



Sexual relationships and IBD

Introduction

The symptoms and severity of inflammatory bowel disease (IBD) can vary enormously, and so can its effects on sexual relationships as well as attitudes towards sex. Some couples may find the condition makes hardly any difference to their love life. Some manage to deal with temporary difficulties, perhaps through a combination of humour and mutual understanding. For others however, it may be much harder. If you are having a flare-up, or your symptoms are not yet controlled, the last thing you might feel like or think about is sex.

Your enjoyment of a full sex life may be affected in several ways: anxiety about incontinence during sex; fear about your partner's reactions; negative feelings about yourself and your body or a decrease in your desire or ability to have sex because of physical problems caused by IBD. If you haven't a partner, such thoughts may make you wonder if you'll be able to establish a relationship with anyone.

Coping with fears

A major fear for many people with IBD is incontinence during sex. One recent study of women with Crohn's disease found that half were frightened of having an 'accident' during sex. Even though actual incontinence during sex did not seem to be common, the fear itself can be just as inhibiting. If you are terrified of losing control of your bowel, it may be impossible to let yourself go sexually. For men, the anxiety may cause difficulty with getting an erection. Such fears are bad enough with a familiar partner; with a new partner they can be devastating.

Fear of pain during sex affects many women with IBD. About one third of women in the study mentioned above sometimes found sex painful. If you fear pain you may avoid sex altogether, not only when you have symptoms.

There may be other fears. Some people worry that scarring from surgery or simply having bowel problems will make them seem unattractive to a partner. Those with a stoma are very likely to be embarrassed and anxious about its effects on sex and their partner, at least at first. *(There are some organisations listed at the end of this leaflet which may help you with this.)*

Anyone with active IBD may fear making inappropriate noises or smells during sex and, while some couples may be able to laugh together about them, in other cases the sufferer may feel humiliated or embarrassed. Worry about this loss of control may make the people with IBD unwilling to receive oral sex from their partner when they otherwise might.

Sometimes it is not necessarily a sudden need to go to the loo that worries people with IBD, but how their partner will react if the sudden need arises in the middle of love-making. Will their partner feel frustration, irritation, anger, disgust? 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.

Some fears can be helped in a practical way. For instance, if you have been prescribed anti-diarrhoea drugs to help you maintain bowel control at certain times, then taking the drug on occasions when you or your partner hope to make love may give you added confidence. If you are not sure whether this medication would be appropriate, choose the doctor or nurse you find most approachable and ask him or her confidentially what they think.

Feeling fear is stressful. The more you are able to talk about your fears 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 will reassure them and help them to feel a part of what's going on for you. Some people find counselling helpful to deal with their fears.

Physical difficulties

Cramping pain, exhausting bouts of diarrhoea and extreme tiredness lasting weeks or months are going to put anyone off sex. Occasionally, for some people, their abdomen can be so tender that even a cuddle can be excruciating. Even when the illness is not active, the condition may still cause tiredness and affect sexual desire. All this can be extremely hard for a partner to understand.

Some sufferers may have other specific problems at times. For some women with Crohn's disease, rectal scarring, abscesses and fistulae can affect the vagina, making penetration during sex extremely painful or temporarily impossible. Following surgery to remove the rectum some women find tenderness in the area can cause pain during sex, but hopefully, only temporarily.

If the possibility of causing pain is a major concern for either partner, it may be helpful for the person who feels the pain to control the level of movement and penetration during love-making. This may be easier if that partner is the one on top. Some may be worried that intercourse may harm the person with IBD or a couple may wonder when it is 'safe' to begin sexual activity again after an operation. Whatever your concern, approach a doctor or specialist nurse you feel comfortable with to discuss it confidentially.

Removal of the rectum may cause difficulties with erection or ejaculation for men. This is usually temporary and much less likely to occur with recent and improved surgical techniques. For gay men the impact of losing the rectum may make it difficult to come to terms with this surgery and counselling may help.

None of the drugs prescribed for IBD specifically affect desire or performance, but having to use a liquid retention enema at night may well have a psychological effect on self image and sexual feelings.

Difficult feelings

You may feel guilt towards a partner if you are very often too unwell or too fearful to have sex, and you may feel particularly pressurised with regard to sex if you would both like a family. However patient and understanding your partner may be, 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 with the fear that it will raise expectations of full intercourse.

If severe pain absorbs almost all of your attention for a while, it may feel impossible to make any concessions to a partner's feelings about your relationship. You may then have to cope with the fear that he or she may leave you or resort to an affair. It helps enormously if you are able to talk honestly with your partner about your fears. Just airing concerns can lessen any negative feelings that are present.

But it isn't easy to be open or fully communicative all of the time, especially if you are feeling ill. If you find it hard to express feelings or are struggling to deal with your own embarrassment or disgust with

your own body, it may not be possible at all. If your partner is not supportive, this makes everything very much harder and you may question your relationship.

If you do not have a partner, making new relationships under these circumstances can be daunting. 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.

Starting a relationship

When you are attracted to someone and hope to develop a relationship with them, it's important 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. Be clear and concise in your explanations of your illness, but never 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 disclose, but it is perhaps better done earlier on in a relationship, once you feel more sure of your partner. This not only relieves your anxiety, but if there is an adverse reaction, the let down will not be as harsh as it might be later. If someone makes you feel unwanted because of your IBD, consider whether they are worth your involvement. Don't let rejection lead to self-rejection. Be amongst people who care for you. Use your strengths and talents to rebuild your self-esteem. Better to get on with your life, manage your illness and make space for the partner who will accept the whole you.

Being intimate

If you are in a committed relationship, the more you are able to talk freely about your illness and share with your partner how it makes you feel, the closer you will become. 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, however overwhelming and embarrassing IBD may sometimes make you feel, 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 find someone they can trust and talk openly with about their feelings and their relationships. 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. NACC has 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** weekday evenings between 6.30 and 9pm.

You may feel that counselling, with or without a 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 through many of their local offices. See local directory or the website: www.relate.org.uk and for the Scottish branch of Relate see

Couple Counselling Scotland - ☎ 0845 119 6088 or website: www.couplecounselling.org

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

The British Association for Counselling and Psychotherapy

BACP House, 35-37 Albert Street, Rugby, Warwickshire CV21 2SG

☎ 0870 443 5252 Fax: 0870 443 5161 Website: www.bacp.co.uk Email: bacp@bacp.co.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 Useful Organisations

Colostomy Association

15 Station Road
Reading, Berks RG1 1LG

Website: www.colostomyassociation.org.uk

☎ Freephone: 0800 587 6744 (24 hours daily)

The Continence Foundation foundation.org.uk

307 Hatton Square,
16 Baldwins Gardens
London EC1N 7RJ

Website: www.continence-

☎ Helpline: 0845 345 0165 M-F 9.30am-1.00pm

Trained advisers can provide helpful advice and contact details for a local Continence Adviser.

Gay Ostomates Organisation

Website: www.gayostomates.org Email: info@gayostomates.org

Provides news and information on products etc for ostomists and the chance to arrange social events for all age groups in London, Manchester and Birmingham areas.

ia

(The Ileostomy and Internal Pouch Support Group)
Peveerill House
1-5 Mill Road
Ballyclare
Co Antrim, Northern Ireland BT39 9DR

Website: www.the-ia.org.uk

☎ Freephone 0800 018 4724 or 028 9334 4043

Outsiders

Sex and Disability Helpline:

Website: www.outsiders.org.uk

☎ 0707 499 3527 weekdays 11am-7pm

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This document has been prepared by NACC as general information on the subject and is not intended to replace specific advice from your own doctor.

NACC is a voluntary Association which has 30,000 members and 70 Groups throughout the United Kingdom. The Association also provides a supportive listening service called NACC-in-Contact which is available to anyone affected by Inflammatory Bowel Disease. Membership of the Association costs £12 for the first year and £10 subsequently. Additional donations to help the work of the Association are always welcomed. NACC, 4 Beaumont House, Sutton Road, St Albans, Herts, AL1 5HH. Information Line: 0845 130 2233 NACC-in-Contact: 0845 130 3344

Administration Line: 01727-830038 Fax: 01727-862550

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