

Mental health and wellbeing

Your guide when you have Crohn's or Colitis

When you have Crohn's or Colitis, it can be easy to prioritise looking after your physical symptoms. But coping with a long-term condition can have a big impact on your emotional wellbeing too - research suggests that people living with Crohn's or Colitis may be twice as likely to experience mental health problems as the general population.

But you're not alone. We're here to support you and this information will help you to:

- look after your mental wellbeing
- understand the link between Crohn's and Colitis and mental health problems
- recognise common mental health conditions
- find out how to get the help you need.

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Your mental wellbeing

Taking care of your mental health is just as important as taking care of your physical health. This is even more vital when you live with Crohn's or Colitis. Almost half of all people with the conditions say it has affected their mental health.

It takes guts to live with regular pain and fatigue, a condition that fluctuates and can cause distressing symptoms. Because many of these are invisible you might even play down how much they're affecting you. And if you're forced to cancel plans at short notice again, it can be tempting to turn your frustration inwards.

But it's important to remember that these feelings aren't irrational or a sign of weakness, and **you're not alone**. Understanding your condition and how it affects your mental health, learning what works for you and getting the support you need can help you to improve your mental wellbeing. **And we're here to help.**

“You don't have to put on a mask to cover up how you're truly feeling, it's OK not to be OK!”

Rebecca, 33 living with Crohn's

What is mental health?

Good mental health has been described as a state of wellbeing in which you are able to:

- feel relatively confident in yourself and have positive self-esteem
- feel and express a range of emotions
- build and maintain good relationships with others
- feel engaged with the world around you
- live and work productively
- cope with the stresses of daily life
- adapt and manage in times of change and uncertainty.

Good mental health and wellbeing allows us to connect with each other, earn a living and enjoy life. It's so much more than not having a mental illness.

Crohn's and Colitis and your mental health

Living with a long-term condition like Crohn's or Colitis can trigger lots of different feelings and emotions. You may feel anxious, frustrated, scared, or angry. Not knowing what might happen in the future may make you feel helpless and uncertain, and you may even have feelings of guilt or shame²³.

These feelings are completely normal, and many people with Crohn's or Colitis experience them from time to time. Long-term health conditions are a lot to deal

with, and it's natural that you might struggle to cope sometimes. Give yourself space to accept your feelings, and understand that they won't last forever.

For some people, these negative feelings can become overwhelming and stop you from living your life to the full. You may experience stress, anxiety, low mood, or depression. If this is the case for you, it can be helpful to understand more about your mental health, recognise the feelings and know what you can do.

A mood diary or [mood tracker App](#) can help you keep a record of how you're feeling. You can also share this with your health professionals.



Crohn's and Colitis and mental health problems can both be taboo subjects and difficult to talk about. The more you can share with friends, family, and your healthcare team the better it can be. Encourage them to try our **In My Shoes: 24 Hours with Crohn's or Colitis** app, this app allows anyone to experience first-hand what it's like to have Crohn's or Colitis.

The It Takes Guts [talking](#) toolkit can help you start the conversation. If you want to tell people about your condition and your mental health so they know how it affects you - the toolkit can help. You'll find tools, tips and support to start a conversation that can change lives.

“Often the hardest thing is to admit to yourself that there's a problem. Don't be afraid to talk, those around you may already feel that something's wrong before you've recognised it. This can make starting the conversation easier.”

Peter, 58 living with Crohn's

How Crohn's and Colitis can affect your mental health

You're more likely to be at risk of experiencing mental health problems at certain times such as:

- when you're first told you have Crohn's or Colitis - at diagnosis
- when you have a flare-up and symptoms come back after you'd been feeling better
- after you've had surgery - especially if it leaves scarring or you have a stoma.
- experiencing side-effects of your treatment for Crohn's or Colitis. If you're taking steroids you may experience extreme highs and lows in your mood. Find out more in [Steroids](#)
- if your condition stops responding to the medicines you're taking
- living with ongoing invisible symptoms such as fatigue or pain.

It can help to be aware of the time when you may be more at risk of changes in your mental wellbeing. You can get then get the help and support you need.

When the condition is active around 6 out of 10 people have been shown to experience mental health problems, compared to up to 2 out of 10 when gut symptoms are better.

Body image and self-esteem

The physical changes you may experience can affect the way you feel about your body. This could be due to Crohn's or Colitis directly such as changes in weight, scarring from operations, or you may be coming to terms with a stoma. Unwanted effects from some medicines such as steroids might mean cosmetic changes such as a rounded "moon" face, growth of unwanted body hair or stretch marks, can also affect how you feel about yourself. It can be hard to get used to how your body may look or feel.

A poor body image can impact on your self-esteem and may mean you avoid social situations, experience social anxiety or symptoms of depression or disordered eating. Feeling this way can also have a big impact on your sexual relationships. See our information on **Sexual Relationships** for more support.

Blaming yourself

You might wonder if it's something you've done that means you now have Crohn's or Colitis and blame yourself. For some people it may trigger feelings of hostility or resentment to other family members - why me not them? If this is how you feel it can be more difficult to adjust to the 'new normal' of living with the condition. It's important to remember that your condition isn't your fault - there's nothing that you did or didn't do that caused your Crohn's or Colitis.

Stigma and isolation

Gut symptoms and mental health problems may both leave you feeling stigmatised and isolated. This may be because diarrhoea, pain, or fatigue limit how much you can go out with friends and family, which sets you apart. These feelings can increase the risk of depression or anxiety.

Finding a community of people who understand what you're going through can really help. Crohn's & Colitis UK have Local Networks of volunteers across the country, or you can connect with people online through our Facebook Forum.

How your mental health can affect Crohn's and Colitis

Struggling with your mental health can make it more difficult to manage your Crohn's or Colitis and get the help you need. You might struggle to find the motivation to look after yourself, or find it easy to forget taking your medicine.

Getting the help that you need to improve your mental health can make a real difference to living well with your condition. We know this isn't always easy. But knowing what to look out for, understanding when you might be most at risk and talking to friends, family and your healthcare team can make a real difference. People who have their mental health under control have fewer flare-ups, feel

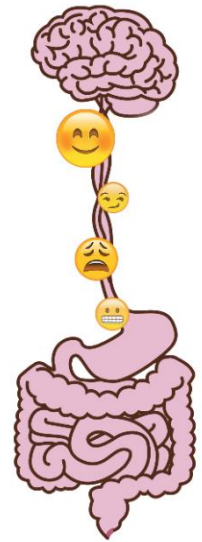
better able to cope with pain, and are less likely to have severe symptoms that require surgery or going to hospital.

Brain-Gut axis

There's also another relationship between Crohn's and Colitis and mental health - it's called the Brain-Gut axis. There's evidence of a direct two-way link between the gut and the brain. The term Brain-Gut axis refers to this direct link between mental and physical health in conditions such as Crohn's and Colitis.

Anxiety or depression can lead to new gut symptoms. Equally, experiencing symptoms in your gut has been linked to developing new psychological symptoms. The inflammation in your gut which causes some of the symptoms of Crohn's or Colitis can also directly affect how you feel.

The good thing is that keeping gut inflammation under control may directly help to improve your mental health. This makes it even more important to keep looking after yourself and find a treatment that works for you. Early evidence also suggests that some medicines used to treat mental health problems such as antidepressants may have a positive effect on improving gut inflammation.



Brain – Gut axis

Common mental health challenges

Stress

Stress is a natural part of life, and the sort of stress that you might experience if you're taking an exam or running a marathon can have positive benefits. But for many people with Crohn's or Colitis the ongoing stress of living with the condition can make symptoms worse and increase the risk of a flare-up.

The stress of some major life events such as moving to a new house, getting married or divorced have been found to be associated with a flare-up around three months later.

Anxiety

There are many reasons why you may become anxious when you live with Crohn's or Colitis. You may worry about possible symptoms and the fear associated with experiencing them.

“Going out can sometimes feel overwhelming and give you so much anxiety, always wondering where the toilet is, or worrying will I suddenly feel ill when I'm out.”

Ally, 23 living with Crohn's

These anxieties are not always constant but may arise in relation to a certain situation. So, anxiety can get worse if you don't have easy access to a toilet but then return to a normal when you reach home.

Or you may worry about treatment with medicines because of concerns about side effects or possible complications that might lead to going into hospital and needing surgery - even if the risks are small. You're more likely to have problems with anxiety when your condition is active. Getting your anxiety under control can decrease your chances of having a flare-up or needing steroid treatment.

Symptoms of anxiety can include:

- faster, irregular, or more noticeable heartbeat - [this can also be a symptom of anaemia](#)
- feeling lightheaded and dizzy- [this can also be a symptom of anaemia](#)
- headaches
- chest pains
- loss of appetite - [this can also be a symptom of Crohn's or Colitis](#)
- feeling tense or nervous
- worrying about the past or future
- feeling tearful
- not being able to enjoy your leisure time
- problems concentrating.

It may not always be easy to recognise that anxiety is the reason you're acting differently, and some of the symptoms may be like those of Crohn's or Colitis.

Find about more about Anxiety from [MIND](#)

Low mood

Everyone feels low or down from time to time and it's common after distressing events or major life changes, such as a diagnosis of Crohn's or Colitis, new symptoms or experiencing side effect from a medicine. But sometimes periods of low feeling can happen for no obvious reason.

Symptoms of low mood can include feeling:

- sad
- anxious
- more tired than usual or unable to sleep
- angry or frustrated
- low in confidence or self-esteem.

Low mood will often improve after a few days or weeks and there are some easy things you can try and small changes you can make that will usually help improve your mood. See [What you can do](#)

Depression

If the feelings of low mood last more than 2 weeks, it could be a sign of depression.

You're most at risk of depression when your Crohn's or Colitis symptoms are worse. But coping with the fluctuations and unpredictability of the condition can cause ongoing stress and you may experience anxiety and depression even if your symptoms are well controlled.

Symptoms of depression can include:

- not getting any enjoyment out of life
- feeling hopeless
- not being able to concentrate on everyday things.
- having suicidal thoughts or thoughts of harming yourself.

If you do have thoughts of suicide or harming yourself tell someone you trust, call the Samaritans on 116 123 or go to your nearest Accident and Emergency.

If you're experiencing depression, finding the motivation to look after yourself and take your medicines can feel impossible.³⁴ But getting your Crohn's or Colitis under control can also help improve your mental health.^{15,24}

To find out if you have depression your GP or IBD team are likely to ask:

During the last month have you often been bothered by

- feeling down, depressed, or hopeless?
- having little interest or pleasure in doing things?

Find out more about depression from [MIND](#)

Disordered eating

The effect that food has on your symptoms, together with needing to change your diet or take medicines like steroids that affect your weight, can change how you feel about eating. For some people this can lead to a difficult relationship with food such as binge eating or finding it hard to manage food avoidance or cravings.

Eating disorders, such as anorexia or bulimia, can occasionally cause similar symptoms to Crohn's and Colitis, including abdominal pain, weight loss and being sick. Because of this, some people find it difficult to get the right diagnosis. It is also possible to have Crohn's or Colitis and an eating disorder at the same time. But sometimes friends or family may make assumptions about eating disorders if you experience dramatic changes of weight. Find out more about eating well with Crohn's or Colitis in [Food](#).

What you can do to improve your mental wellbeing

“Somebody asked how I was looking after my mental wellbeing and that was the kick start I needed. Now I listen to audiobooks, go for regular walks, volunteer with Crohn’s & Colitis UK and our local community library “

Peter 58, living with Crohn’s

- Keep your Crohn’s or Colitis under control by taking your medicines regularly.
- Find a community of people who understand what you’re going through. Crohn’s & Colitis UK have Local Networks of volunteers across the country, or you can connect with people online through our Facebook Forum.
- Learn a about the condition and treatments from good sources of information such as [Crohn’s & Colitis UK](#). Understanding the benefits as well as risks of treatment, and finding new ways to manage troubling symptoms, can help relieve some of your anxiety. If you’re worried about any aspect of your condition, ask your IBD team or call the Crohn’s & Colitis UK [Helpline on 0300 222 5700](#).
- Talking about your Crohn’s or Colitis can help others to understand what you’re going through, and help you feel less alone. The [In My Shoes](#) app - can really help people friends, family, and colleagues to understand your condition.
- **Try an App** - there are many available to help you manage different aspects of your mental wellbeing and mental health. Try [MIND](#) or the [NHS](#) - who have assessed these to ensure they meet NHS standards. It may be a question of trial and error to find what works for you - but they’re not a substitute for accessing treatment.
- **Get help** - ask your health professional to arrange for you to see a psychologist or appropriate counsellor. See **Getting the help you need**. In some areas you may be able to [access mental health services directly](#).
- **Exercise** - There are very few ‘quick fixes’ when it comes to mental wellbeing, but regular exercise really helps. It could be the gym, a swim, or a walk with the dog. Doing a little exercise whenever you are able - even if you start with a few minutes each day - can make you feel better and help you sleep. It can reduce some of the emotional intensity you’re feeling. Work with whatever feels right for you - research shows benefit from low intensity walking, moderate intensity continual exercise and High Intensity Interval Training (HIIT). Building up your exercise levels can be a great goal and can help with fatigue too.



“I’d built up a lot of negativity around the condition, thinking that my body was useless, and I couldn’t do all the things I wanted to do. Running helps me push back those negative thoughts and know that my body can still do stuff. I soon realised what a positive effect it was having on my mental health.”

Tom, living with Crohn’s

If you have a stoma [Colostomy UK](#) have exercises for you

- **Relaxation** - Relaxation techniques can reduce anxiety, pain and stress levels and improve your mood.¹⁷ it’s important to find time to focus on yourself, even with a hectic schedule. MIND have some great tips for [relaxation](#)
- **Give back to the community** - Volunteering can boost your mental wellbeing by involving you with your community, gaining new skills and providing a sense of pride and achievement. It can also help you connect with other like-minded people and reduce isolation. Crohn’s & Colitis UK offer many exciting [volunteering opportunities](#), some of which can be done from home.
- **Talking - to friends and family** - Talking about things can help you process what you’re going through and give you a fresh perspective. For some people, talking over their worries with a friend or family member is enough, while others may benefit from talking to a trained counsellor.

If you find it tricky to start the conversation try the It Takes Guts tool - [Talking about mental health](#)



Getting the help you need

Your GP or IBD team should be able to arrange for you to get the psychological support you need. This is especially important if you’re managing pain or fatigue or if you’re being considered for stoma surgery. The type of therapy that works best for you will depend on the challenges you are facing.

All IBD teams are different, but the IBD standards and NICE state the team should include access to a psychologist or counsellor. **Don’t be afraid to ask to see these health professionals.**

Treatments

Talking therapies.

“I was struggling to accept the need to take such powerful medication with potentially serious side effects. My therapy encouraged me to challenge and eventually overcome my concerns.”

Helen, 38 living with Ulcerative Colitis

There are different types of talking therapies available. Some studies have shown that people with Crohn’s and Colitis feel more able to cope with symptoms after receiving psychological support, and are more likely to continue taking their medicines.

But remember that feeling better takes time, and that your mood is likely to improve gradually, not immediately.

“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.”

Leanne, 25 living with Crohn’s

Although more research is needed, some people with Crohn’s or Colitis have found that their stress levels reduced after talking therapies, which led to improvements in their gut symptoms as well as psychological well-being.

Acceptance and Commitment Therapy - ACT

Acceptance and Commitment Therapy (ACT) is a talking therapy that starts by accepting that Crohn’s or Colitis won’t go away. It encourages you to focus on positive activities that you value, even when symptoms continue.

The aim is to encourage you to adopt positive life values and to accept adverse experiences, including thoughts, feelings, and sensations that are an inevitable part of life with Crohn’s or Colitis. ACT doesn’t try to get rid of negative thoughts or feelings but encourages you to accept that these exist while at the same time making a commitment to move toward your values. ACT uses a range of different training exercises to help you become open, aware, and active.

ACT is also being studied to see if it is effective in improving people’s ability to cope with long-standing pain in Crohn’s Disease.

Mindfulness

Through practising yoga, meditation, music, art, or something else you enjoy, focusing on the present without drifting into concerns about the past or future can really benefit your mental health.

Mindfulness interventions build on this. In Crohn's and Colitis, the aim is to develop skills for managing stress. This has been shown to improve mood and these improvements have lasted for over 6 months after the treatment stopped. It's also been shown to help alongside medicines to improve psychological³⁰ symptoms and to help people cope with symptoms during a flare-up.^{17,31}

“Being in the present moment is my key... you can't change the past or control your future. Being in the present moment and taking it day by day really helps me to reduce anxiety.”

Sharon, age 40 living with Colitis.

Cognitive Behavioural Therapy (CBT)

The aim of CBT is to help you explore and change how you think about your life, and free yourself from unhelpful patterns of behaviour. You set goals with your therapist and may carry out tasks between sessions. For example, you may learn to catch and change unhelpful thinking patterns, try relaxation exercises, and change behaviours like avoiding going out and isolating yourself.

This type of therapy has been shown to improve depression and anxiety in people with Crohn's and Colitis.

“It's important to recognise negative thinking habits and challenge them. If I feel ill, it's probably because I ate something that disagreed with me rather than a flare-up. And even if it is a flare-up, there's a lot I can do to manage it.”

Sarah, 36 living with Crohn's

Medicines

Around 3 out of 10 people with Crohn's and Colitis take antidepressant medicines to manage depression or anxiety. But currently there aren't any guidelines to suggest which ones might be most effective. Find out from [MIND](#) about medicines are available. Your GP or IBD team can talk you through the pros and cons of these approaches for you.

Some of these medicines may help with other symptoms such as pain. Early studies suggest they may also influence inflammation outside the brain and so improve not only mood but some gut symptoms. Research is continuing in this area, some of which is supported by [Crohn's & Colitis UK](#).

Organisations that can help

MIND - www.mind.org.uk

Samaritans - www.samaritans.org

Every Mind Matters - www.nhs.uk/oneyou/every-mind-matters

Lifeline - for people living in Northern Ireland www.lifelinehelpline.info

Breathing Space - for people living in Scotland breathingspace.scot

Help and Support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning publications on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships, school and employment. We'll help you find answers, access support and take control.

All publications are available to download from our website:
crohnsandcolitis.org.uk/publications

Our helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- help you understand more about Crohn's and Colitis, diagnosis and treatment options
- provide information to help you live well with your condition
- help you understand and access disability benefits “
- be there to listen if you need someone to talk to
- help you to find support from others living with the condition

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk
See our website for LiveChat: crohnsandcolitis.org.uk/livechat

Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum

Help with toilet access when out and about

If you become a member of Crohn's & Colitis UK, you will get benefits including a Can't Wait Card and a RADAR key to unlock disabled toilets. This card shows that you have a medical condition, and combined with the RADAR key, will help when you need urgent access to the toilet when you are out and about. See our website for further information: crohnsandcolitis.org.uk/membership or call the membership team on 01727 734465.

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