

## Sexual relationships and IBD

### Introduction

For many people having a sexual relationship is an important part of their lives. While some couples find that Inflammatory Bowel Disease (IBD), which includes Crohn's Disease and Ulcerative Colitis, makes little difference to their love life, others find that the symptoms of the disease, medication or surgery can interfere with their enjoyment. If you have IBD, you may find that you have less interest in sex when your disease is active.

This information sheet looks at how the physical and emotional aspects of IBD can impact on sexual relationships, and makes some suggestions that may help to overcome concerns you may have.

### How may IBD physically affect sexual relationships?

Common IBD symptoms include cramping pain and diarrhoea, which can be very painful and tiring. Some people with IBD may become undernourished because their body cannot absorb nutrients properly. This may make them feel weak and lacking in energy. If you have any of these symptoms you may not feel like sex at all, and look for other ways of being intimate with your partner. See below: *Being intimate*.

Some women who have Crohn's Disease have rectal scarring, abscesses or fistulas (abnormal channels connecting the bowel to the skin or surrounding organs – see our leaflet: *Living with a Fistula*). These symptoms may make sexual intercourse extremely painful or temporarily impossible. In some cases, it may help to use a lubricating jelly during intercourse.

Sometimes women find that after surgery to remove the rectum, tenderness in the area can cause pain during sex. Surgery can also alter the position of the organs in the pelvis, which may make sex uncomfortable.

If you have ongoing pain and wish to have sexual intercourse it may help to try different sexual positions. It may be easier for you to control the level of movement and penetration during love-making if you are the one on top.

If you are not sure when it is 'safe' to begin sexual activity again after an operation, approach the doctor or specialist nurse you feel most comfortable with to discuss it confidentially.

For a very small number of men with IBD, there may be problems with getting or keeping an erection or with premature ejaculation. However, this happens similarly in the general population and, generally, there is an improvement over time. Some men, especially those over 50, may also have difficulties getting an erection or with ejaculation after surgery to remove the bowel (proctocolectomy – see our information: *Surgery for Ulcerative Colitis*). However, this is usually temporary and the improved surgical techniques used nowadays make it much less likely to happen.

If these problems continue, you may find it helpful to talk to your specialist doctor or nurse about referral for possible treatment, such as a penile implant or medication (for example, Viagra).

For some people, who may include gay men, the impact of losing the rectum may make it difficult to come to terms with this surgery. It may help to go for individual or couple counselling.

### **What about drugs used for IBD?**

None of the drugs used for IBD are generally known to affect sexual desire or performance. However, you may feel unattractive and put off sex if you have to use a liquid enema at night and if you are on steroids your sexual satisfaction may be affected. Also, possible side effects from steroids may make you feel less desirable. Some people gain weight and their face may become more round whilst on steroids. Others may feel depressed and lose interest in sex. These side effects usually go away when the drug is reduced or stopped. (See our booklet: *Drugs used in IBD.*)

### **How may IBD emotionally affect sexual relationships?**

A major fear for many people with IBD is having an 'accident' during sex. Even if it doesn't happen, the constant worry about the possibility of it happening can be just as off-putting. For men, the anxiety may cause difficulty with getting an erection. It may give you more confidence if, when you wish to make love, you take an anti-diarrhoeal drug, such as loperamide or lomotil, to help you control your bowel. It is a good idea to check with your specialist doctor or nurse whether this type of medication is suitable for you.

You may be worried too about your partner's reactions if you need to rush to the loo in the middle of love-making. Will they feel frustration or irritation? When the wrong things happen at the wrong moment, it can be hard in even the strongest relationships for a partner not to react negatively sometimes. If you are feeling particularly vulnerable, this can hurt.

If you have active IBD you may worry about making inappropriate noises or smells during sex, which may make you

feel embarrassed. Worrying about this loss of control may make you unwilling to have oral sex with your partner when otherwise you might.

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

How you feel about your body may concern you. You may be underweight and feel that your partner won't find you attractive. You may feel embarrassed about scars from surgery or having a fistula (see page 1) or stoma (an opening on the skin from surgery). (See *Other Organisations* at the end of this leaflet for stoma support, and our information on *Surgery for Crohn's Disease and Ulcerative Colitis.*)

The fear of pain during sex can particularly affect women with IBD. If you fear pain you may avoid sex altogether, not only when you have symptoms. You may feel guilty about avoiding sex, particularly if you and your partner would like a family. Even if they are patient and understanding, you may still feel anxious if you think they are quietly waiting and hoping that you are going to instigate sex. Sometimes just seeking a comforting cuddle can feel out of bounds because you fear that it will raise expectations of full intercourse. You may even fear that your partner may leave you or resort to an affair.

Having any of these concerns can make you feel anxious and stressed. You may find it hard to express your feelings or you may be struggling to deal with your embarrassment. It can be difficult to talk openly about sex even if you do not have IBD; if you do, you may find it even more difficult to talk about how your condition can impact on your desire for sex. However, the more you are able to talk about your concerns to your partner, the more relaxed you are likely to feel. If you

shut out your partner from what you are thinking and feeling, they may feel rejected and may think they have done something wrong. Sharing your feelings can reassure them and help them to feel a part of what's going on for you. Some people find counselling helpful to deal with these challenges.

It is not uncommon for people with IBD to become depressed, which can also affect their interest in sex. If you do feel depressed, it would help to discuss this with your GP to consider anti-depressant medication and/or counselling.

### **Starting a relationship**

If you do not have a partner, you may feel discouraged from making new relationships when you have IBD. Deciding whether and when to tell and what to say is not easy. Rejection is hurtful, and there is always a fear that another person will not be able to cope, because of their own inhibitions or embarrassment.

When you are attracted to someone and hope to develop a relationship with them, try to feel comfortable about yourself. We send out unconscious messages to potential partners about our ability to love ourselves and to deserve the love of others. It is helpful to 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.

The question of what to tell a new partner about IBD will always be a tricky one. Only you will know exactly when, what and how to tell them, but it may be better done earlier on in a relationship, once you feel more sure of your partner. This is likely to relieve your anxiety and, if there is an adverse reaction, the let down is more likely to be less harsh than it might be later. If someone makes you feel unwanted because of your IBD, consider whether they are worth your involvement. Try to be amongst people who care for

you and use your strengths and talents to keep your self-esteem.

### **Being intimate**

If you are in a relationship, you can be intimate in different ways. You do not have to focus on sexual intercourse to give and receive sexual pleasure. When you feel able to talk openly with your partner, you can agree at times not to have sexual intercourse and explore other ways to be sexually intimate. Experiment, for instance, with the sense of touch, with each partner letting the other know what 'turns you on'. You could try using aromatic oils to massage each other, creating an intimate atmosphere with music and candles.

Finally, remember that, even if at times you feel overwhelmed and embarrassed by your IBD, it is only one part of who you are. Try to keep in mind the whole relationship: your shared experiences, dreams and goals.

### **Who can you talk to?**

People sometimes find it very helpful to talk openly about their feelings and relationships with someone they can trust. You may have a close friend who will listen, or you may want to find someone outside of your family and friends to share your problems with. We have a service called NACC-in-Contact where people who have a personal experience of IBD offer confidential, supportive listening by telephone.

You can call **NACC-in-Contact** on **0845 130 3344 weekdays from 1-3.30 pm and 6.30- 9pm.**

### **Further help**

You may feel that counselling, with or without your partner, may help. Your GP or hospital specialist may be able to refer you or suggest a general or psychosexual counsellor.

**RELATE** also offers psychosexual counselling for straight, lesbian, gay, bi- and trans-sexual couples through many

of their local centres. See your local directory or the website: [www.relate.org.uk](http://www.relate.org.uk) and for the Scottish branch of Relate see:

### **Couple Counselling Scotland –**

☎ 0845 119 2020 or website: [www.couplecounselling.org](http://www.couplecounselling.org)

For details of suitably trained counsellors in your area you can contact:

### **The British Association for Counselling and Psychotherapy**

BACP House  
15 St John's Business Park  
Lutterworth, Leicestershire LE17 4HB  
☎ Helpdesk: 01455 883316  
Website: [www.bacp.co.uk](http://www.bacp.co.uk)  
Email: [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

If you have any queries or would like a copy of Crohn's and Colitis UK's other information mentioned in this leaflet, you can email: [info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk), or call the **Crohn's and Colitis UK**

**Information Line on 0845 130 2233.**

**The line is open Monday to Friday from 10am – 1pm** (excluding Bank Holidays). There is an answerphone service outside of these hours.

You may be interested in our other information sheets that concern relationships:

Fertility and IBD  
Pregnancy in IBD  
Information sheets can also be downloaded from the Crohn's and Colitis UK website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

### **Suggested reading**

**Living a Healthy Life with Chronic Conditions** 2nd Edition by K Lorig & others. Bull Publishing Co. California. 2000. ISBN 0-923521-53-4

**Living with a long-term illness** by F Campling & M Sharpe. Oxford University Press. 2006.  
ISBN 0-19-852882-5

### **Other Organisations**

#### **Bladder & Bowel Foundation**

SATRA Innovation Park, Rockingham Road, Kettering, Northants NN16 9JH  
☎ Nurse helpline: 0845 345 0165

Email: [info@bladderandbowelfoundation.org](mailto:info@bladderandbowelfoundation.org)

Website: [www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)

#### **Colostomy Association**

2 London Court, East Street  
Reading, Berks RG1 4QL  
☎ Freephone: 0800 328 4257  
(24 hours daily)

Website: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

#### **Gay Ostomates Organisation**

Website: [www.gayostomates.org](http://www.gayostomates.org)  
Email: [brian@gayostomates.org](mailto:brian@gayostomates.org)  
Provides news and information on products etc for ostomists and the chance to contact other ostomists.

#### **ia**

(The Ileostomy and Internal Pouch Support Group)  
Peeverill House  
1-5 Mill Road  
Ballyclare  
Co Antrim, Northern Ireland BT39 9DR  
☎ Freephone 0800 018 4724 or  
028 9334 4043

Website: [www.the-ia.org.uk](http://www.the-ia.org.uk)

#### **Lesbian and Gay Foundation**

Princess House  
105-107 Princess Street  
Manchester  
Lancashire M1 6DD  
☎ Helpline 0845 3 30 30 30 6pm-10pm

Website: [www.lgf.org.uk](http://www.lgf.org.uk)  
Email: [helpline@lgf.org.uk](mailto:helpline@lgf.org.uk)

#### **Ostomy Lifestyle**

4 The Courtyard  
Eastern Road  
Bracknell RG12 2XB  
☎ Helpline: 0800 731 4264  
Website: [www.ostomylifestyle.org.uk](http://www.ostomylifestyle.org.uk)

## **Outsiders**

### **Sex and Disability Helpline:**

☎ 0707 499 3527 weekdays 11am-7pm

Website: [www.outsiders.org.uk](http://www.outsiders.org.uk)

Email: [sexdis@Outsiders.org.uk](mailto:sexdis@Outsiders.org.uk)

## **The Terence Higgins Trust**

314-320 Gray's Inn Road

London WC1X 8DP

☎ Helpline: 0845 1221 200 weekdays

10am-10pm weekends 12 noon-6pm

Email: [info@tht.org.uk](mailto:info@tht.org.uk)

Website: [www.tht.org.uk](http://www.tht.org.uk)

Information, support and advice on sexual health, sexuality and relationships.

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***We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, St Albans, Herts AL1 5HH, or email [h.terry@crohnsandcolitis.org.uk](mailto:h.terry@crohnsandcolitis.org.uk)***

**Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.**

**Membership costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.**