



# Emotional Factors

## CCSG Information pamphlet No. 5

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This booklet sets out to answer the questions most commonly asked about the relationship between emotional factors and the cause and course of inflammatory bowel disease (IBD). It can be a traumatic experience being told you have a chronic illness and understandably you will have some worries about your disease and your future. However, you should remember that the majority of people with IBD learn to accept their illness and adapt to it so that they can lead mostly normal lives.

### ***What is the cause of IBD?***

Currently, the development of IBD is understood to occur as follows. First, you must be genetically susceptible. Then, early in your life, you must come in contact with some agent or substance that, through some defect in the normal intestinal defence system, is able to penetrate the intestinal wall. This sets up an inflammatory response. A defect in regulating the inflammatory response must also exist so that, once the immune system is activated, a complex process is started that the body is unable to stop.

### ***What effect can IBD have on patients' quality of life?***

Developing a chronic illness can have significant effects on quality of life. Personal relationships can suffer and healthy spouses can find it difficult to cope with chronic illness in a partner. Unmarried patients may find it more difficult to form lasting relationships.

Chronic illness can also result in a loss of independence. When hospitalisation is needed the patient may need to depend on others to deal with day-to-day activities such as paying bills.

Older people tend to accept chronic illness better than young people whose feeling is generally "why me?" In the initial stages that patient is likely to feel angry and feel that

others don't understand. This attitude can result in a careless approach to treatment instructions.

In contrast, it should be noted that by far the majority of people with IBD go on to lead relatively normal lives, especially during periods of disease remission (which may be prolonged).

### ***Can tension and anxiety cause Crohn's disease or ulcerative colitis?***

There is no evidence for this. There is mixed opinion about the role of stress as a precipitating factor in people with preexisting IBD. However, IBD is not a psychological illness and is not a result of the type of person you are.

### ***Friends and neighbours often say that nerves and emotional upset cause colitis. Who is right?***

When lay people and sometimes physicians speak of colitis, they may mean the specific disease ulcerative colitis, or they may be referring to a completely different condition known as the irritable bowel syndrome, also called spastic colon or spastic "colitis". Abnormal functioning of the bowel causes irritable bowel syndrome. Unlike ulcerative colitis, irritable bowel syndrome is not associated with inflammation or structural changes in the intestine. The cause of irritable bowel syndrome is not fully understood either, but it is widely believed that emotional factors play a strong part. In ulcerative colitis, a condition that is associated with inflammation or structural changes, there is no evidence that emotions play a causative role. This brochure can be offered as a reference when friends and colleagues seem to think that being "overly emotional" causes Crohn's disease or ulcerative colitis. 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. In a controlled study done in the USA, a group of investigators analysed the emotional and personality aspects of patients with IBD and of healthy individuals. There were no significant differences between the personality traits of patients with IBD and "normal" controls.

***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. It has been observed that flare-ups of IBD can occur at the time of stressful situations, either physical or emotional. For instance, the first onset of IBD may occur at the time of an attack of a viral or other infectious illness. It also appears likely that some flare-ups of the disease can be triggered by nervous tension or by emotionally stressful life situations. However, this flare-up effect should be carefully separated from the primary cause of IBD, which is not emotionally based.

***Can the symptoms of Crohn's disease and ulcerative colitis, such as severe pain and chronic diarrhoea, cause emotional problems?***

Indeed they can. Different people cope with physical illness in different ways. Some people can cope with severe illness without an extraordinary emotional reaction while others may experience emotional distress.

***What are some of the responses of individuals to IBD?***

Some patients find it difficult to cope with a serious organic and chronic illness such as IBD. Such diseases pose a threat to the person's physical well-being and feeling of security, and he or she may develop signs of anxiety, insecurity and dependence. These reactions constitute a response to the illness and are not its cause. Despite excellent medical and surgical management 40-60% of patients with IBD describe their quality of life as fair to poor. In addition, 30-50% of patients with severe disease experience clinical depression, especially in Crohn's disease.

***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 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 patients could have done or could have avoided doing that might have prevented developing this disease. Guilt feelings are entirely unjustified and unwarranted. Indeed, they make it more difficult to cope with the difficult physical burden that patients with IBD 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 above, there is no basis to assume any guilt or causation in 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. It's not their fault.

***What is the best way to deal with the fear of a flare-up of the diseases?***

The main way to deal with IBD is to seek effective treatment. Most patients with IBD can now be treated very well by means of anti-inflammatory drugs administered by a physician who is expert in dealing with the diseases. It has also been shown, particularly in ulcerative colitis, that with low dose maintenance therapy of sulfasalazine or related agents such as mesalazine (Pentasa®, Asacol®) the recurrence rate can be markedly diminished in responsive patients.

***How do you deal with attacks of gas, diarrhoea or pain in a public place?***

For your own comfort and peace of mind, it helps to plan your itinerary when you are away from home. Be very practical. Learn where the rest rooms are located in restaurants, shopping areas, on a trip or while using public transportation. Carry the CCSG "Can't Wait Card" to help you access toilets in shops and restaurants that would otherwise be unavailable. Always carry extra underclothing or toilet tissue in case of

sudden need. Also 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.

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 that they can do but allow you to handle your pain in the way that is best for you.

***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 medication and be sure that you have enough supply to cover your needs. If possible, ask your physician to give you some names of physicians who practice in the area that you plan to visit. It is advisable to carry with you a letter from your physician describing in detail any surgical procedures you have had done and the medication you are taking. Some people with IBD find it useful to have a "Medic Alert" bracelet or similar.

Remember, most developed countries have IBD societies or foundations and their members will be happy to help you get care should you need it. Your local CCSG can provide contact details. Sometimes a phone call to your gastroenterologist at home will be a worthwhile expense to get some advice on medication levels or simple strategies for alleviating symptoms. Many Crohn's patients feel better having clear fluids for 24-36hrs or not eating at all for the same time. However, should symptoms return after resuming normal eating then medication is clearly needed and advice should be sought immediately.

***Are tranquillisers recommended to cope with the anxiety and fear that goes with IBD?***

Tranquillisers can be very useful for some patients but are not necessary for all. If anxiety is difficult to handle, the careful use of tranquillisers can be very helpful, especially during acute flare-ups of the disease or during any stressful life situation.

***Is psychiatric consultation advisable for any patients with IBD?***

In 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 colitis patients are usually able to offer the supportive help, including emotional support, that is so necessary.

However, for patients who wish to see a psychiatrist, or for patients who manifest more severe emotional disturbances, psychiatric consultation and cooperation with a psychiatrist can be useful. Care should be taken to find a psychiatrist who is experienced in dealing with IBD patients so that optimal therapy can be obtained.

***Can other professionals, such as psychologists, family therapists and social workers, be of help to patients with IBD?***

They can, in selected situations and again with great care to select those professionals who are specifically versed in dealing with patients with IBD.

***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. Sometimes other patients with IBD can suggest the names of appropriate therapists. The patients should be aware, however, that while such treatment can offer support in coping with illness, it does not have any effect on the primary illness per se.

***Are there special attributes in a psychotherapist that are particularly helpful to patients with IBD?***

Yes, it is important that in addition to possessing the standard skills, the therapist be genuinely interested in treating patients with IBD. The therapist should be thoroughly familiar with the normal and erratic course of these illnesses, should be acquainted with the various complications of IBD, and familiar with the various drug therapies utilised. It is also of the utmost importance that the physician rendering the primary care for the IBD and the psychotherapist maintain close

working relationship, so their efforts to help the patient are cooperative.

***How are youngsters affected by IBD in terms of its emotional impact?***

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. Thus, the percentage of individuals who manifest emotional problems in conjunction with IBD is somewhat higher in the younger age groups, among teenagers and young adults, than among older adults. Otherwise, the principles mentioned earlier apply to youngsters as well as adults.

***Is there an effect of ileostomy surgery on the patient's emotional state or coping ability?***

Surgery is recommended for a minority of patients with IBD, when drugs cannot control the disease. 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 benefit. With modern surgery and pre- and post-operative care, the dangers of serious complications from surgery are quite low. Some patients who have not been able to be helped by medical drug treatment or standard resections of the bowel may have to undergo surgery for the creation of an ileostomy. This form of surgery poses some additional problems of adjustment. However, most patients with the help of informed and informative physicians can more easily cope with the problems. The Ostomy Society addresses these questions in their numerous publications and meetings, and can often provide very helpful counsel for the surgery patient both during the pre-operative stage and following the surgery. This counsel is usually provided through an extensive in-hospital and home visitation program. One of the major concerns expressed at this time is about acceptability by sexual partners. Experience has shown that sexual activity is improved rather than worsened, especially in patients who were acutely ill prior to surgery.

***Could you list some of the attributes in patients with IBD that might contribute to a good prognosis?***

Ideally the patient should accept IBD realistically, without self pity, without guilt feelings, and without blaming others for his or her illness. If possible, the patient should deal with the disease in a straight forward and matter-of-fact fashion and learn about the disease and treatments. This will make it easier for friends and family to accept the illness as part of their relationship with the patient.

The patient should go about his or her daily activities as much as possible, follow physician's instructions and maintain a positive attitude and optimistic outlook upon life.

The patient should have the drive to get back to life if he or she has partially withdrawn, and should not attempt to escape the realities of life by retiring to a sick bed.

The patient should not use his or her illness to manipulate others in the family and should seek help from family members only when necessary.

It should be emphasised that following the physician's advice with respect to clinical treatment is an important aspect of coping with illness.

***What is the role of self-help groups such as the CCSG?***

In general, patients adjust better to their disease once they understand it. A common comment is that "surprises frighten me more than facts". Reassurance, explanation and educational materials are important components of treatment. The experience of physicians is that patients benefit from talking with others who share the same experiences and as a result encourage their patients to join self-help groups such as the CCSG.