



Crohn's and Colitis
Foundation of Canada

Fondation canadienne des
maladies inflammatoires
de l'intestin

THE HEART OF THE MATTER



Sexuality and IBD

THE HEART OF THE MATTER

Human beings are sexual beings. We live, we love, we have intimate relationships and many of us have children. Our spirits are nurtured by our loved ones and part of that relationship includes sex.

But now, you or someone you care about has been diagnosed with inflammatory bowel disease (IBD). Along with a host of questions about the symptoms, treatment approaches, medication and surgery, there come lifestyle concerns that also deal with fatigue, confidence and maybe even depression. Any one of these issues can have a dampening effect on self-image and sexual desire.

The Crohn's and Colitis Foundation of Canada (CCFC) understands that IBD is a chronic disease that not only affects the body, it can also affect the spirit. Like most chronic diseases, the longevity of the illness, the treatments, the concerns over flare-ups and the symptoms during an



attack can occasionally decrease your desire for physical intimacy.

You are not alone, even if at times you feel as if you are the only person carrying this burden. The way you are feeling is natural and quite honestly, is normal under the circumstances. But know this – whether it is you or someone you care about, IBD can be managed and so can its effect on sexual desire. Like all things related to you and your condition, learning about the disease is an empowering process that will give you a feeling of regaining control over your health.

To that end, this booklet examines the effects of IBD on your relationships and in particular, your sexual relationships. We don't claim to be counselors or sex therapists, but we can share information about IBD with you and you can then incorporate some of these thoughts into strategies that work for you and your partner.



THE MIND-BODY CONNECTION

We are going to take a step sideways for a moment and talk about PNI. Please bear with us as we explore this topic which may seem unrelated, but is in fact the heart of the matter when it comes to you, sex and IBD.

Psychoneuroimmunology or PNI, is a fascinating branch of science that investigates the incredible relationship between our minds, our thoughts and our immune system. Increasingly, researchers and physicians are realizing that our thoughts and our emotions can play a significant role in our health. Conversely, our health can also greatly influence our thoughts and emotions.

What does that mean to someone with IBD?

Potentially it means that the gut inflammation which is causing you so much physical distress such as nausea, vomiting, diarrhea and abdominal pain may also elicit feelings of lethargy, apathy and even depression. Alternatively, during times of emotional upheaval or stress, someone suffering from a flare-up of IBD may have an enhanced negative experience of their symptoms.

Note we did **not** say that emotional upheaval or stress cause IBD, nor do they necessarily provoke a flare-up; research does not support that. However, stress can amplify the way the symptoms of a flare-up are **experienced** by the sufferer, and that perception constitutes nine-tenths of reality.

On the flip side of PNI, positive thoughts generate positive feelings and studies have shown that in some cases, this can result in positive physiological events. While there is a great deal of scientific debate on the "power of positive thinking" and healing, there is a growing body of evidence in PNI that supports the merits of cultivating an upbeat attitude. And even if that attitude has no effect on the physical status of your IBD, it will certainly help you to feel better about your life!



WHAT HAS ALL OF THAT GOT TO DO WITH ME AND SEX?

Glad you asked. Believe it or not, sex has health benefits. As we saw in the field of PNI, the tight-knit relationship between feeling good emotionally and feeling good physically has some real and tangible results.

Notwithstanding the positive effects of intimacy in a caring and committed relationship, research has shown that the benefits of regular sex include:

- Mood improvement and 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 as well as improved sleep
- Increased levels of endorphins which help to reduce overall sensations of pain

BUT I JUST DON'T FEEL LIKE HAVING SEX

That is understandable. Besides, you don't have to have sexual intercourse for you and your partner to enjoy each other emotionally and physically.

Hugging, cuddling and kissing are great ways to express your love, whether they are preludes to more intimate activity or an end unto themselves.

Between the symptoms of IBD, your medications, possible surgery and its after-effects, it's possible that you may not be into sexual intercourse for awhile.

Let's examine these factors more closely.

Complications of IBD

Nausea, vomiting, diarrhea, abdominal cramping – any or all of these are not exactly seductive preludes to a romantic evening. In addition, some people develop fistulas (abnormal tunnels of infection that have developed inside the gut and burrowed their way to the skin or a neighbouring organ) as a result of IBD. The location of the fistulas (anus, vaginal area) can cause pain during sex due to tearing, and their presence can also be viewed by some as unclean or unpleasant.

If you are feeling like you would rather be left alone to suffer in silence than have sex with your loved one, can anyone blame you?

Having said that, this is not all about you. Your partner has needs as well, and even if you are not feeling like sex, how is your partner feeling? Her needs are important too if your relationship is to remain strong; what considerations are there in your mind for meeting those needs?

We are not trying to lay a guilt trip on you; that is the last thing you need. We are, however, trying to raise your sexual consciousness to a level that includes your emotional and physical well-being as well as that of your partner. Sex is not just about the act; it is about the relationship.

Diet

When your IBD is in an acute (active) phase, you may have a tendency to avoid food because of the accompanying symptoms that plague you after you eat. In addition, your small bowel may not be functioning well and your ability to absorb nutrients is diminished. All of this could lead to a state of malnutrition that contributes to feelings of fatigue. Fatigue is hardly an aphrodisiac, so take good care of your diet to minimize these problems. Even if that doesn't help your sex life, it will help you avoid a state of malnutrition. Please see our booklet, "Food for Thought: Diet and IBD" for more detailed information about your diet and your health.

Medications

Steroids are known to have a dampening effect on sexual drive as well as sexual function. In addition, the weight gain associated with steroids can affect your own sense of a sexy body image. Fortunately, most people are not kept on steroids for prolonged periods of time and while on these medications, are kept on a dose that is as low as possible. So the good news is that steroid-related diminishment of sexual desire is time-limited.

Sometimes antibiotics are prescribed for the treatment of IBD. Occasionally these drugs will cause a vaginal discharge in women. While the discharge could be considered unpleasant at the worst and inconvenient in the least, it does not pose a risk to anyone and should not pose a deterrent to sex.

Surgery

Surgery is necessary to treat certain conditions of IBD. Some of these procedures can result in an ostomy (an opening of the large intestine onto the skin of the abdominal wall) and an ostomy bag, or appliance, for the collection of feces. Please see our booklet "The Cutting Edge: Surgery and IBD" for more information on IBD surgery.



The presence of an ostomy bag can be daunting. At first the self-consciousness and embarrassment of having an appliance can cause an alteration in your body-image and a decrease in your feelings of "sexiness." Also a fear of the bag dislodging or leaking during sex can be inhibiting. But it doesn't have to be that way.

Research has shown that sexual activity actually increases for many people after they have had an ostomy because their health is greatly improved post-operatively. With better health comes increased sexual drive. For loving and committed couples, the presence of an ostomy is not a deterrent to a fulfilling sex life.

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

YOUR BRAIN IS YOUR LARGEST SEX ORGAN

All of the above factors play a huge role in your self-image of sexiness and your sex drive. But as we discussed in the section on PNI, your thoughts and

emotions play an enormous role in how you perceive yourself and how you feel physically, as well as your capacity for arousal and desire.

Your brain truly is your largest sex organ. How you think about yourself, in spite of medication-induced weight, moon face, an ostomy and appliance or a fistula, is far more important than whether or not you have the face and body of Canada's next top model.

Remember: sex doesn't begin south of your neck; it starts in your head!

DO I OR DON'T I?

So far in this booklet, we have been talking about sex on the assumption that you have known your partner for a while. But what happens when you are just starting a new relationship and the prospects of becoming intimate are likely? When do you tell someone about your IBD and about the challenges you face? How do you tell them about your ostomy or your fistula? Will it turn them off?

The old adage "Honesty is the best policy" still applies. Trust your instincts as to the "when," but when you do decide to share your condition with someone, be straightforward. Try to avoid a pity-party and just deal with the facts surrounding your IBD and your health status. It may sound trite, but if the person you are considering having a sexual relationship with is worth your affection, they will appreciate your candor and accept you as you are. Caring sex is not about the collision of skin between two bodies, it is an exchange of emotion expressed in a physical act.

If the person you care about has a negative reaction to your truth, and he "heads for the hills," he is not someone in whom you want to invest your precious energy and attention. Be happy that you found out earlier, rather than later, in the relationship.

WHAT NOW?

As the saying goes, "You're all fired up and ready to go": you and your partner want your intimate times to be as pleasurable as possible. What are some of things you can both do to achieve that?

Here are some tips that people have found helpful:

- First of all, if intercourse is just not on the agenda for you at this time, there are alternatives. Hugging, cuddling, kissing, manual or oral stimulation provide other ways of expressing your love for your partner without actually having sex.
- It may seem like we are stating the obvious, but be sure that your lifestyle ensures you are well-rested, eating well and exercising regularly. All of this contributes to a healthier frame of mind as well as a healthier body.
- Try a lubricant to enhance the 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 about the one you choose, as the silicone-based lubricants will deteriorate sex toys made with silicone, and oil-based gels may cause an allergic reaction in some people. Read the labels carefully and be sure to try a test spot before you use one.
- If you have an ostomy and appliance, empty the bag before having sex. This minimizes the possibility of an accident and gives you greater peace of mind, 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, plan to have sex at that time. Leaving your shared moments to spontaneity may result in lots of anticipation but very little conjugation.

- Experiment with different sexual positions. Some positions will be more comfortable, and therefore more pleasurable, for you than others. Be sure to share your likes and dislikes with your partner, communicating honestly about what worked for you (and her) and what didn't.
- Avoid alcohol and tobacco. Both of these substances can affect your sexual performance and in some cases, aggravate your symptoms.

COMMUNICATE, COMMUNICATE, COMMUNICATE

We want to leave you with one final thought – 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.

Especially important to the integrity of your relationship, genuine communication between you and your partner is an absolutely essential ingredient to having a mutually satisfactory sex life. As we said before, sex does not start south of your neck; it starts in your head. Your thoughts and therefore your feelings are often predicated on what you say and what you hear. So talk – feed your mind with the shared thoughts and feelings from your partner. And do the same for him.

It's like cognitive sex. Share your minds before you share your bodies.



CROHN'S AND COLITIS FOUNDATION OF CANADA

One excellent way for you to develop a support network is through the local chapters of the Crohn's and Colitis Foundation of Canada (CCFC).

Find the chapter closest to you by going to

<http://www.cffc.ca/English/involve/community.html>

CCFC local chapters are a great way to meet people with a common interest in IBD and to learn about tips for managing your condition. Educational events are often held in support of those seeking answers to questions about IBD.

CCFC also has many other booklets and educational information available on our website at

<http://www.cffc.ca/English/info/brochures.html>

We invite you to visit us there or contact your local chapter for free copies of our booklets. CCFC is here for you as you embark on a journey to learn all you can about Crohn's disease and ulcerative colitis.

Join the Crohn's and Colitis Foundation of Canada and help us in our fight to eradicate IBD from the world. Together we will find the cure.

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**For more information on Foundation activities, visit
our website (www.cffc.ca) and join our team today!**

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