

CCFA National Headquarters

386 Park Avenue South, 17th Floor
New York, NY 10016-8804





The Intimate

Relationship of

Sex and IBD

It's a small word, but it generates a lot of talk: sex. For people with inflammatory bowel disease (IBD), however, talk of sex and sexuality can be derailed by disease, medication, and surgery, all of which might have an impact on sexual function. Also, the symptoms of IBD can affect body image, deterring people from pursuing a sexual relationship. Here, we review the aspects of Crohn's disease and ulcerative colitis that can interfere with the development of sexuality and sexual relationships, and discuss how you can overcome these obstacles.

Growing Up

Children learn about sexuality as their bodies change. For kids with IBD, this process may be delayed. "About 30 percent of children with Crohn's disease, and a much smaller percentage of kids with ulcerative colitis, may experience growth failure," says Douglas A. Drossman, M.D., a gastroenterologist and psychiatrist at the University of North Carolina, Chapel Hill. "This might delay sexual maturation, but once puberty hits, hormonal cycles tend to be normal."



This delay may worry some kids. "Children feel 'normal' by comparing themselves to peers and then validating impressions with parents," notes psychologist Morton L. Katz, Ph.D., of Houston. "If a girl with IBD starts menstruating later than her friends, she'll ask, 'What's wrong with me?' It's important to respond directly and with interest, not anxiety and nervousness. You can say, 'People develop at different rates. I'm glad you asked!'"

Adjusting to puberty is unsettling for any child. "Girls' breasts begin to hurt and boys start getting erections," says Dr. Katz. "These experiences startle kids, causing a sense of dependency on parents. Kids with IBD feel even less sure of themselves, because of other things they can't control. They can't get together with friends without some anxiety about what they will eat or when they'll need a bathroom."

Jack Elster*, a 24-year-old man from New Orleans, was diagnosed as having IBD at age eight. "Kids picked on me for gaining weight when I was on steroids," he recalls. "I also was the only one with a permanent bathroom excuse. People didn't understand that it wasn't a luxury."

*These names have been changed.

Parents can make the difference during these unsteady times. "Parents need to respond with support, caring, and information about the physical changes," says Dr. Katz. "They can neutralize the impact of teasing by encouraging kids to wonder, 'What's wrong with the kid who's teasing me?'"

Parents also can serve as role models. "Every kid grows up looking at *Seventeen* or *Sports Illustrated*," says Dr. Katz. "As a result, their focal point for adequacy is a perfect body. It's important for parents to emphasize that they value more than physical perfection." Your support can ensure that your child will grow up to be a well-adjusted adult who lives life to the fullest extent despite IBD.

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Sexual Function and IBD

Unfortunately, adults with IBD may find some physical barriers to a healthy, pleasurable sex life. "Sexual function can be impaired either because of medications or complications," says Dr. Drossman. "Steroids can affect sexual drive and function. Usually, however, most patients with IBD are kept off steroids for prolonged periods of time, or are kept on as low a dose as possible. Sulfasalazine is associated with a dose-related reduction in sperm count, but not in sexual performance. [A 5-ASA product can be used instead.]"

Some complications can be especially disturbing. "The development of fistulas [abnormal channels that connect the bowel to the skin or surrounding organs] occasionally affects sexual function," Dr. Drossman notes. "In particular, a rectovaginal fistula occurs in a small percentage of women with complicated Crohn's disease. Also, anal intercourse may aggravate a fissure [tear] or other disease in the anal area."

Melody Thompson, a 35-year-old woman from Shreveport, LA, had a complicated case of Crohn's before her ileostomy. "For three years I had full-blown disease in my large and small colon and rectum," she says. "I had five fistulas, and at one point they almost tore into my vagina. I know my husband loves me, because we went so long without having sex."

"Metronidazole or anti-inflammatory agents, such as 6-mercaptopurine, can be used to reduce the inflammation of fistulas," says Dr. Drossman. "Otherwise, a lubricating jelly may help during intercourse."

In more complicated cases, “Surgery can eliminate most, if not all, of the problems,” says Ian C. Lavery, M.D., Staff Surgeon at the Cleveland Clinic Foundation. “There may still be discreetly placed drains that cause only minor inconvenience.”

Some surgery for Crohn’s disease or ulcerative colitis, such as the creation of an ostomy or ileoanal pouch, requires removal of the rectum. “In these cases, there is a slight risk of injury to the pelvic autonomic nerves, which control erection and ejaculation,” notes Dr. Lavery.

“For the well-trained surgeon, there are recognizable areas where risk to the nerves is greatest. Dysfunction from surgery should be very, very uncommon if the surgery is performed correctly. It does occur on rare occasions when surgery is particularly difficult because of severe disease that has destroyed a lot of tissue.

“In women, disturbing the pelvic nerves can decrease clitoral sensation. The removal of the rectum allows organs to change position. The uterus can fall back, the ovaries can fall into the pelvis, and this can lead to dyspareunia [pain on intercourse].”

Remedies for impotence caused by surgery or medications include a rubber band or erection ring, which maintain erections; penile implants; and most recently developed, Viagra® (Pfizer). It is critical that men see a physician with experience in these treatments before using them. In studies of women who have ostomies and suffer dyspareunia, emptying the pouch has been reported to decrease the pain.

Getting Physical

Most people with IBD are physically capable of having sexual intercourse, but there are times when they just don’t feel like it. “The mood” can be dampened by a fear of incontinence, abdominal pain, fever, or sheer tiredness.

“I was in a relationship when I first got sick,” says Chris Hill, a 27-year-old woman from St. Louis who has ulcerative colitis. “But it ended and I haven’t dated a lot since then. I’m sick and tired all the time, and I’m embarrassed about always going to the bathroom.”

“My symptoms hit hardest right after my wedding—cramping and diarrhea,” says Dan Kreher, a 33-year-old man from St. Louis. “I did not have much energy to be terribly frisky. My wife was sympathetic, but I was trying to act like it was no big deal.” Marcia Wilson*, a 49-year-old New Orleans woman, also developed Crohn’s disease within one year of her

marriage. “You’re torn,” she says. “You don’t feel like having sex, but you don’t want to turn off your partner.”

Larry Shapiro, 36, has found that open communication with his wife is the best track when sex is not an option. “If I’m under the weather, I can say, ‘It won’t happen tonight,’” the St. Louis man says. “Just like she would say it to me if she was not feeling up to it—it’s not personal.”

It may help couples to talk about what will feel comfortable and pleasurable despite the pain, says Dr. Katz. “People need predictability to feel comfortable in a relationship,” he notes. “Sometimes you can’t be close, but you can talk about your feelings and fantasies. Don’t forget, there are ways that people can be sexually intimate that don’t involve intercourse.”

Melody agrees. “My husband and I went back to our courting days—kissing and hugging without expecting to have sex,” she recalls. “If your husband starts kissing you, it’s a given that it will lead to sex. With Crohn’s and an ileostomy, you want to hug and kiss without expecting anything else. It helps me to relax. You have to make sure they understand, however, that it’s not personal. I love him dearly, but this [illness] is inside of me.”



"A healthy Individual will not make one body part the focus of his or her erotic pleasure," says Dr. Katz. "He or she will focus on enjoying all senses, including sight, sound, smell, taste, and touch. A mature sexual attitude does not necessarily entail intercourse." Exploring other options involves understanding the dynamics of sexual pleasure, as well as thinking about what "turns you on" individually and letting your partner know.

Finally, don't sell short the simple things that enhance sexual desire and function—adequate rest and exercise, good diet, cleanliness, and setting the mood with music, lingerie, or a sexy movie. For people with ostomies, it might help to empty the pouch before sex, and some prefer to camouflage it with specially designed underwear.

The Body Beautiful, Still

Beyond the pain and the fatigue of IBD, some adults also struggle with a poor body image. "Feeling stigmatized can affect sexual arousal," notes Dr. Drossman.

In particular, the side effects of prednisone, a corticosteroid used often in treating IBD, can affect body image. "I was on and off prednisone for two years," notes Lisa. "I had a pimply, puffy face. I gained a lot of weight, and I'm a pretty small person. Family and friends that hadn't seen me for several years didn't recognize me." Marcia adds, "We didn't have a full-length mirror in the house for the five years that I was on prednisone, because I didn't want one around."

A negative body image is a strong deterrent to relationships. "Dating is very stressful," says Jack. "When you walk up to a person, they don't see your innermost person. Their opinion is based on looks—it's sad, but true.

Gay men in particular are very looks oriented. It's difficult to face that when you're gaining and losing weight because of prednisone."

Larry recounts his experiences as a counselor for people with IBD. "A number of people were afraid to leave bad marriages because they were afraid no one else would want them," he says. "Others were not as assertive within relationships, for fear of undermining them."

To combat a negative body image, it's important to keep an eye on the big picture, which includes all aspects of your looks and personality. "It's critical for effective sexual functioning that a person has a realistic sense of

themselves," advises Dr. Katz. "If you crop a picture too close, you don't integrate what's swell with what's not swell."

Achieving this view can be a matter of sheer will. "I didn't want to maintain my sexual relationship with my husband because I felt inferior," says 33-year-old Angela Grupas of St. Louis, who suffers from Crohn's colitis. "My skin tags [stretched skin caused by anal hemorrhoids] bothered me the most. I tried to get rid of them medically, and it was impossible. I then realized that my inability to have sex was mental, and I said to heck with it!"

Larry deals with the impact of his disease in similar fashion. "It might make me more self-conscious if I'm having an episode with bleeding, but if I want to have sex, I'm going to do it anyway. My disease has been a part of my life since I was 13, and I never let it stop me from doing anything."



An ostomy may seem like an extra hurdle in this effort. "I had some bitter times with it," Melody says. "At first I tried to wear larger clothes so that no one would know. Through a lot of prayer and a wonderful husband, I got over it. Now I wear whatever I want—no one will know. And I'll talk to anyone about it, especially if it will help."

Dr. Lavery comments, "People are understandably apprehensive about ileostomies, and many postpone surgery. This fear relates to body image. However, once surgery is done, patients often reflect that they have never felt better and only regret not having the operation sooner."

Although a healthy body image has to originate within you, reassurance from others is important to its development. "My mom always assured me that I looked good," says Jack. "She knew that once I was 'out there' I wouldn't be able to hide, and I'd have to accept who I am. My boyfriend also is very supportive. I'll stand in front of the mirror and say, 'Look at these stretch marks,' and he'll say, 'I don't see anything!'"

Melody adds, "When you lose control over going to the bathroom, and your husband helps you, you think, 'How can he think I'm sexy after that?' But my husband has been wonderful. This disease turned our lives around and it never bothered him."

Once people accept the totality of their image, disease and all, it's time to communicate this image to others. There's no doubt that opening up to potential partners about your illness can be stressful. "I told one person who was really understanding," says Lisa. "One of his mother's friends had colitis. But it takes a while even for friends to understand the scope of it—that I can't just go out to a ball game and drink a beer!"

Jack comments, "You try to be as honest as you can, but you don't want to talk about having a terrible disease in the first few dates." Angela adds, "It's also the conversation that IBD sufferers have—all that talk about bodily functions wouldn't put anybody in the mood!"

Couples should talk freely about the illness, symptoms, and experiences, says Dr. Drossman. "Some of my patients have attempted to hide various aspects of their disease from their partner, and it never worked out. Sharing personal concerns can actually draw people closer."

How you share information is important. Keep it simple. In the beginning, there is no need to include every detail about IBD—you'll have plenty of conversations as the relationship progresses. Share yourself with honesty and confidence, not anxiety and pessimism. People will take their cues from you.



Dr. Lavery adds a note for people with ostomies. "Studies show that people who are well adjusted have little difficulty in adjusting to an ileostomy when it comes to sexual relationships. People who have a stable relationship with their partner rarely have problems because of the ileostomy. If there is an unstable relationship before surgery, this can well be the event that leads to separation."

Open discussion includes bemoaning the limits that IBD places on your sexual activity. "A couple of times a year, it's okay to forget about all the good things you have, and feel sorry for yourself," says Dr. Katz. "If somebody didn't wish that they or their spouse did not have a chronic disease, they wouldn't be normal."

Finally, remember that relationships are more than physical pleasure. "When you are frustrated with the limitations of sexual activity, you have to keep in mind the whole relationship," says Dr. Katz. "You have shared conversations, dreams, and goals."

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Let's Talk About Sex

People's experiences in speaking with physicians about sex vary. "Most gastroenterologists that I have seen treat the gut and that's all," says Marcia. Whereas Angela recalls, "My gastroenterologist and colorectal surgeon discussed my problems with intercourse, and they were educated about body image issues." Jack adds, "When I told my gastroenterologist that I was gay, he told me of his concerns about anal disease."

If you are experiencing problems in sexual drive or function, please talk to your physician, whether or not he or she asks for the information. If you do not feel comfortable discussing these issues with your gastroenterologist, perhaps you would feel more at ease talking to your primary care physician or gynecologist.

Consult your surgeon for concerns about surgery and sexual function. "In our department another valuable resource is the enterostomal therapist (ET)," adds Dr. Lavery. "Sometimes patients, particularly females, are more comfortable discussing intimate details with another female or the ET than with the surgeon. However, the surgeon cannot abrogate the responsibility to discuss sexual function with the patient."

If you are having difficulty in starting or maintaining a sexual relationship, there are several forums in which to air your concerns. "People should start in a support group," advises Dr. Katz. "If you still feel uncomfortable or that no one understands, you can talk to a therapist. You can seek a referral from your physician or clergy, or anonymously, by calling churches and synagogues in the area to see who is recommended most."

The nature of IBD can be daunting to a sexual relationship. Educate yourself and your partner, open your mind to new possibilities, and discuss problems in a forum that is comfortable and encouraging. Do your best to keep these diseases from interfering with truly intimate relationships.

Recommended Reading

The **United Ostomy Association (UOA)** publishes excellent brochures about sexuality and sexual function: **“Sex, Courtship and the Single Ostomate,” “Sex and the Female Ostomate,” “Sex and the Male Ostomate,”** and **“Gay and Lesbian Ostomates and their Caregivers.”** Although written for people with ostomies, the information on sexual function, relationships, and body image will serve anyone with IBD very well. To order, contact UOA at 19772 MacArthur Blvd., Ste. 200, Irvine, CA 92612-2405; by phone, (800) 836-0826; by fax, (714) 660-9262; on the Web, www.uoa.org; or by email, uoa@deltanet.com.

CCFA offers brochures on a variety of related topics, including **“Women’s Issues”** (which provide information about pregnancy and IBD). To order, please call the foundation at 800-932-2423.

There are many books published about sex—it’s a popular topic! Reading is a good way to explore sexual issues in private. Some recommendations

are **The New Joy of Sex** by **Alex Comfort, M.D., D.Sc.** (Random House, 1995) and **Sex for Dummies** by **Ruth Westheimer, Ph.D.** (IDG Books Worldwide, 1995). For a comprehensive list, contact the **Sexual Information and Education Council of the United States (SIECUS)** at 130 West 42nd St., Ste. 350, New York, NY 10036-7802; by phone, (212) 819-9770; by fax, (212) 819-9776; by email, siecus@siecus.org; or check out their Web site at <http://www.siecus.org>.



You also can contact the **American Association of Sex Educators, Counselors and Therapists**, at P.O. Box 238, Mount Vernon, IA 52314; by fax, at (319) 895-6203; or by e-mail, at AASECT@worldnet.att.net.

Another certifying organization is the **American Association for Marriage and Family Therapy**, which you can contact at 1133 15th St., N.W., Ste. 300, Washington, D.C. 20005-2710; by phone, (202) 452-009; by fax, (202) 223-2329; by email, coamfte@aamft.org; or on the Web, <http://www.aamft.org>.

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** The mission of WE CARE (Women Educators, Clinicians, and Researchers in IBD) is to develop an organization that facilitates and advocates women as leaders, educators, researchers, mentors, and scholars in the area of IBD.*

CCFA's mission is to cure and prevent Crohn's disease and ulcerative colitis through research, and to improve the quality of life of children and adults affected by these digestive diseases through education and support.

Please Become a CCFA Member

Since its founding in 1967, CCFA has been dedicated to seeking the cause of, and cure for, Crohn's disease and ulcerative colitis. This national nonprofit organization also helps people with Crohn's disease or ulcerative colitis learn about their condition through support programs and educational materials. CCFA provides books, newsletters, brochures, an extensive Web site (www.cdfa.org), public awareness programs, camps for kids, and educational seminars like this one for people with Crohn's disease or ulcerative colitis and their family and friends.

Your CCFA Membership Benefits

As a member of CCFA, you will have access to a number of educational and support opportunities, including:

- Membership in your local chapter
- Subscription to *Foundation Focus* (CCFA's national magazine) and to your local chapter's newsletter
- Discounts on CCFA books, written in easy-to-understand terms to help you understand and live with Crohn's disease or ulcerative colitis
- An invitation to participate in your local chapter's support groups and educational programs
- Opportunities to participate in annual fundraising events

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You can receive the benefits of CCFA membership for one full year by calling the foundation at 800-932-2423, ext. 212, or by visiting www.cdfa.org.



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