuine communication between you and your partner is an absolutely essential ingredient to having a mutually satisfying sex life. It may take courage at the beginning, but talking becomes easier with practice – for both of you. Sex starts in your head: thoughts and feelings are often predicated on what we say to ourselves and each other. To celebrate shared experiences and hear positive words is important – for both of you.

Talk – feed your mind with thoughts and feelings from your partner. And do the same for them. Let your partner know what they are doing well, and how they please you. Have them share what you do that pleases them. Tackle issues with compassion and empathy. Speak simply and specifically – avoid phrases or words that could be interpreted in different ways and explain what things mean to you and how you feel.



Crohn's and Colitis Canada is the only national, volunteer-based charity focused on finding the cures for Crohn's disease and ulcerative colitis and improving the lives of children and adults affected by these diseases. We are one of the top two health charity funders of Crohn's and colitis research in the world and the largest nongovernmental funder in Canada. We are transforming the lives of people affected by Crohn's and colitis (the two main forms of inflammatory bowel disease) through research, patient programs, advocacy, and awareness. Our Crohn's & Colitis – Make it stop. For life. Campaign will raise \$100 million by 2020 to advance our mission.

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For more information on Crohn's disease or ulcerative colitis visit our website **crohnsandcolitis.ca** or call 1-800-387-1479 Follow **@getgutsycanada** on **f O Y**

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