

## **Supporting someone** with Crohn's or Colitis

<u>Crohn's</u> and <u>Colitis</u> don't just affect the person living with the condition. They can also have a huge impact on friends and family too. We're here to support you if you know someone living with the condition.

This information covers things you can do to help, and how to look after yourself at the same time.

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## Key facts about supporting someone with Crohn's or Colitis

- Crohn's and Colitis are the two main types of Inflammatory Bowel Disease, or IBD.
   They are not the same as irritable bowel syndrome (IBS).
- Crohn's and Colitis are lifelong conditions of the gut, but they can cause symptoms outside the gut, too. They can be unpredictable and they affect everyone differently.
- If you don't have Crohn's or Colitis, it can be difficult to understand what it's like. But even small things can help.
- Ask the person with Crohn's or Colitis what support they need or would like. This
  varies from person-to-person.
- Just being there to listen without judgement can be really beneficial.
- You may need to be flexible with any arrangements you make together. They might have needs you have not thought about, or be too unwell to attend at short notice.
- From a practical point of view, they may appreciate help with everyday tasks like shopping, transport to appointments, collecting prescriptions, or childcare.
- Remember that it's important to look after yourself, too.

## What do I need to know about Crohn's and Colitis?

Sam's my wife and I look after her, just the same as she looks after me when I've broken my ribs snowboarding or whatever. Her IBD doesn't embarrass me - I am there no matter what for her.

#### Timm

Husband of Sam, living with Colitis

<u>Crohn's Disease</u>, <u>Ulcerative Colitis</u> and <u>Microscopic Colitis</u> are all types of Inflammatory Bowel Disease, or IBD. The main symptoms include tummy pain, <u>diarrhoea</u>, <u>fatigue</u>, and weight loss. Not everyone has all of these symptoms, and they might be worse in some



people than others. Crohn's and Colitis can also affect parts of the body outside the gut, causing mouth ulcers, joint pain, and problems with the eyes, skin, bones or liver.

Treatment for Crohn's and Colitis varies from person-to-person. It may include tablets, injections, drips (intravenous infusions), enemas, specialist liquid foods, or surgery.

If you don't have Crohn's or Colitis, it can be difficult to understand what it's like. You could ask the person affected to try to explain, but remember it isn't always easy to talk about bowel problems. Our <u>talking toolkit</u> might help them find the right words.

Key points to remember about Crohn's and Colitis:

- They are lifelong conditions. Treatment can help keep Crohn's or Colitis under control, but symptoms can flare up again. Right now, there's no cure. But we're helping fund <u>research</u> to improve the lives of people affected by Crohn's and Colitis and eventually find a cure.
- They affect everyone differently. You may know someone whose symptoms rarely trouble them, but others may need <u>surgery</u> or lifelong <u>medicine</u>. The way each person is affected can also change over time.
- IBD is not the same as IBS. Irritable bowel syndrome (IBS) can cause some symptoms that are similar to Crohn's or Colitis. Although IBS can be difficult to deal with, it can usually be managed with lifestyle changes and medicines that you can buy from pharmacies. Unlike Crohn's or Colitis, IBS does not cause bowel inflammation or blood loss. It's generally less serious than IBD.
- They are invisible conditions. A person may seem perfectly fine on the outside even if they have painful and distressing symptoms.
- They are unpredictable. You may be confused when you see your friend or relative
  out and about when just last night they cancelled plans with you, but symptoms
  can change a lot from one moment to the next.
- Crohn's and Colitis are not contagious. You can't catch Crohn's or Colitis by spending time with someone who has it. There's nothing your friend or family member could have done differently that would have prevented them from developing it.



The more you know about Crohn's and Colitis, the more you'll be able to support someone living with the condition. There's a lot of misleading information online, so it's best to focus your search on reliable sources such as Crohn's & Colitis UK or the NHS website. Our information all about Crohn's and Colitis is a good starting point. We also have information on a wide range of topics, from food and medicines to coping with symptoms and everyday life.

Before you start finding out about Crohn's and Colitis, it's important to check how much your friend or relative wants you to know about their condition. Some people may feel their privacy is being invaded if their friends know details about the symptoms they're having. Or that their parents are trying to take control from them by doing all the research on possible medicines. Some people want to avoid knowing too much about their condition altogether, so telling them facts about it may be unwelcome. Discussing this beforehand, or reading about the condition together, can help avoid misunderstandings.

## How can I help my friend or loved one cope when they're unwell?

It's natural to feel anxious and helpless when someone you care about is unwell. It can be hard knowing that you can't take their condition away. The good news is that you can play a huge role in helping them live well with it. Crohn's and Colitis are largely hidden conditions that can cause stigma, fear and isolation. So just letting your friend or relative know that you're there for them can be a great comfort. Here, we outline some simple things you can do to support them emotionally.

• Be there to listen if they want to talk. Sometimes they might prefer just to carry on as normal and not talk about their illness. But at other times they may appreciate someone to open up to. They might find that some people dismiss what they're going through, like comparing it to IBS or suggesting it can be cured by changing their diet. It's important to show that you believe them when they talk about their symptoms, and that they are not a burden to you. Instead of feeling sorry for them, it's good to take time to really understand what they're going through.



 Help them see the funny side. At times, having a sense of humour about the situation can make them feel better. It can help them realise that they don't need to be embarrassed about their symptoms in front of you.

> Our son was an older teenager when diagnosed with Crohn's and as a family we were able to talk openly about the symptoms he was suffering via black humour. The 'Bristol Poo Scale' was a much-debated subject between us all!

#### Joanna

Parent of a son with Crohn's

- Put yourself in their shoes. Tasks that seem straightforward to you can be more difficult for someone with Crohn's or Colitis, and they may have concerns that you might not have thought about. For example, they may seem overly anxious about taking a long journey, or fussy about when and where they're going to eat. Try to understand that quick access to toilets can be crucial, and being careful about their diet may be a key way they manage their symptoms. Try not to judge if they seem reluctant to do heavy housework or work long shifts. It is not a sign of laziness it's likely to be more than they can physically manage in a day. It helps to be flexible and accommodating in your plans and to consider their needs. You could try our <a href="In My Shoes app">In My Shoes app</a>, which helps friends, family or colleagues experience what it's like to live with Crohn's or Colitis for 24 hours.
- Help boost their confidence if they start to look different. Surgery scars or weight changes can have a negative effect on body image, so they may appreciate reassurance that you don't see them differently. Some people with Crohn's or Colitis may also have a feeding tube going into their nose to provide them with nutrients when they're not able to eat. They may feel self-conscious about this, especially when it means they can't join in at mealtimes. Others may need <u>surgery</u> to have part of their bowel removed. This may mean they no longer poo through their bottom. Instead, their bowel is brought out through the wall of their tummy,



and they wear a stoma bag that collects the poo. We have separate information on <a href="living with a stoma">living with a stoma</a> if you'd like to find out more about how they work.

Multiple medications and diet restrictions can cause problems with family and friends who don't understand I have to take a tablet at a set time or eat something now. Many times, I've found myself in a challenging situation because the people I'm with don't want to eat yet! I carry snacks and water wherever I go.

#### Julia

Living with Crohn's

- Be understanding when they can't make it to an event or cancel plans at the last minute. Crohn's and Colitis can be very unpredictable, which can make planning things in advance more challenging. Your friend or loved one likely feels disappointed about letting you down, so it's important to understand that it's out of their control. It's helpful to reassure them that it's no trouble to make adjustments. Living with Crohn's or Colitis may also have caused a strain on their finances. They may not be able to work full-time or in stressful roles while they're unwell, or they may struggle with prescription costs and transport to hospital. This can mean some tough decisions about what they can afford to say yes to. If possible, find a way to work around their situation so they can still be involved. For example, you could go to see them at home if they're unable to attend an evening out.
- Keep them in the loop when they've missed something. If they're regularly missing out on work, school or social events because of ill health, they can feel isolated. This can have a negative effect on their mental health. Keeping them updated on what's been going on will help them feel that they're still part of the group. It also helps them to feel like themselves, and not like they're defined by their condition.



While it's important to be mindful of not making them feel left out, it can be nice for them to know you haven't forgotten about them.

After meeting a very special person almost 7 years ago, it still amazes me to this day how strong he is. After being diagnosed he fully took it in his stride and will always continue to fight the battles that face him. If his experience has taught me anything, we all face our own challenges and we will never know what someone is going through. But having the people around you who love and care about you makes the challenges worth fighting.

## **Emily**

Friend to a person living with IBD

- Don't judge their food choices. It's understandable to think that gut issues may
  have been caused by poor diet. But there's no evidence that any particular food
  can cause or cure Crohn's or Colitis. The relationship with <u>food</u> is different for
  everyone living with Crohn's or Colitis. Foods that may help one person may do
  nothing or even make symptoms worse in another.
- Join in with raising awareness. This is a great way to show your friend or relative that you're not embarrassed by their condition, and you're passionate about helping them. You could follow <a href="Crohn's & Colitis UK">Crohn's & Colitis UK</a> on social media, raise money at a school bake sale or campaign to make us Charity of the Year in your workplace. You could get together with a group of friends to <a href="fundraise">fundraise</a> or take part in one of our <a href="events">events</a>. Make sure the person with Crohn's or Colitis is comfortable with what you're planning. And check they're OK with others knowing about their condition if you plan to mention their name. We have more information on how you can <a href="make">make a difference</a>.



Help them find a community if they want to. Helping your friend or loved one connect with other people who know what they're going through can be really beneficial. People with Crohn's or Colitis who take part in events run by their hospital or our <u>local networks</u> often say it helps them feel that they aren't alone. We also offer <u>virtual social events</u>, which can be a great way to connect with other people even if they don't feel up to going out. But this is not for everyone, so check what your friend or family member is comfortable with.

## Is there anything practical I can do?

As well as emotional support, you may be able to offer help with the practical challenges of living with Crohn's or Colitis. Striking a balance between helping and letting your friend or loved one control their own life can be tricky. As with anyone, it's important for people with Crohn's and Colitis to maintain as much of their independence as possible. Everyone is different, and some people appreciate more support than others. It's important to talk to your friend or family member to find out what they need. This will vary from person to person. It could involve things like helping with housework, shopping, or arranging childcare.

I find it hard that I can't really do anything to help. I can't cure it and when she's ill I can't make her feel better. You feel pretty useless. It's important to allow yourself moments of anger and sadness, because if you don't, you'll just end up bottling it up and it will become too big.

#### Timm

Husband of Sam, living with Colitis

Remember to check that your friend or loved one is comfortable with the level of support you're providing. Things may change as they become used to dealing with their condition,



or as their symptoms vary. It's also important that you're happy with the amount you're helping, and you're not taking on more than you're able or comfortable with.

Here are some ideas on how you may be able to help with some of the key challenges of living with Crohn's or Colitis:

## **Fatigue**

Many people with Crohn's or Colitis experience fatigue. Fatigue is ongoing tiredness, lack of energy or exhaustion that doesn't improve even after rest or sleep. It can affect concentration and make it hard to remember things.

Although it sounds strange, exercise can improve fatigue. You could suggest doing some gentle exercise together, to make it more fun and less of a chore. But remember that sometimes your friend or loved one might not be able to manage even light activity. Having a regular sleep pattern is also important for people with fatigue, so try not to make regular plans that you know interfere with their usual bedtimes.

If they're finding it difficult to focus, you could help by sharing your class or work notes with them. You can plan more relaxing ways to spend time together when your usual activities may be too much of a strain. Or catch-up online if they don't feel up to meeting in-person. Offering a lift so they don't have to drive or deal with public transport can also be an enormous help.

You might find our **information on fatigue** and ways to cope with it helpful.

#### Pain

Crohn's and Colitis can cause severe tummy, joint or back pain. You could ask what helps your friend or family member manage their pain, and support them with it. This may be yoga, avoiding certain foods, or taking the right pain medicine. Some people find hot water bottles helpful, but make sure they're not placed directly against the skin to avoid skin damage.



Some studies have shown that slow deep breathing and mindfulness exercises like meditation can help with pain. You can find lots of apps, online tools or in-person courses to help with this. You could try doing them together to make it into a fun routine.

You could help them keep a note of their pain or other symptoms so they can spot any patterns or possible triggers. You might also encourage them to keep a food diary if they want to find out if any foods affect their symptoms. But it's important that they don't make big changes to their diet without talking to their dietitian or IBD team. It could mean they miss out on nutrients that their body needs.

Pain can be difficult to describe to healthcare professionals, so you could help your friend or relative find the right words. They might say their pain is aching, cramping, stabbing, burning, shooting, tender or throbbing. This can be useful to tell their nurse or doctor, to help work out the best way to manage the pain. You could also help them rate their scale on a score of 0 to 10, where 0 is no pain and 10 is the worst pain they can imagine.

Never offer someone with Crohn's or Colitis non-steroidal anti-inflammatory drugs (NSAIDs). These include ibuprofen, diclofenac or high-dose aspirin. These medicines could make their symptoms worse. We have more about pain relief in our information on other treatments for Crohn's or Colitis.

Seeing someone you care about in pain can be distressing, especially when it feels like there's nothing you can do. Just validating their pain and helping them find ways to cope with it can go a long way. People who feel more in control and have better social support are able to cope better with their pain.

## **Medicines**

The thought of having to take medicines long-term can be overwhelming for some people with Crohn's or Colitis. Information about medicines and their possible side effects can be scary and difficult to process. Some people prefer their family to research it for them. We have information on <u>medicines used to treat Crohn's and Colitis</u> that you might find helpful.



You could also ask if they'd like someone to collect their prescriptions, remind them to take their medicines, or encourage them to keep taking their prescribed medicines even when they feel well.

Some medicines for Crohn's and Colitis need to be injected by the person themselves at home. This can be frightening at first, and having someone with them can put them at ease. A specialist nurse may be able to train you to help them, or to do their injections for them.

#### **Access to toilets**

People with Crohn's or Colitis sometimes need to use toilets urgently. Keep this in mind when planning trips or events. Try to be patient if you end up waiting for them for a while, or if they suddenly rush off to the toilet. Some people might also struggle with continence. We have separate information about <u>managing bowel incontinence</u>, including tips on helping them prepare if they're worried about episodes of bowel incontinence or accidental bowel leaks.

You could also encourage them to become a <u>member of Crohn's & Colitis UK</u>, or <u>gift membership</u> to them. By doing this they will receive a 'Can't Wait Card', which explains that they need to use the toilet urgently. They'll also receive a free Radar Key to unlock disabled toilets. People with Crohn's or Colitis are sometimes confronted about using accessible toilets by people who don't understand about invisible illnesses. They may appreciate having someone to support them in these situations.

## **Appointments and procedures**

People with Crohn's or Colitis might have lots of medical appointments. Dealing with these and fitting them into everyday life can be challenging.

You could help your loved one make a list of things they want to discuss at the appointment, to make sure they don't forget anything. You could offer to attend appointments with them to keep them company or to help them take in what the health professional says. Our information on <a href="mailto:medical terms">medical terms</a> might be useful to understand some of the terms you might hear.



People with Crohn's or Colitis sometimes need tests or procedures that require sedation. This can make them drowsy, so they're not allowed to drive or travel home alone afterwards. If you're able to, it's helpful to offer them a lift, and keep them company until they feel better again.

Some people with Crohn's or Colitis need surgery. Afterwards, they may feel weak and tired. They may be unable to do any lifting or driving for a while. Offering to do things like cooking and cleaning could be a great help so they can focus on their recovery. We have more information about <u>surgery for Crohn's Disease</u> and <u>surgery for Ulcerative Colitis</u>. It covers what to expect before and after surgery. It includes information on the impact of surgery on everyday life, which can be helpful for friends and families. It covers topics like diet, work, exercise, relationships, fertility and travelling.

Sometimes Sam would be so tired that she would forget things that the consultant had said, so I started going with her to appointments. It's just another pair of ears to listen and another voice to say the things that she might forget or not think about.

#### Timm

Husband of Sam, living with Colitis

## **Explaining to others**

You may be able to help your friend or loved one by advocating for them. For example, if someone questions why they often cancel arrangements or are picky about food or seem lazy, you could strongly but gently stand up for them. Helping others understand the impact of your friend's condition can be helpful, as long as it's something your friend is comfortable with. You could offer to help them work out what to say if they want to have these conversations themselves, so they can find the best way to explain what they want other people to know.



## Support at work or school

Some people with Crohn's or Colitis might need support or adjustments at work or school. You could help them find out what they need and how to get it. We cover these in some of our other resources:

- A guide for employees covers support people with Crohn's or Colitis are entitled to at work, and adjustments that can make coping with work easier
- A guide for employers outlines how employers and managers can help provide a safe, inclusive and supportive work environment for people with Crohn's or Colitis
- A factsheet for schools explains how school staff can support children with Crohn's or Colitis

<u>CICRA</u>, a charity supporting children with Crohn's and Colitis and their families, has more information for schools.

## **Financial support**

Depending on their circumstances, your friend or family member might need, or be eligible for, financial support. We have other resources about this:

- <u>Finances</u> covers financial support that may be available, like benefits, grants, and help with health, housing and transport costs
- <u>Disability benefits</u> lists benefits that some people with Crohn's or Colitis might be eligible for

We also have guides on who may be able to claim <u>personal independence payments</u> (PIP) or <u>disability living allowance</u> (DLA), and how to do it. It's important to know that having Crohn's or Colitis does not mean someone is automatically eligible for these benefits. Many people who apply may not be successful.

If they live in England, you could also help them buy an NHS <u>prescription prepayment</u> <u>certificate</u> to help with prescription costs. This is cheaper than paying standard prescription charges for anyone who needs 4 or more prescriptions over 3 months, or 12 or more a year.



## I'm worried about our relationship changing

Supporting someone who has a long-term condition can sometimes put a strain on family and friends. It can be difficult if you feel that your relationship with the person you care about has changed. They might seem more irritable than usual if they're in a lot of pain, or be too tired to do the things they used to do. It's important to remember that they're still the same person they've always been, just in a different situation. Periods of ill-health, known as flare-ups, don't last forever. Medicines or surgery usually help control symptoms and they should be able to live life to the full again. It can help to try to see their Crohn's or Colitis as something separate from you both – an external challenge that you face together.

The psychological aspects of my Mum's Crohn's have been the most difficult to relate to – you just see her as your Mum when you're young, not a whole person with her own issues! Open and honest conversations are really the only way to get through it, and to remember that your support is appreciated, even if it doesn't always seem that way.

#### **Nicky**

Daughter of Anne, living with Crohn's

You might feel that your relationship is becoming unbalanced, and the only time you spend together is when you're looking after them. It's important to make time to do something you both enjoy together. They will probably appreciate the chance to feel like themselves again and not just a patient. This includes not feeling like they're being protected from difficult situations just because they're unwell.

When the person you support is having a flare-up, you may have to take on more responsibilities. This can be a lot to deal with, especially if you're a young person and this is the first time you've had to look after someone. Try to share responsibilities with other



people in your family or social circle so that you're not overwhelmed. The NHS has **information for young carers,** including **how to get help and support** if you need it.

If you're the parent of someone with Crohn's or Colitis, you might find it difficult to deal with any mood changes your child has. Crohn's and Colitis can be a lot to cope with on top of all the other challenges young people face. Try to be as understanding as possible if they seem irritable or stressed. You might find it helpful to hear other young people share their experiences of living with Crohn's and Colitis. They cover things like school, leaving home for the first time, and transitioning into adult care.

If there are other children in the family, it can be hard to meet everyone's needs. It's important to be as honest as possible with siblings about what's going on. Although they may be scared about the treatment their brother or sister might need, they can worry if their parents keep information from them. They can also feel very protective of their sibling, and might worry about them being bullied at school.

Our story <u>Meet our Crohn's and Colitis cats</u> is for children affected by Crohn's or Colitis, whether they have the condition themselves or know someone who does. We also have information on <u>talking to your child</u>. This has tips on how to explain Crohn's and Colitis to younger children.

If your child has had Crohn's or Colitis from a young age and you're used to looking after them, it can be hard to adjust as they want to take more responsibility themselves. Our information on <u>transition to adult care</u> outlines the transition process, how you can help and how you can start giving them more independence. Even when your child becomes an adult, you will probably still worry about their health. It's important to talk to them to find out how much involvement they're comfortable with.

We offer <u>virtual social events</u> where people can share their experiences and tips for living with Crohn's and Colitis. These are not just for people who have the conditions – they're also open to family, friends or colleagues. Some of the sessions are specifically for parents and carers.

If you're the partner of someone with Crohn's or Colitis, your sex life might change. This could be because your partner's tired, worried about bowel incontinence, in pain, or



taking medicines that lower their sex drive. It could be because you're scared of hurting them or making their symptoms worse. If you can, you should try to be as honest as possible about how you feel. It's likely your partner has similar concerns themselves. We have separate information on <u>sex and relationships</u>, which might help you think and talk about sex, intimacy and relationships.

You may also have questions about having children together. Having Crohn's or Colitis does not generally affect fertility. But having some types of surgery might have an impact. Most women with Crohn's or Colitis can expect to have a normal pregnancy and a healthy baby. We have more information about <u>reproductive health</u> and <u>pregnancy and breastfeeding</u>.

## Don't they just need to think more positively?

There is no evidence that stress or emotions cause Crohn's or Colitis. But some people do feel that stress can trigger a flare-up or make their symptoms worse.

Try to let your loved one express their feelings without dismissing them when they feel down. Living with Crohn's or Colitis can be extremely draining, and there may be times when they feel fed up or depressed. These feelings are perfectly natural. Telling them they need to think more positively might make them feel you don't understand how serious the condition can be.

If you think your friend or loved has anxiety or depression and is finding it hard to cope, you could suggest they talk to their GP or IBD team. They can help them access the support they need. This may be medicines or talking therapies. Talking therapies can help people with Crohn's or Colitis cope better with their symptoms. They can also help lower stress levels and improve mental wellbeing.

We have more about this in our information on <u>mental health and wellbeing</u>.



## I'm concerned that they're not looking after themselves

It can be disheartening if you feel a friend or loved one is not looking after their health, especially when they have a long-term condition. For example, you may notice that they miss doses of their medicine or ignore worrying symptoms. This can be frustrating, but it's important to accept that they need to make their own choices. There are limits to what you can do to support someone else.

If the person is in immediate danger, call 999.

Do your best to be patient. You can't force someone to talk, but you can make sure they know you're there for them when they feel ready. You may be tempted to suggest a particular remedy, like a herbal supplement you've read about. Be careful how you phrase these suggestions. People with Crohn's or Colitis are used to being told by well-meaning people that their illness can be cured with a natural approach, but this is not the case. You could say something like, "I've heard good things about [...], but I don't want to suggest this if it's not the sort of thing you're interested in." Try not to take it personally if they don't try your suggestion, and accept that they are responsible for their own health. Making decisions about their treatment could be the main way they feel in control of their condition.

It was devastating to watch my 15-year-old son suffer and him not really wanting to deal with it. I felt helpless as all I could do was do the 'admin' of appointments/prescriptions etc. Thankfully as he's matured, he has accepted his diagnosis, regularly takes his meds and keeps himself well.

#### Angela

Parent of Keenan, living with Crohn's



Sometimes you might feel you can tell when your loved one is becoming unwell before they do. For example, they may not realise they've been more tired than usual when they get home. You could try making a list of warning signs together while they are well, which can make things easier to talk about when you notice things changing. It's a good idea to decide together how they want you to help if they have a flare-up. Remember that you don't want to be overbearing or treat your friend or loved one like a patient.

## What can I do to look after myself?

Supporting someone with Crohn's or Colitis can be rewarding and can bring you closer together. But it can also come with challenges. It's important to find the right balance between supporting them and looking after yourself.

Pace yourself and be realistic about the support you can offer. This can be a long-term commitment, so ensure you take plenty of time for yourself as well.

## **Nicky**

Daughter of Anne, living with Crohn's

To make sure you have enough energy to help someone else and look after your own wellbeing, you could try the following tips:

- Be realistic about what you can do. Your help is extremely valuable, but you cannot support your loved one effectively if you do not look after yourself too. Setting boundaries may be difficult for both of you, but they're important to ensure that you both understand your roles. You can reassure them that you're still there for them even at times when you can't physically help.
- Be honest about your feelings. Often friends and family try to protect each other by hiding when they're struggling, or not speaking up when they have concerns. Being honest about your feelings may make it easier for your loved one to open up about theirs.



- Don't burn yourself out. Be sure to take breaks if you're feeling overwhelmed. You
  may feel guilty about taking time for yourself, but you'll be able to support the
  person you care about much better if you look after yourself properly. If you have
  religious beliefs, taking part in religious activities can be helpful.
- Confide in someone. Looking after someone with Crohn's or Colitis can have a big impact on your life as well as theirs, and it's important you feel supported. If you feel your friends don't understand what you're going through, connecting with others in the same situation can be really helpful. You could join our closed Facebook forum or attend one of our in-person Local Network events or virtual social events. But check that the person you support is comfortable with this.
   Carers UK also offers support and information. You might want to consider counselling if you feel overwhelmed.
- Don't do it alone. Take any support that's available to you and share your caring responsibilities with others if you can.

## I don't think I'm making a difference

I just check in, offer to help out and occasionally send sunflowers to cheer my Mum up. With no big fix for IBD, it is the little things that matter.

#### **Nicky**

Daughter of Anne, living with Crohn's

When someone you care about is unwell despite your best efforts, it can feel demoralising. Try to remember that it isn't your fault. Crohn's and Colitis are lifelong conditions and can be difficult to control. Your loved one's health is no reflection on your efforts. You're also probably doing a lot more than you realise. Small things can have a big impact, and just being there for them can help a lot.

Research has suggested that people with Crohn's or Colitis who are lonely and stressed have worse health-related quality of life. So just keeping them company and helping



them relax can be a great help. By supporting them to overcome their anxieties and develop coping strategies to deal with symptoms, you'll be making a real difference in their life.

Talk, not just together but with your family and friends and other people who live with it. Openness is super important. I think because we have not been embarrassed by it, our children are not embarrassed by it, so they don't hide it away. They say to kids at school 'that's my mum, she's ace'.

#### **Timm**

Husband of Sam, living with Colitis

## Other organisations

- Carers Trust: <a href="https://carers.org/">https://carers.org/</a>
- Carers UK: <a href="https://www.carersuk.org/">https://www.carersuk.org/</a>
- CICRA (a charity supporting children with Crohn's or Colitis and their families):
   <a href="https://www.cicra.org/">https://www.cicra.org/</a>

## Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information 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 and employment. We'll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information



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: <a href="mailto:facebook.com/groups/CCUKforum">facebook.com/groups/CCUKforum</a>.

#### Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See <a href="mailto:crohnsandcolitis.org.uk/membership">crohnsandcolitis.org.uk/membership</a> for more information, or call the Membership Team on 01727 734465.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.



## **About Crohn's & Colitis UK**

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit <u>crohnsandcolitis.org.uk</u>.

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We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest

You can also write to us at Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE or contact us through the Helpline: 0300 222 5700.

# CROHN'S & COLITIS UK

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Patient Information Forum