



SEXUAL RELATIONSHIPS AND IBD

INTRODUCTION

Sexual relationships are, for many of us, a very important part of our lives. Even when we are not in a relationship, our sexuality usually remains a key part of who we are and how we choose to live.

If you have Crohn's Disease or Ulcerative Colitis (the two main forms of Inflammatory Bowel Disease - IBD) you may find that your condition can affect you in a number of ways. A common cause for concern, although people don't always like to talk about it, is the potential impact of IBD on sex and sexual relationships.

This leaflet has been written for people with IBD and their partners to provide information on this topic. It looks at how common IBD symptoms and treatments, and the feelings often associated with these, can affect the physical and emotional aspects of a sexual relationship. It also includes some suggestions that might help you deal with any difficulties, and details of other sources of help and advice.

Many of the issues covered in this information sheet are likely to be very similar regardless of sexual orientation. However, people with IBD who identify themselves as lesbian, gay, bisexual or transgender may be concerned about whether to talk to their IBD team about their sexual relationships. Whatever your sexual orientation, you may be concerned about how some treatments may affect your sexual practices. These concerns are discussed in this sheet too.

LEGAL AGE OF CONSENT

In the UK, the age of consent to any form of sexual activity is 16 years old for both men and women. The sexual health charity FPA have further information on this (see **Other Organisations**).

PRACTISING SAFE SEX

If you are having sex, it is important to consider use of condoms to protect against sexually transmitted infections (STIs) and pregnancy. Visit the NHS Choices website for further information on contraception: www.nhs.uk

Women with IBD taking oral contraceptives can be at increased risk of developing blood clots. Speak to your GP or IBD team if you have any concerns about contraception, and how that might be affected by your IBD, or drugs you might be taking for your IBD.

COMMON IBD SYMPTOMS AND THEIR EFFECT

Tiredness and fatigue

Fatigue or extreme tiredness is a very common symptom of IBD. Diarrhoea, painful cramps, anaemia, and poor appetite or problems absorbing nutrients can leave you weak and lacking in energy.

As a result, you may be feeling just too tired for sex, especially during a flare-up – and perhaps even too tired to explain.

However, if you can, you may find it helpful to talk to your partner about your tiredness. (See **Talking to your partner** for more about this.) It isn't always easy for people in good health to understand fully just how exhausting IBD can be. Our information sheet, **Fatigue and IBD**, may be useful in this situation. This includes suggestions of ways to deal with fatigue and tiredness. It is also worth talking to your doctor about your symptoms. Fatigue can be difficult to treat but it may be that your tiredness or fatigue can be reduced by a change in medication or by treatment with an iron or vitamin supplement.

If you feel very tired at night, it might be worth timing sex for when you are less tired. It may also help to step back a little, and rather than always trying to have full sex, to look for other ways of being intimate with your partner. See below for more about **Being intimate**.

Fistulas/abscesses

Some people with IBD, especially those with Crohn's Disease, can develop abscesses, fistulas or scarring of the skin around the anus or around the vagina. (A fistula is an abnormal passageway or link between the bowel and the skin or other surrounding organs. For more information see our leaflet, **Living with a Fistula**.) These complications can be embarrassing and may make sexual intercourse extremely painful, or even temporarily impossible. If you have scarring of the skin, abscesses or fistulas, you may find using a lubricating jelly before penetrative vaginal sex is helpful. However anal sex must be avoided if you have significant stricturing (narrowing) of the anus, or abscesses or fistulas in this area. Make sure your doctor is aware that you have a fistula or abscess as these problems can often be treated medically or with surgery. Your doctor or IBD nurse will also be able to advise you on how to manage your fistula on a day to day basis, including which sexual practices are safe.

Incontinence

A major fear for many people with IBD is that they might have an 'accident' (for example, a bout of diarrhoea) during sex. Even if it doesn't happen, the constant worry about the possibility of it happening can be very off-putting. For men, the anxiety may cause difficulty with getting an erection.

You may find going to the toilet and emptying your bowel before sex makes you feel more confident about avoiding an 'accident.' Taking an anti-diarrhoeal drug, such as loperamide (Imodium/Arret) before sex may also help you control your bowel. However, these sorts of anti-diarrhoeals are not suitable for everyone with IBD, and should not be taken during a flare-up, so check with your doctor or IBD team before buying a supply.

You may also feel more confident if you and your partner try and have sex at the times of day when your bowel is less active.

If you are particularly worried about incontinence during intercourse, ask your doctor or IBD team to refer you to a continence specialist. They will be able to advise you about other ways to manage this problem.

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When I was first diagnosed, I never felt confident enough to be open about being gay. But I have since learnt that it is important to be open and honest with people, because you are much more likely to be able to get the support you need.”

David, age 29
diagnosed with Indeterminate Colitis
in 2015

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I felt like a different person when I had the surgery. I didn't like my scars or the fact that I now had a stoma. My husband told me the scars didn't matter to him, and it made no difference to how he felt about me because the surgery had saved my life. I found this hard to believe until he asked what if it had been the other way round and he had the scars and the stoma. It made me realise that it wouldn't change how I feel and I would still love him all the same.”

Annie, age 53
diagnosed with Ulcerative Colitis in 2011

Abdominal Pain

IBD can cause chronic (ongoing) abdominal pain and tenderness. If this affects you, it may help to try different sexual positions. It may be easier to control the level of movement and penetration during sex if you are the one on top. Talk to your IBD team about ways to manage your pain, and whether painkilling medication might be useful. However, some types of painkillers, such as non steroidal anti-inflammatory drugs (NSAIDS) which include aspirin, ibuprofen and diclofenac are not recommended for people with IBD.

TALKING TO HEALTHCARE PROFESSIONALS

The amount of contact you have with healthcare professionals such as your GP and your hospital IBD team will depend on the severity of your IBD and your response to treatment.

If you are lesbian, gay, bisexual or transgender, you may worry about interacting with medical and nursing staff, particularly if they don't know your sexual orientation. But healthcare practitioners, including IBD nurses, receive guidance about the needs of lesbian, gay, bisexual and transgender people, so should understand how to support you.

You may feel nervous about being open about your sexual practices or sexual orientation, especially as you may feel very vulnerable if you are unwell. However, if you can be open at the beginning of your relationship with healthcare professionals, it may make your future experiences with them easier.

Whatever your sexual preference, you may find having your partner with you during appointments may help to make you feel more supported, and they can remind you afterwards of what was said.

THE EFFECTS OF SURGERY

Surgery for IBD can often involve removal of part of the small intestine or part or all of the colon and rectum. This may result in an ileostomy or colostomy, or, for Ulcerative Colitis, the creation of an internal ileo-anal pouch (IPAA). For more information on common operations for IBD, see our leaflets: **Surgery for Crohn's Disease** and **Surgery for Ulcerative Colitis**.

It is very common for people facing stoma surgery to be worried about how it might affect their relationships. Everyone and every relationship is different and it will take time for you and your partner to get used to living with your stoma. But it will gradually become part of your lives. However, in general, having a stoma bag should not be a barrier to having an active sex life. Many people with a stoma have fulfilling sex lives. Provided the stoma bag is attached securely it should not be affected by the sexual position you choose. There are also different types and sizes of bag available, designed to be much more discreet than the usual options.

Your stoma care nurse will be able to help you with support, advice and practical tips. These may include, for example, ensuring the bag is empty before you have sex, swapping it for a much smaller bag or using a decorative cover. You may also find it useful to contact a specialist patient organisation such as the Ileostomy and Pouch Support Group (IA) or the Colostomy Association. (For more details, see **Other Organisations** at the end of this leaflet).

Research on the effect of being given a stoma has found it can improve libido (desire) and sexual satisfaction for people with IBD – probably because people with a stoma no longer have many of the troublesome symptoms of IBD.

Some of the research on IPAA or ‘pouch surgery’ has shown that it can also have a positive effect on sexual functioning.

However, other studies have found that surgery may, for example, lead to increased tenderness of the abdominal wall or in the rectal area. It can also alter the position of the organs in the pelvis. This can make having sex more uncomfortable, even painful. As mentioned earlier, a different sexual position may help. Your IBD team or your colorectal surgery team may also be able to give you useful advice.

In men, particularly those over fifty, surgery to remove all or part of the bowel may occasionally cause or worsen difficulties with erections and with ejaculation. A small number of men with IBD may experience this sort of problem even without surgery (and of course it can also happen in men without IBD). These difficulties may be only temporary and may resolve over time. If they continue, it might be helpful to talk to your IBD or colorectal surgery team about referral for treatment, for example with medication (such as Viagra) or a penile implant.

For some people, the removal of the rectum can impact on their preferred sex activities, such as anal sex. For more information about this, see **IBD and anal or oral sex** below.

In anyone, surgery can affect not only our physical shape and how our bodies work but also how we feel about ourselves. See the next page for more discussion on this point.

IBD AND ANAL OR ORAL SEX

Anal penetrative sex can be enjoyed by both men and women, using fingers, toy or a penis. Tenderness in the area due to IBD or following surgery, or the presence of perianal fistulas, may interrupt this practice.

Currently, there are no studies to indicate whether having penetrative anal sex might, for example, trigger a flare-up. There is also little guidance about how long you may need to wait, after surgery to form an internal pouch, before having anal sex. However, your IBD team or surgeon should be able to advise you. They can also refer you for support from specialist counsellors, if you feel this would be helpful.

Some people choose to insert fingers, a sex toy or a penis into a stoma. This is not recommended as the bowel attached to the stoma is quite thin and bendy. Penetration of the stoma could lead to serious bowel damage.

Some people practise oral-vaginal, oral-penile and oral-anal sex. You and your partner may feel concerned about this if your bowel cannot be guaranteed to behave well. The use of a dental dam (a small square of vinyl placed over the vulva or anus), provides a barrier for safer sex and may ease your concerns during oral sex. Your IBD team would be able to advise you where you can buy these.

THE EFFECTS OF DRUGS USED FOR IBD

Most of the drugs used for IBD have not been found to affect sexual drive or performance.

However, there is some evidence that steroids can affect sexual satisfaction. They can also cause mood changes and depression, which may lead to loss of interest in sex. Other steroid side effects, such as weight gain, rounding of the face and acne may make you feel less desirable. Talk to your doctor if you are being affected in this way. A different steroid or a change in the way you take your medication may help reduce these side effects.

Some people with IBD become depressed (see the **Depression** section on the next page) and take anti-depressants. These drugs have been linked to impotence problems. Methotrexate, an immunosuppressive drug sometimes prescribed for IBD, has also been linked to impotence.

A small number of drugs sometimes used to treat IBD, including methotrexate, may affect fertility and/or the development of an unborn child. Therefore, it is very important that methotrexate should not be taken by either partner when trying to conceive, or by women when pregnant. For more information on this see our leaflets, **Fertility and IBD** and **Pregnancy and IBD**.

The way that some drugs are taken for IBD may affect sex. For people with IBD affecting the lower part of the colon and rectum, mesalazine and steroids may be given as topical treatments by enema or suppository that apply drugs directly to the affected area in the bowel. Enemas use a specially designed applicator (containing the drug as a liquid or foam) that is inserted into the anus (back passage) and reaches into the colon. Suppositories are small 'bullet-like' capsules of drug inserted into the rectum via the anus. Your IBD team might suggest you take these just before you go to sleep, which could affect when you have sex. You might want to time sex earlier so that it doesn't affect taking your medication. Speak to your IBD team if you have any concerns about how and when to take your medication, and what effects this might have.

FEELINGS AND EMOTIONS

IBD and its treatments can also have emotional and psychological effects on personal and sexual relationships.

Some people with IBD struggle with poor body image (for example, you may be unhappy with your weight). If you have had surgery for IBD, you may feel embarrassed about scars. Or you may still be coming to terms with a stoma. It can be difficult to feel sexy if you are unhappy or dissatisfied with how you look or how your body works. Worrying about how your partner will react can add to these negative feelings and make maintaining your self-confidence even more difficult.

Another anxiety may be about how your partner will react to more day-to-day aspects of IBD. What if you need to rush to the loo in the middle of sex? Or make inappropriate noises or smells? Will they feel frustration or irritation? Even in the strongest relationships, partners can sometimes say or do the 'wrong thing', perhaps, at least partly, out of embarrassment. If you are feeling particularly vulnerable this can be hurtful.

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When I met my partner I was embarrassed about the scars on my stomach. But I made sure I told him about my Crohn's and my surgery, and I encouraged him to look into it. We have been a couple for 3 years now and I can honestly say that he is not at all concerned about how my body looks. I believe it is me that is more bothered by it. He says it makes me who I am. ”

Marie, age 49

diagnosed with Crohn's Colitis in 1987

Sometimes you may not feel like having sex - either due to your IBD symptoms, or because you don't feel much desire. This sort of situation is very common and can make people feel stressed and anxious, especially if they then feel guilty about it. It is natural to feel this way – coming to terms with the impact of a long term condition like IBD is not easy.

If you cannot enjoy your usual sexual practices, this can have an impact on your relationship. Having individual or couple counselling may help you to come to terms with any changes in how you feel about your self-image (see **Talking to your partner** below).

You may be able to access counselling with a specialist through your local NHS sexual health clinic. See NHS sexual health clinics in **Other Organisations** for further details.

DEPRESSION

Some people with IBD might become depressed, which can affect their interest in sex. Men who are depressed often find it more difficult to get an erection, and both men and women can find that their sexual satisfaction is decreased. Anxiety and depression are common in people with IBD, which is not surprising when you consider the disruption that can be caused by the unpredictable and fluctuating nature of the condition. If you are troubled by depression, or are worried that you might be depressed, speak to your GP or IBD team. Both counselling (see above) and anti-depressant medication can be effective. However, some anti-depressant medications may decrease sex drive or cause sexual problems, such as difficulty maintaining an erection, or experiencing orgasm. If you develop these or other side effects from anti-depressant medication, contact your GP or IBD team to see if you can try an alternative medication.

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Sometimes even when I feel well enough to be sexually intimate, it is my partner who becomes worried that I will be too sore, too tired or that he will hurt me in some way, due to the ongoing symptoms of my Crohn's. I make sure that we talk about his worries, and that I reassure him that I feel OK and I want to be intimate with him. ”

Keira, age 28

diagnosed with Crohn's Disease in 1998

TALKING TO YOUR PARTNER

One of the best ways to deal with these sorts of fears is to talk about them. This may not be easy. Many people find it very difficult to talk openly about sexual matters, regardless of whether or not they have an illness such as IBD. But, discussing your fears and worries with your partner can often relieve a lot of anxiety and greatly improve mutual understanding. Also, the more you are able to talk about your concerns to your partner, the more relaxed you are likely to feel. It may help to alleviate their worries, as they might be concerned too, for example, about hurting you. If you shut your partner out from what you are thinking and feeling, they might feel rejected or think they have done something wrong. Sharing your feelings can reassure them and help them to feel a part of what's going on in both of your lives.

It may be that your preferences and needs have changed because of your IBD symptoms or treatments. Perhaps activities that used to bring you pleasure are now uncomfortable or painful. Talk to your partner about this - and also what you would like to do and what still feels good. Discussing such sensitive issues can be difficult at first, but it will get easier with time and should help you feel more emotionally intimate.

Some couples find that having a sense of humour can be a real help. While it is important to be sensitive and caring, sometimes being able to see the funny side of things, and having a laugh about it, can ease the situation and bring you together.

You (and your partner) may find it useful to discuss some of these issues with a sympathetic member of your IBD team. IBD nurses are often very supportive.

If you find it really difficult to talk through your feelings and worries with your partner, you might like to think about seeking help from a specialist relationship counsellor. A counsellor with experience of working with people with chronic illnesses may be particularly helpful. For more information on how to find a counsellor, see our information leaflet: **Counselling and IBD**.

BEING INTIMATE

If you are in a relationship, you can be intimate in many different ways. You don't have to focus on sexual intercourse to give and receive sexual pleasure. You might agree with your partner to avoid the sexual activities you don't want to engage in, and to explore other ways to be sexually intimate. Find a time that you are not rushed when you could try experimenting. This could be, for instance, with the sense of touch, each letting the other know 'what turns you on', and spending more time on these sensations. You could try using aromatic oils to massage each other, creating an intimate atmosphere with music and candles. Another idea is to try bathing together, or even taking it in turns to bathe each other. The key aim is to find activities that will bring you closer together in a way you both enjoy.

STARTING A NEW RELATIONSHIP

You might feel discouraged from making new relationships when you have IBD. Deciding whether, when and what to say to a new partner is not easy. You may be wondering how much they really need to know. Do you tell them before you begin to get close, or wait until the relationship is more established? What if they can't cope with the news of your IBD, due to their own fears, inhibitions or embarrassment?

When you are attracted to someone and hope to develop a relationship with them, try to feel comfortable about yourself. Feeling good about yourself improves your self-confidence which others pick up on. This in turn gives a more positive impression. Try and be clear and concise in your explanations of your illness and to avoid being apologetic. Being lovable and having self-worth doesn't depend on a body part.

Talking about your IBD to a new partner may be difficult, but it might be better done earlier on in a relationship, as soon as you feel you would like your partner to know this key fact about you. This is likely to relieve your anxiety, and if there is a negative response, the let down should be less of a blow than it might be later on in the relationship.

You could try thinking about a difficult conversation you've had in the past – and the ways you approached this. You can use the same techniques to tell your partner about your Crohn's or Colitis.

If you're struggling to find the right words, our Talking Toolkit may help: ittakesguts.org.uk/talk/talking-toolkit

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Having Ulcerative Colitis and dating in the gay community can feel daunting, but I have found being upfront early on helps, because it means that I don't have to hide my Ulcerative Colitis from anyone. Reading up and being informed about the condition has made me feel more confident to speak up early.

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Robert, age 24
diagnosed with Ulcerative Colitis in
2013

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Marie told me about her Crohn's Disease on the day we met. I didn't know anything about Crohn's, so she suggested I look it up, which I did.

Marie is very conscious of the scars from her surgery, but I feel that the scars are part of who she is, a sign of what she has been through and what makes her such a special person. Everyone in life has some kind of story.

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—
Dave, partner of Marie, age 49
diagnosed with Crohn's Colitis in 1987

If someone does react badly and makes you feel unwanted because you have IBD, consider whether they are really the sort of person you want to spend time with.

Finally, remember that, even if there are times when you feel overwhelmed and embarrassed by your IBD, it is only one part of who you are. You, as a person, have very many other facets, and your best relationships will be those that involve you as a complete and unique individual.

HELP AND SUPPORT FROM CROHN'S & COLITIS UK

All our information sheets and booklets are available to download for free from our website: www.crohnsandcolitis.org.uk. You can also get copies from our office – call or email the Information Line (see below).

Crohn's & Colitis UK Helpline: 0300 222 5700, open Monday to Friday, 9 am to 5 pm, except Thursday open 9 am to 1 pm, and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our Hatfield office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn's and Colitis Support: 0121 737 9931, open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and is available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

OTHER ORGANISATIONS

Bladder & Bowel Foundation

Nurse Helpline: 0845 345 0165

Email: info@bladderandbowelfoundation.org

Website: www.bladderandbowelfoundation.org

British Association for Counselling and Psychotherapy

Tel: 01455 883300

Website: www.bacp.co.uk

Email: Bacp@bacp.co.uk

Colostomy Association

Helpline: 0800 328 42357

Email: cass@colostomyassociation.org.uk

Web: www.colostomyassociation.org.uk

FPA

Website: www.fpa.org.uk

IA (Ileostomy and Internal Pouch Support Group)

Tel: 0800 018 4274 0800 018 4724

Email: info@iasupport.org

Website: www.iasupport.org

NHS sexual health clinics

For more information about sexual health clinics and how to find your nearest clinic:

Website: www.nhs.uk/NHSEngland/AboutNHSservices/sexual-health-services/Pages/guide-to-sexual-health-services.aspx

Outsiders

Sex and Disability helpline: 07074 993527

Website: www.outsiders.org.uk

Email: sexdis@outsiders.org.uk

Relate (Counselling for every type of relationship)

Helpline: 0300 100 1234

Website: www.relate.org.uk

The Terence Higgins Trust

Helpline: 0845 1221 200.

Email: info@ttht.org.uk

Website: www.ttht.org.uk

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at evidence@crohnsandcolitis.org.uk. You can also write to us at Crohn's & Colitis UK, 1 Bishop Square, Hatfield, AL10 9NE or contact us through the **Information Line: 0300 222 5700**.

ABOUT CROHN'S & COLITIS UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 28,000 members and 50 local groups throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's & Colitis UK. To find out how call **01727 734465** or visit www.crohnsandcolitis.org.uk

