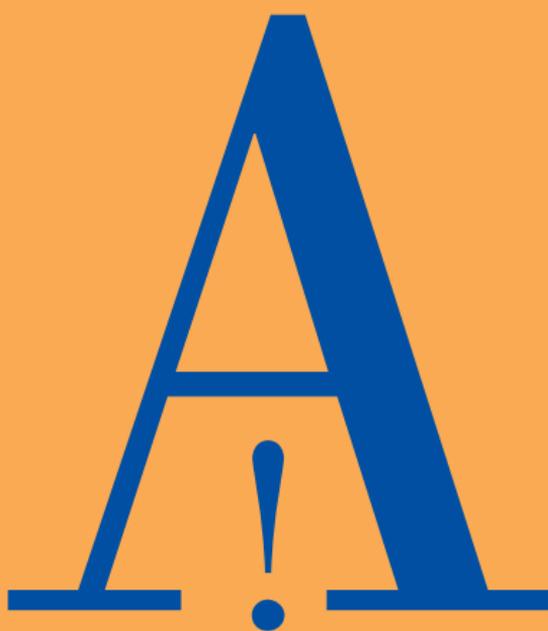




Crohn's Disease and Ulcerative Colitis:
Emotional Factors



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The Crohn's & Colitis Foundation of America is a non-profit, volunteer-driven organization dedicated to finding the cure for Crohn's disease and ulcerative colitis. CCFA sponsors basic and clinical research of the highest quality. The foundation also offers a wide range of educational programs for patients and healthcare professionals, and provides supportive services to help people cope with these chronic intestinal diseases. CCFA programs are supported solely by contributions from the public.

We hope that this brochure will help you to better understand these illnesses, and to become an active member of your healthcare team.

Crohn's disease and ulcerative colitis affect virtually every aspect of a person's life. If you, or someone you care about, has one of these inflammatory bowel diseases (IBD), you're bound to have questions about the relationship of psychosocial and emotional factors to these illnesses. Here are some of the most commonly asked questions and their answers, based on a broad range of clinical experience.

WHAT IS THE CAUSE OF ULCERATIVE COLITIS AND CROHN'S DISEASE?

The origin of IBD is still unknown. It is possible that a combination of factors may be the underlying cause of Crohn's disease and ulcerative colitis. Researchers theorize that IBD patients may be genetically predisposed to an immunological deficiency, which allows a foreign agent, such as a virus or bacterium, to trigger the disease.

CAN TENSION AND ANXIETY CAUSE THESE DISEASES?

There is no evidence for this. IBD is a biological disorder. Tension and anxiety can modify how patients experience any such disorders, but they do not cause either disease.

FRIENDS AND NEIGHBORS OFTEN SAY THAT COLITIS IS CAUSED BY NERVES AND EMOTIONAL UPSET. IS THIS CORRECT?

When laypersons, and sometimes physicians, speak of “colitis,” they may mean the specific disease known as ulcerative colitis, or they may be referring to a completely different condition known as irritable bowel syndrome (IBS). IBS is also called spastic colon or spastic “colitis.” These terms have caused considerable confusion. IBS is a disturbance of the function of the colon. While IBS can be very painful, it is much less serious than IBD, because it does not cause any inflammation in the intestine. Unlike ulcerative colitis and Crohn’s disease, IBS is not associated with structural changes in the intestine or bleeding. It does not cause harmful complications, require treatment with powerful medications, or lead to surgery.

The cause of IBS is not fully understood either, but in many cases, emotional factors play a strong part. Information about IBS is available from the International Foundation for Functional Gastrointestinal Disorders (IFFGD), P.O. Box 17864, Milwaukee, WI 53217; tel.: 888-964-2001; Web site: www.iffgd.org; e-mail: iffgd@iffgd.org.

There is no evidence that emotions cause ulcerative colitis or Crohn’s disease. You may want to offer this brochure as a reference when friends and colleagues seem to think that IBD is caused by being “overly emotional.” It is very important to correct this common and erroneous impression.

ARE CERTAIN PERSONALITY TYPES MORE PRONE TO DEVELOP ULCERATIVE COLITIS OR CROHN’S DISEASE?

No. Beginning about 50 years ago, it was believed that IBD was part of a group of medical disorders that were characteristic of certain personality traits and a specific biological predisposition. The latest research does not bear out this concept. In fact, during this earlier period, studies showed that psychoanalysis actually worsened the cases of ulcerative colitis. Of course, this does not mean that people with IBD today should hesitate to see a psychologist or a psychiatrist (see below, “Is Psychiatric Consultation Advisable for People With IBD?”), if they feel that it would help them cope with the emotional impact of their illness. But it is important to remember that, since the underlying cause of IBD is biological, not emotional, only medical therapy can control the illness itself. It is now recognized that there are no personality traits that predispose to

the development of IBD, and today, there are many more mental health professionals who are experienced in treating people with these illnesses.

DO EMOTIONAL FACTORS PLAY ANY PART AT ALL IN THE COURSE OF IBD?

Body and mind are inseparable and are interrelated in numerous and complex ways, something now recognized in medicine. In many centers, mind-body institutes are flourishing. It has been observed that at times of physical or emotional stress, patients may experience flare-ups of symptoms, such as increasing abdominal pain or diarrhea. This relates to changes in the physiologic functioning of the gastrointestinal tract, and decreased resistance to inflammation, rather than to increased inflammation. It has now been shown that severe chronic stress can lead to increased inflammation. These effects, however, should be carefully separated from the primary cause of IBD, which is not emotionally based. The symptoms of many diseases, even those with no known biologic cause, can get worse in stressful situations.

CAN THE SYMPTOMS OF CROHN'S DISEASE AND ULCERATIVE COLITIS, SUCH AS SEVERE PAIN AND CHRONIC DIARRHEA, CAUSE EMOTIONAL DIFFICULTIES?

Indeed they can. Different persons cope with physical illness in different ways. Some people can cope with severe illness without an extraordinary emotional reaction. Other individuals experience emotional distress when they develop a serious organic and chronic illness like IBD.

WHAT ARE SOME OF THE RESPONSES OF INDIVIDUALS TO IBD?

It is not surprising that some patients will find it difficult to cope with a serious and chronic illness, be it juvenile diabetes, rheumatic heart disease, asthma, or IBD. Such diseases pose a threat to their health-related quality of life, including their physical and emotional well-being, their social functioning, and even their self-concepts. In these situations, individuals may have emotional responses that include anxiety, depression, denial of chronic disease or needs for dependence. These reactions constitute a response to the illness and not its cause. When these emotional responses interfere with daily functioning, then it is important for the patient to work on ways to improve his or her psychological response. This may be accomplished individually, with family or friends, the patient's physician, or a mental health counselor.

ARE PATIENTS JUSTIFIED IN FEELING GUILTY THAT THEY HAVE BROUGHT THE ILLNESS UPON THEMSELVES, AND THUS CAUSED PROBLEMS TO THEMSELVES AND THEIR FAMILIES?

Not at all. Guilt feelings may be the result of the patient's thinking that IBD is caused by psychological factors, and that somehow the patient might have brought on this disease by not controlling his or her emotions. There is no basis for this way of thinking. IBD is not caused by emotions, nor is there anything that you could have done or could have avoided doing that might have prevented this disease. Guilt feelings are entirely unjustified and unwarranted. Indeed, they make it more difficult to cope with the physical and emotional burden that IBD patients have to bear. It is, therefore, important to dispel such guilt feelings.

ARE FAMILY MEMBERS JUSTIFIED IN FEELING GUILTY THAT THEY SOMEHOW BROUGHT ON THE DISEASE IN THE PATIENT/RELATIVE?

Not at all. As noted above, there is no basis to assume any guilt in causing the onset of IBD, either on the part of the patient or on the part of any family members, such as a husband, wife, children, parents, or siblings. They can be reassured that genetic transmission of the disease is only 5-7% if one parent has Crohn's, and less if the disease is ulcerative colitis.

WHAT IS THE BEST WAY TO DEAL WITH THE FEAR OF A FLARE-UP OF THE DISEASES?

The best way to deal with IBD is to seek effective treatment. Most people with IBD can now be managed very well by means of anti-inflammatory drugs. Numerous topical and oral medications have been shown to be effective therapy, particularly in ulcerative colitis. Your physician, who is the expert in dealing with these diseases, will decide which medication is best for your particular condition. In addition, it is important to realize that a good patient-physician relationship makes it possible to deal effectively with almost any complication.

HOW DO YOU DEAL WITH ATTACKS OF GAS, DIARRHEA, OR PAIN IN A PUBLIC PLACE?

For your own comfort and peace of mind, when you are going away from home, it helps to plan your itinerary in advance. Be very practical. Learn where the rest rooms are located in restaurants, shopping areas, on a trip, or while using public transportation. Always carry extra underclothing or toilet tissue in case of sudden need. Try to be matter-of-fact about your needs and your attacks of pain. In this way, you will be able to help yourself and gain cooperation from others because they will follow your lead and understand. Learning more about how your body reacts to certain food groups also may be a big help. You might want to try an elimination diet, in which you stop eating certain foods, then gradually reintroduce them to see how your gut reacts to each one. Avoiding foods that your gut cannot tolerate may help keep you well.

Close friends are aware that your condition causes you to have severe pains that come and go. They can learn, with your help, that despite their good intentions, there is little they can do but allow you to handle your pain in the way that is best for you. (CCFA's "Diet and Nutrition" brochure provides more information on this topic.)

ARE THERE ANY SPECIFIC SUGGESTIONS FOR PATIENTS WHO ARE PLANNING TO TRAVEL?

Always tell your physician about your travel plans. Learn the generic name of your medications and be sure that you have a large enough supply to cover your needs. If possible, ask your physician to give you some names of physicians who practice in the area you plan to visit. If you're planning to travel to underdeveloped countries, a consultation with a travel medicine specialist may be worthwhile. You can find more tips about traveling with IBD, as well as a list of IBD foundations overseas, on CCFA's Web site (www.ccfa.org).

WHAT TYPES OF MEDICATIONS ARE RECOMMENDED TO COPE WITH ANY PSYCHOLOGICAL DIFFICULTIES THAT MAY OCCUR IN RELATION TO IBD?

Generally, medications are not needed for psychological distress that is associated with a flare-up of IBD. Some individuals may experience a great many psychological difficulties (primarily anxiety or depres-

sion), however, and it may be helpful to be placed on a medication. A patient's physician may make this decision, or, in occasional cases, refer the patient to a psychiatrist. Anti-anxiety medications usually are used for brief periods of time. Antidepressant medication may be used for either severe symptoms of depression or for management of chronic pain resulting from the disease. In general, the medications used for treating psychological distress will not interfere with the medications used for treating IBD.

IS PSYCHIATRIC CONSULTATION ADVISABLE FOR PEOPLE WITH IBD?

For the majority of patients who experience some anxiety and other emotional responses to the illness, formal psychotherapy is not needed. Physicians who have experience with Crohn's disease and ulcerative colitis patients often are able to offer help, including the emotional support that is so necessary.

However, for some patients who experience severe emotional disturbance or who are eager to find more effective ways of coping with their disease, referral to a psychologist or psychiatrist can be useful. Care should be taken to find a mental health professional who is familiar with IBD, and who can understand some of the psychological difficulties of having this disorder.

HOW CAN ONE GO ABOUT FINDING THE PROPER THERAPIST?

Preferably, the attending physician should be able to assist the patient in finding the proper therapist. This decision may be based on the type of treatment indicated (psychotherapy, relaxation training, consultation for medication, etc.), or the experience and skill of the therapist. Sometimes other IBD patients can suggest the names of appropriate therapists.

ARE THERE SPECIAL ATTRIBUTES IN A PSYCHOTHERAPIST THAT ARE PARTICULARLY HELPFUL TO IBD PATIENTS?

Yes. It is important that, in addition to possessing the standard skills, the therapist be genuinely interested in treating IBD. It helps if the therapist is thoroughly familiar with both the normal and erratic course of these illnesses, is acquainted with the various complications of IBD, and is familiar with the various drug therapies used. It also is important that the primary physician and the psychotherapist maintain a close working relationship to ensure that their efforts to help the patient are cooperative.

WHAT IS THE EMOTIONAL IMPACT OF IBD ON YOUNGSTERS?

Youngsters tend to be more severely affected by any organic illness than individuals who have established a place in life for themselves and have learned to cope with adversity. For example, adolescence is a time when we seek to become more independent and more self-sufficient as a part of normal maturation. Chronic illness may impose a dependency on family, physicians, or the healthcare system. This can be a particularly difficult adjustment for adolescents. Therefore, it is no surprise that emotional difficulties, especially denial of illness, may be somewhat greater in the younger age groups than among older adults. Otherwise, the principles mentioned earlier apply to youngsters as well as adults.

DOES ILEOSTOMY SURGERY HAVE AN EFFECT ON THE PATIENT'S EMOTIONAL STATE OR COPING ABILITY?

Surgery is recommended for a minority of IBD patients, when the disease cannot be controlled by drugs. When surgery is needed, it poses some immediate risk to the individual, but in the appropriate circumstances, this risk should be outweighed by the expected benefits. With modern surgery and pre- and postoperative care, the dangers of serious complications from surgery are low. Some patients unable to be helped by medical treatment or standard resections of the bowel may have to undergo an ileostomy. People with ostomies must wear a pouch on their abdomen, into which wastes are emptied. This form of surgery poses some additional problems of adjustment. Most patients, however, can more easily cope with the problems with the help of informed and informative physicians. Organizations such as the United Ostomy Association (36 Executive Park, Suite 120, Irvine, CA 92714; www.uoa.org) and the J-pouch support group (www.j-pouch.org) can be very helpful resources. The national and local ostomy associations address these questions in their numerous publications, meetings, and Web sites, and often can provide helpful counsel for the surgery patient both during the pre-operative stage and following the surgery. This counsel usually can be provided through an extensive in-hospital and home visitation program.

One of the major concerns of people who face ostomy surgery is whether they will be able to enjoy a healthy sex life. Experience has shown that sexual activity improves rather than worsens, especially in people who were acutely ill before surgery.

WHAT ARE SOME OF THE ATTRIBUTES THAT MIGHT CONTRIBUTE TO A GOOD PROGNOSIS?

Ideally, the patient can accept IBD realistically, without self-pity, without guilt feelings, and without blaming others for his or her illness. If possible, the person with IBD will deal with the disease in a straightforward and matter-of-fact fashion, making it easier for friends and family to accept the illness as part of their relationship with the patient. The patient is able to go about his or her daily activities as much as possible, follow physicians' instructions, and maintain a positive attitude and optimistic outlook on life. The medical community's recent acknowledgement that a good quality of life is a major goal of the physicians who treat IBD will help patients to resume their lives, in spite of the disease. With the support of healthcare specialists, friends and family, and with proper treatment, you can learn to control your gut, rather than the other way around.

Sometimes a patient's behavior can cause difficulties—for example, if the person uses the illness to manipulate others in the family. Such problems can be approached by a good clinical psychologist or other mental health professional who is experienced in treating people with chronic diseases.

Following your physician's advice about clinical treatment is crucial to coping with your illness. In addition, several coping strategies can help you gain better control over your condition. These techniques tend to lower stress levels and improve daily functioning. Coping strategies include social support (for example, participating in a support group), education, problem-solving, and positive reevaluation of distressing experiences.

In short, most experts agree that psychosocial dysfunction is a part of IBD in certain individuals, rather than a cause or a unique feature of the disease itself. There is no doubt that living with a chronic illness can pose many challenges. But it's equally important to remember that most people with IBD live full lives, in spite of their illness: They go to school, work, raise families, travel, and play sports. By learning all you can and working as a team with your family, friends, and healthcare specialists, you, too, can take charge of your illness and enjoy all that life has to offer.



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