



York Teaching Hospital
NHS Foundation Trust

Emotions following a diagnosis of Inflammatory Bowel Disease

Information for patients, relatives and carers

① For more information, please contact:

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Caring with pride

Introduction

People can experience a wide range of emotions when they are diagnosed with Inflammatory Bowel Disease (IBD). For some the diagnosis may come as a huge shock, while others may feel some relief that there is an explanation for the symptoms they have been experiencing.

Some common emotional reactions are:

- Shock / disbelief – “I can’t believe I have this illness”
- Numbness – “I cannot / will not think about this”
- Fear – “what does the future hold?”
- Anxiety – “I can’t cope with this”
- Anger – “who is to blame for this?”
- Sadness – “what has been lost, or what will be?”
- Resignation or Acceptance – “I’ll have to get on with it”

Remember that there is no right way to feel in the early stages. Being diagnosed with a chronic illness can change the way we feel about ourselves and the future, so it is very normal to experience a lot of strong emotions. Generally, these feelings should settle down in the following weeks and months.

Understanding new information

With IBD, there can be a lot of new information to take in. Your medical team will talk you through the details of your illness. This might include different treatments and medications, lifestyle changes, or things to expect in the future.

It can be difficult to process information when emotions are running high. Some people find it helpful to have a friend or relative with them at appointments to help them understand and remember the details. Taking away written information can also be helpful. Some people like to do their own research on the internet or through contacting support groups, while others already know about IBD through their past experiences.

Everyone is different when it comes to taking in new information. You might only want to know as much as necessary at first so as not to feel overwhelmed. On the other hand, you might want to know as much as possible in order to feel more in control. It is important to talk to your medical team about how you are feeling in the early stages so that they can understand how to best support you in understanding and managing your illness.

Can stress or negative emotions alone cause IBD?

There is no evidence that stress or negative emotions can cause IBD to develop. It is not known exactly why some people get IBD, but it is thought to be a combination of genetic, environmental, and biological factors.

Does IBD cause any emotional problems?

Living with IBD can be challenging and people often find it difficult to talk about, particularly as we tend not to talk about our bowels in everyday conversation. The impact of the symptoms can cause a range of feelings such as frustration, sadness, and anxiety.

Do emotions play any role in the symptoms?

There is some evidence that stress and negative emotions can make symptoms worse in people with IBD. Again, it is not known exactly how this happens, but all emotions can affect the way the body is working, and we generally tend to feel more unwell when stressed or upset.

Does that mean I need to avoid getting upset?

We all experience negative feelings at times and it is not possible to avoid this. Sadness, stress, frustration and anxiety are all normal human emotions. Remember that these emotions are **not** the cause of IBD. However maintaining a sense of psychological wellbeing as part of management of IBD is beneficial, and it can be useful to seek help if you are experiencing strong negative emotions very frequently.

Coping with IBD in the longer term

Over time, most people find that they will adjust emotionally to a diagnosis of IBD. This can mean different things to different people; however, it usually requires finding ways to live with IBD without it getting in the way of the things that are most important in life. This might include making changes to lifestyle or diet, or getting into a routine with treatment and medication. We know it is helpful for people to feel a sense of control over their IBD and its management.

It is also important that people feel supported by others. This might be mainly from family and friends. However, it is also important to be open and honest with your Consultant and IBD Nurses. If you are really struggling with your emotions, they can talk to you about the possibility of being referred for counselling or psychological support. It can also be helpful to have contact with other people living with IBD, which can be helped by attending a 'Newly Diagnosed event' at the hospital or through organisations such as Crohn's and Colitis UK (www.crohnsandcolitis.org.uk).

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

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Teaching, training, and research

Our Trust is committed to teaching, training, and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

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PALS can be contacted on 01904 726262, or email pals@york.nhs.uk.

An answer phone is available out of hours.

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