



## INFORMATION SHEET

# COUNSELLING FOR IBD

## INTRODUCTION

If you have Crohn's Disease, Ulcerative Colitis or another form of Inflammatory Bowel Disease (IBD), you may find at times that your illness has a considerable impact on your life and emotional wellbeing. If this occurs, you may find it helpful to talk to a counsellor. This information sheet looks at what is usually meant by counselling, how it may be able to help you, and ways to find a counsellor or therapist.

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In my experience, admitting the “need” for counselling is a significant part of the process. It's not an instant transformation, and you'll still have bad as well as good days. But I found it a good outlet to talk about the issues that I didn't feel comfortable discussing outside. It has definitely helped me get through periods of struggle with my condition.

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**If you feel that your diagnosis or any aspect of living with IBD has caused great distress or aggravated a mental health condition such as depression, you should notify your GP immediately, call the Samaritans on 116 123, or attend your nearest Accident and Emergency if you feel at risk of harm to yourself.**

## WHAT IS COUNSELLING?

Counselling is a ‘talking therapy’. While some people feel that support from friends and loved ones is enough to get them through difficult times, counselling can offer a safe, confidential place to talk about your concerns in a way you would not normally do with friends and family. Counsellors are specially trained to listen to you carefully. They will not judge you or tell you what to do, but should listen to what you are saying, and help you make sense of your world by exploring your thoughts and feelings. They will try to understand the issues that are causing you concern, and help you find ways to cope with them.

Sometimes counselling may be referred to as psychotherapy, or just ‘therapy’. These words are often used interchangeably as ‘umbrella’ terms that cover a range of talking therapies.

## ARE THERE DIFFERENT KINDS OF COUNSELLING?

There are many different types of counselling or talking therapy. Examples include Cognitive Behavioural Therapy (CBT), person-centred therapy, psychodynamic therapy and mindfulness therapy. Different therapists will have had different training, and will have different ways of working with people. Some will use one type of therapy, while others may incorporate techniques from several forms of therapy.

There is currently no conclusive evidence that one method is more suitable than another for people with IBD. The type of therapy that works best for you will depend on the particular issues you are facing, and the type of support you need. Also, there is some evidence that the strength of the relationship between you and the therapist matters more than the type of therapy used.

Counselling may be given in different ways, for example one-to-one, in groups, as a family or as a couple. It can take place face-to-face, by telephone or online.

More information about types of therapy can be obtained from organisations such as the British Association for Counselling & Psychotherapy (BACP), and the United Kingdom Council for Psychotherapists (UKCP). See **Other Organisations** at the end of this information sheet for contact details.

## HOW CAN COUNSELLING HELP ME?

Being diagnosed with a long-term illness can trigger many different emotions. You may feel shocked, scared, angry or depressed. Not knowing what might happen in the future may make you feel helpless and uncertain, and you may even have feelings of guilt or shame. Certain aspects of the illness may start to affect your everyday life. For example, the side effects of medications and surgery can lead people to struggle with body image and self-esteem. Anxiety and embarrassment around needing the bathroom frequently when away from home can also be a significant worry. These feelings are not uncommon, and are experienced by many people with IBD from time to time. For some people these feelings can become overwhelming, and are made much worse by past events and experiences. If this is the case for you, it can be helpful to talk through what you are feeling with a counsellor.

For some people, talking over their worries with a friend or family member is enough. But for others, it can be very helpful to talk to someone who is not emotionally attached, and can look at things from a different perspective. A professional counsellor can do this.

Some people may find it difficult or embarrassing to talk to someone about their feelings. Or, they may worry that seeking counselling might be seen as a sign of 'weakness'. However, seeking counselling shows that a person has acknowledged their difficulties, and is taking responsibility for resolving them. Seeking help takes honesty and courage. Taking action in this way can help you feel more in control of your life and the difficulties of living with IBD.

While counselling cannot remove your IBD, it can help you to feel stronger despite having the condition. The counsellor can offer you support and encouragement in trying to disentangle your difficulties, and examine the way you see your illness and its impact on your life. This can make a real difference in helping you manage your condition. Some studies have shown that people with IBD feel more able to cope with symptoms after receiving psychological support, and are more likely to continue taking their medications.

You may find counselling helpful whether you are newly diagnosed or have been living with IBD for some time. It may be particularly useful if you have recently had, or are preparing for, surgery. Young people in particular may find counselling very helpful in coming to terms with their condition. If you are living with IBD, counselling may also be beneficial for your family, as the condition can often affect loved ones.

## CAN COUNSELLING HELP REDUCE STRESS?

Many people with IBD feel that stress plays a role in their symptoms. Research also suggests that in some cases, stress may trigger flare-ups or make symptoms worse. Although more research is needed, some people with IBD have found that their stress levels reduced after counselling, which led to improvements in their IBD symptoms as well as psychological wellbeing.

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Never knowing when you might flare, you can find yourself being overcautious about everything, which then impacts your enjoyment in life. Learning to retrain your mind in how you handle things, and reminding yourself it isn't your fault, takes away some of the anxiety of the condition.

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Leanne, age 25  
diagnosed with Crohn's Disease in 2007

## HOW CAN I FIND A COUNSELLOR?

There are a number of different ways to find a counsellor.

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I received counselling from a specialist IBD therapist through the IBD team at my hospital. I was struggling to accept the need to take such powerful medication with potentially serious side effects. It also helped me immensely to address the anxiety I was feeling about leaving the house in the morning. My IBD therapist encouraged me to challenge and eventually overcome my concerns.

”

Helen, age 38  
diagnosed with Ulcerative Colitis in 2006

- **Your GP**

It is worth asking your own doctor about counselling first, as your GP surgery may employ a counsellor. If not, your GP may be able to refer you to other counselling services that are provided by the NHS. However, there is often a long waiting list for NHS counselling, and you may have limited choice over what type of therapy you receive.

- **Your IBD team**

A small number of hospital IBD clinics may provide access to counselling or psychological support. IBD therapists will have a detailed understanding of the specific issues associated with IBD, which can be helpful for those who may feel embarrassed at having to explain their symptoms to a counsellor.

- **Improving Access to Psychological Therapies (IAPT)**

IAPT is an NHS service in England that offers therapies to help people with anxiety and depression. Each IAPT service may be referred to locally by a different name. In some areas it may be possible to self-refer yourself through a Single Point of Access (SPA), which means you do not need to go through your GP if you don't want to. It may be helpful to advise the person making the telephone assessment that you have IBD, as many IAPT services prioritise long-term health conditions and you may be seen sooner. IAPT is not currently available in other areas of the UK, but your GP may be able to advise you on other options.

- **It's good to talk**

“It's good to talk” is the British Association for Counselling & Psychotherapy's national online directory, designed to help you find a reputable and suitable counsellor or psychotherapist in your area. Therapists on the register have specialist skills and knowledge, and have undergone training and supervision. You can search by area, by therapy need, by type of approach or by therapy offered in languages other than English. See **Other Organisations** for contact details.

- **Employer or place of education**

Another possible source of free counselling may be through your employer, if you are working, or your university or college, if you are a student. Many larger employers provide Employee Assistance Programmes that usually include confidential counselling services that are independent of the employer. School-based counselling is universal in Wales and Northern Ireland.

- **Local voluntary sector services**

You may find there are local voluntary sector counselling services, which you can approach directly. Such agencies may offer free counselling, or charge according to your income. However, there is often a waiting list. You could search online or check your local phone book for a list of counselling organisations. You could also contact your library or local Citizens Advice, who may be able to help.

- **Private counselling**

If you want to see a private counsellor, you will be charged a fee. Some counsellors may offer reduced rates if you are on a low income or claiming benefits. An advantage to private counselling is that you may be able to choose someone who can see you immediately. However, there are currently no laws covering who can call themselves ‘a counsellor’. It is important to check that they are a member of a professional body such as the British Association for Counselling & Psychotherapy (BACP) or the United Kingdom Council for Psychotherapy (UKCP). Both of these organisations have lists and contact details for professionally accredited

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Counselling has helped me to accept the negative feelings I had about my condition. It made me see that my illness is something to live with but must not define who I am. Through counselling I found the strength to be more assertive at work in requesting reasonable adjustments without feeling that I was making unreasonable requests.

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counsellors and therapists who have agreed to practice according to a Code of Ethics and Practice. Both BACP and UKCP have a complaints procedure. They also provide guidance on how to choose a counsellor or psychotherapist. See **Other Organisations** for their contact details.

- **Private health cover**

If you have private health cover, you may be able to access counselling through your provider. The amount of counselling you can have may depend on the type of provider plan you have.

## WHAT HAPPENS ONCE I'VE IDENTIFIED A POTENTIAL COUNSELLOR?

Your first contact with any counsellor or therapist will probably be by telephone or face-to-face, although you may be able to contact some by email. You can explain some of your reasons for seeking counselling, so that you and the counsellor can work out whether they may be able to help you.

Counsellors will expect you to have questions, so feel free to ask them any you may have. You may wish to ask about their experience, including whether they specialise in certain problems, or have helped people with similar problems to you. Some counsellors specialise in helping people with long-term illnesses, and you may find this type of experience especially relevant. Other things you might like to discuss include:

- The type of counselling that will be used
- Where the sessions will take place
- The frequency and number of possible sessions
- The cost of each session if relevant
- Arrangements for cancellation, for example if you cannot make an appointment at short notice.

You may wish to ask for a written agreement that includes the cost and number of sessions you might have.

Some counsellors offer a preliminary meeting, after which you can decide whether the counsellor and the therapy they offer are right for you. In some cases, there will not be a charge for the initial meeting.

Remember that a good relationship with your therapist is one of the key things that determine whether the counselling is successful. It is important that you have confidence in your counsellor, and feel comfortable talking about all aspects of your illness with them. If you feel any hesitation about the counsellor, or if the relationship is not working out as you would like, it may be helpful to tell the therapist. You do not have to continue with them, and should be free to find another counsellor.

## WHERE CAN I FIND OTHER FORMS OF SUPPORT?

Having support is important for everyone and especially so if you are living with a long-term illness. It can make all the difference in coping with illness and to your quality of life. Living with an ongoing condition can put a strain on relationships with partners, family and friends. Being open with them and sharing your feelings and concerns can help. You could also show them some of our leaflets and booklets such as **Living With IBD**.

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It can take a while to get going. You may feel shy or even doubt the things that you want to discuss for fear of being judged. But the more you talk about things that are on your mind, the more they can help you, no matter how big or small they are.

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**Steph**, age 28  
diagnosed with Ulcerative Colitis in 2008

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The web forums are very reassuring for me when I'm ill as there's always someone else there who can empathise with what I'm going through. Now I'm generally well, I like to share my own positive stories in the hope that it will help and inspire other people with IBD.

”

Ellie, age 21  
diagnosed with Ulcerative Colitis in 2013

Your health team may include a specialist IBD nurse. Specialist nurses often provide considerable support and can usually be reached by phone.

Many people with IBD find it useful to talk to others who also have Inflammatory Bowel Disease. While this isn't traditional counselling, many people find sharing their experiences with a supportive group to be therapeutic, as others with IBD can offer emotional support and tips for coping with the disease. You may be able to find a group for people with IBD by asking your IBD nurse or team, or becoming a member of our online forum. See **Help and Support from Crohn's and Colitis UK** below for details.

## HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

We offer more than 45 publications on many aspects of Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease. You may be interested in our comprehensive booklets on each disease, as well as the following publications:

- **Living With IBD**
- **Fatigue and IBD**
- **Taking Medicines**
- **Managing Bowel Incontinence in IBD**
- **Sexual Relationships and IBD**
- **Living With a Stoma**
- **Talking to my child about my IBD**

All publications are available to download from **[www.crohnsandcolitis.org.uk/publications](http://www.crohnsandcolitis.org.uk/publications)**. Health professionals can order some publications in bulk by using our online ordering system.

If you would like a printed copy of a booklet or information sheet, please contact our helpline.

Our helpline is a confidential service providing information and support to anyone affected by Inflammatory Bowel Disease. Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

Call us on **0300 222 5700** or email **[info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk)**

See our website for WebChat (Live Online): **[www.crohnsandcolitis.org.uk/livechat](http://www.crohnsandcolitis.org.uk/livechat)**

### **Crohn's and Colitis UK Forum**

This closed-group community on Facebook is for everyone affected by IBD. You can share your experiences and receive support from others at [www.facebook.com/groups/CCUKforum](https://www.facebook.com/groups/CCUKforum).

### **Crohn's and Colitis UK Patient Panels**

IBD Patient Panels, which are supported by Crohn's and Colitis UK, are groups of people with Inflammatory Bowel Disease who use their perspective as a patient to work with their IBD healthcare team to help improve their hospital services. Visit the Crohn's and Colitis UK website for further information or email [patientinv@crohnsandcolitis.org.uk](mailto:patientinv@crohnsandcolitis.org.uk).

### **Crohn's and Colitis UK Local Networks**

Our Local Networks of volunteers across the UK organise events and provide opportunities to get to know other people in an informal setting, as well as to get involved with educational, awareness-raising and fundraising activities. You may find just being with other people and realising that you are not alone can be reassuring. Families and relatives may also find it useful to meet other people with IBD. All events are open to members of Crohn's and Colitis UK. Visit [www.crohnsandcolitis.org.uk/membership](http://www.crohnsandcolitis.org.uk/membership) to become a member.

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## **OTHER ORGANISATIONS**

- **British Association for Behavioural and Cognitive Psychotherapies (BABCP)**  
[www.babcp.com](http://www.babcp.com)
- **British Association for Counselling and Psychotherapy**  
[www.bacp.co.uk](http://www.bacp.co.uk)
- **British Psychoanalytic Council (BPC)**  
[www.psychoanalytic-council.org](http://www.psychoanalytic-council.org)
- **Citizens Advice**  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)
- **It's good to talk**  
[www.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.uk)
- **Mind**  
[www.mind.org.uk](http://www.mind.org.uk)
- **United Kingdom Council for Psychotherapy**  
[www.ukcp.org.uk](http://www.ukcp.org.uk)

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at [publications@crohnsandcolitis.org.uk](mailto:publications@crohnsandcolitis.org.uk). You can also write to us at Crohn's and Colitis UK, 45 Grosvenor Road, St Albans, AL1 3AW or contact us through the **Information Line: 0300 222 5700**.

### ABOUT CROHN'S & COLITIS UK

We are a national charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Disease. We have over 35,000 members and 50 Local Networks throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how, call **01727 734465** or visit [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

