

EMOTIONAL FACTORS

What about emotional factors?

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 effect can IBD have on peoples' 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 people 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 people who think like this are 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. 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 ulcerative colitis. Who is right?

When lay people and sometimes doctors speak of colitis, they may mean the specific disease ulcerative colitis, or they may be referring to a completely different condition known as 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 chapter 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 symptoms 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 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 people 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 people with IBD 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 person thinking that IBD is caused by psychological factors, and that somehow the person 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 people could have done or could have avoided doing that might have prevented developing this disease. Guilt feelings are entirely unjustified and unwarranted.

My mood is up and down and I am so irritable with the children and my poor husband. I go to see a counsellor and come to terms with the illness, exhaustion, and feelings of guilt. My life has changed forever because of this disease; I feel I have been robbed of some of the early days, weeks, and months with my babies. I am stronger for the experience though; my relationship with Richard is deeper. - SUZIE

Indeed, they make it more difficult to cope with the difficult physical burden that people with IBD have to bear; it is therefore important to dispel such guilt feelings.

If someone continues to struggle with feelings of guilt despite reassurance, it might reflect that they have become clinically depressed (persisting guilt is one of a number of symptoms of depression). This should be discussed with a doctor and consideration given to specific treatment for depression or whether additional support is required.

Are family members justified in feeling guilty that they somehow brought on the disease in the person/relative with IBD?

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 person with IBD 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 medications administered by a specialist 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 CCNZ "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 people with IBD who are planning to travel?

Always tell your doctor about your travel plans. Learn the brand name and the generic name of your medication and be sure that you have enough supply to cover your needs. If possible, ask your doctor to give you some names of doctors who practice in the area that you plan to visit. It is advisable to carry with you a letter from your doctor 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 people with Crohn's disease 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 anti-anxiety medications recommended to cope with the anxiety and fear that goes with IBD?

Anti-anxiety medications can be very useful for some people but are not necessary for all. If anxiety is difficult to handle, anti-anxiety medications can be very helpful. There are a number of options. During the acute flare-ups of the disease, there may be a role for careful use of sedative (tranquilliser) medications which are very effective but can become addictive if taken longer term. Alternatively, if anxiety is a persistent problem, there may be a role for longer term medication treatment e.g. with a selective serotonin reuptake inhibitor (SSRI) a type of medication used for treatment of both depression and anxiety. Talk with your doctor if anxiety is a significant problem for you.

Is psychiatric consultation advisable for any people with IBD?

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

However, for people who wish to see a psychiatrist, or for people 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 people with IBD?

They can, in selected situations. Where possible, it is important to select those professionals who are specifically versed in dealing with people with IBD.

How can one go about finding the proper therapist?

Preferably, the attending doctor should be able to assist in finding the proper therapist. Sometimes other people with IBD can suggest the names of appropriate therapists. People with IBD 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 people 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 doctor providing the primary care for the IBD and the psychotherapist maintain a 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 together 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 a person with IBD's emotional state or coping ability?

Surgery is recommended for a minority of people with IBD, when medications 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 medications 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 doctors 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 people with IBD that might contribute to a good prognosis?

Ideally the person should accept IBD realistically, without self pity, without guilt feelings, and without blaming others for his or her illness. If possible, the person 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 person.

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

The person 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 person 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 doctor'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 CCNZ and CCSGs?

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 doctors is that people with IBD benefit from talking with others who share the same experiences and as a result encourage their patients to join self-help groups such as CCNZ and CCSGs.

This information is for general informational purposes and does not constitute medical advice. Please seek information and advice regarding your condition and/or treatment from your doctor.



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