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How Crohn's disease can affect your sex life

Sex is a very important part of life for many of us. But those with inflammatory bowel disease (IBD) can find the condition makes getting intimate a little more challenging. We chat to Paula, who has Crohn's, about banishing blushes and not letting IBD get in the way of having a great time in the bedroom.

Most of us are bad enough at talking about sex. But when normal intimacy worries are combined with concerns about [bowel incontinence](#), it's even harder to open up. Luckily 44-year-old Paula, who has [Crohn's disease](#), is no shrinking violet.

"People don't discuss sex and IBD very much. At least, certainly not the type of Crohn's I've got with recto-vaginal [fistulas](#). It just doesn't get talked about at all," she opines. "People are getting more confident talking about stomas these days. But no one discusses the fistula side of it. It's hard when poo is leaking out of the wrong places. But if you're going through it, you need to know you're not alone."

What is Crohn's disease?

Crohn's disease, one of the main types of [inflammatory bowel disease \(IBD\)](#), is a lifelong condition that causes pain and inflammation of the digestive system.

The severity of symptoms and how frequently they occur vary from person to person. While many people with IBD find medication helps with the symptoms, some, like Paula, require operations to remove the severely affected section of the gut.

Over the last two decades, she's had 34 surgical procedures, ranging from hernia repairs to J pouch formations and a total colectomy. And her condition has resulted in several fistulas – small tunnels which form between the end of the bowel and the skin near the anus. They're treated with setons – surgical-grade cord that creates a loop so the fistula can drain.

"I call them 'bows in my bottom'. And I've got three setons right now," Paula reveals. "But although no one can see the seton strings I have in place, some days can be excruciating for me. The fatigue, joint pain and getting up a lot of the night to go to the toilet can be really hard. And of course, the continence side can be embarrassing."

Paula's done with embarrassment though. Relentlessly cheerful, she refuses to let her symptoms dampen her sex life with long-term partner (and husband of five years) Gary.

"I'm very lucky to have been with my husband since we were 18 – we are now 44. He's supported me mentally and physically all the way through," she says.

But it's been a long road to feeling confident for Paula. And like many people with Crohn's disease, she's found the condition affects her sex life in a number of ways.

Isobel Mason, service development IBD Nurse at [Crohn's and Colitis UK](#) says: "There are several important issues that can affect sexual experiences for those living with Crohn's disease and [ulcerative colitis](#). These include tiredness and fatigue, anorectal fistulas and abscesses, fear of being incontinent, abdominal pain and changing body image after surgery and drugs."

Mental struggles

Life after surgery can take some adjustment. Some people with IBD might have an ileostomy or colostomy, where the bowel is rerouted through an artificially created hole (stoma) in the abdomen where poo can leave the body.

Paula had surgery to create a stoma at 21, just a few months after she'd given birth to her first child.

"I really struggled mentally to adjust to my first stoma," she reveals. "And [postnatal depression](#) kicked in then. I'd only just had my baby, woke up with my stoma, and I was so low it was unbelievable."

Back then, one nurse's bedside manner left a lot to be desired.

"And a little later, when I was struggling with feeling attractive and sex, a nurse I confided in dismissed my concerns, telling me: 'Oh, just give your fiancé a blow job, and you'll be alright'," she reveals. "I was horrified."

But despite, numerous surgeries and the odd insensitive medical professional, Gary has always made an effort to make Paula feel as attractive as when they first met. And their activities certainly aren't limited to fellatio.

"He's managed every step of the way to make me feel wanted. For example, he buys me pretty underwear from companies like Vanilla Blush and Ann Summers. Sex is a very important part of a relationship, especially when you've been together so very long. We are lucky to have each other."

Those with IBD who are struggling mentally, like Paula was, don't have to suffer in silence. It's worth speaking with your GP or IBD team, as counselling can be very effective. Medication such as [antidepressants](#) can also be helpful for some people.

Worries about smell

A major fear for many people with IBD is about having an accident – a bout of [diarrhoea](#) or a leaking stoma bag – during sex. Paula blames her perfume obsession on exactly this.

"Since my stoma, I have become obsessed with smell. I have 224 bottles of perfume. I'm also super hygienic and bathe a lot. But Gary's never ever told me I smell."

Paula says she finds bathing prior to sex can help keep her worries at bay. But if minor accidents do happen, it's not a big deal. It's better to laugh them off, rather than dwell on them.

"Gary always says: 'Paula, we all poo. You just poo out of your stomach at the moment. It's nothing to be embarrassed about'," she reveals.

[Crohn's and Colitis UK](#) advises that if you are particularly worried about incontinence during sex, it's worth asking your doctor to refer you to a continence specialist.

Pain during sex

As stomas, fistulas, and setons can alter the position of organs in the pelvis, it can make sex more uncomfortable. Paula points out that sometimes it's just a case of finding a sexual position that works for you, and doesn't cause discomfort.

"Gary is very sexual. He would happily have sex with me three times a day if I was capable, just because he says he fancies and adores me so much. Whereas I'm more comfortable having sex about once a week. And because of my setons, we have to find positions that are comfortable for me. And when they change, we will just have to find another position."

Mason suggests that it may be easier to control the level of movement and penetration during sex if you are the one on top.

"And be open with your doctor, or IBD nurse specialist. If they understand, they may be able to help with painkillers, other medications or support services," she says.

Talk to your partner

Of course, communication is key to a healthy sex life, whether you're with the same person you were with 20 years ago, or about to get intimate with someone new. And besides, one of the best ways to deal with worries is to talk about them.

Paula advises: "Just be you and be honest. If you've been honest about your worries, there are going to be no surprises in the bedroom. You're not going to have to keep the lights off because you're conscious of what's going on underneath your clothes. If the person doesn't accept you for being honest, they're not the right person for you."

"If you are ever feeling like sex is over because you have Crohn's complications, please remember you are beautiful, you are strong and you are an amazing warrior. You can make it through this and love the skin you are in."

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