CROHN'S & COLITIS UK

it takes guts

NEWSLETTER

WINTER 2024-25

East Cornwall & West Devon Network

CONNOR'S CROHN'S STORY

One of our newer volunteers, ***Connor, joined us as a volunteer for the East Cornwall and West Devon network back in September 2024***. Having moved down to Plymouth from Manchester (where he also volunteered) for work and a new challenge, he wanted to continue supporting the cause that has affected his life through his own battle with Crohn's. Here's his story in his own words:

"***I was diagnosed with Crohn's Disease in April 2022 when I was 25 years old***. My journey from experiencing my first obvious symptoms to diagnosis was relatively short compared to many, thanks in part to access to private healthcare provided by my employer at the time."

"My first sign of symptoms appeared just after Christmas 2021, when ***I suddenly started to experience an unexplained, painful stomach ache and an urgency to rush to the bathroom***. At first, I thought it was just a stubborn stomach bug, as nothing else in my life had changed at the time. However, the symptoms persisted over the next month or two and progressively worsened."

"I decided to visit my GP and explain the symptoms I was experiencing — stomach pain, urgency to open my bowels, loose stools, passing blood, and fatigue. Based on these observations, ***they took a faecal calprotectin test (stool sample) and blood tests, which both indicated elevated levels of inflammation***. I was referred for further diagnostic tests, including a colonoscopy and an MRI scan and was eventually diagnosed with Crohn's Disease."

"***I was started on a six-week course of steroids as an initial treatment***. After a brief improvement in symptoms within the first week, the symptoms returned and followed the same pattern whenever I was prescribed oral steroids in the future."

"***The next step in my treatment journey was biologic therapies***. I was told it might take some trial and error to find the right medication, as people respond differently to each treatment. ***Over several months, I tried three different biologic treatments: Adalimumab, Vedolizumab, and Ustekinumab.***"

(Continued on next page)

ALSO IN THIS ISSUE

CONNOR'S CROHN'S STORY (continued)

"Unfortunately, I had limited success with each — either I showed signs of improvement but lost response after a few weeks, or I experienced no noticeable benefit."

"During this time, my symptoms worsened. *I was ill every day with severe stomach pain, joint pain in my lower back and hips, extreme fatigue, and significant blood loss during bowel movements*. Despite this, I continued to work as a Process Engineer for a biotech company. It was challenging due to the fatigue and constant pain, but my employer was very supportive. I also followed advice from my IBD nurses and dieticians on lifestyle changes and diet, such as following a low-fibre diet, engaging in low-impact exercise, and eliminating certain foods and drinks. Unfortunately, these measures made minimal improvement, as my inflammation was quite severe."

"Eventually, *my consultant discussed the possibility of surgery to remove my colon* if the next medication option was unsuccessful. This was a frightening prospect. However, I had done plenty of research using the resources available on the *Crohn's & Colitis UK website* and had spoken with IBD nurses to prepare myself for this potential outcome. And while I understood that people with stomas can live happy and fulfilled lives, it was still a shock to consider this as my reality."

"However, before surgery became necessary, *I was given one final medication to trial: Upadacitinib, a JAK inhibitor* that works differently from the other drugs I had tried. It's an oral tablet taken once a day, starting with a higher dose and tapering down to a maintenance dose after a few weeks. After just one week, I noticed a slight improvement in my symptoms, though I didn't want to get ahead of myself, as this had been the case with other treatments. *Gradually, my symptoms continued to improve*. I stopped passing blood and my energy levels began to return to normal. I started this treatment in September 2023 and I've been back to my normal self ever since!"

"Due to the immune-suppressing nature of the medication, I tend to catch colds more easily, and it takes longer for me to recover from them. I also experience sore throats more frequently, which is a common side effect. However, *I'm able to manage my Crohn's with minimal impact on my life and have returned to doing the things I love, such as exercising, hiking, and climbing*. I make an effort to live a healthy, balanced life, exercising regularly, eating whole foods whenever possible, and keeping my stress levels down."

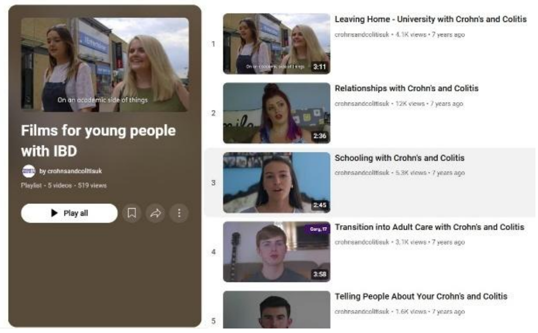
"Every day I need to remind myself to be grateful for my health and the ability to live a full life. *Volunteering for the Crohn's & Colitis UK charity has brought me great joy and fulfilment*, allowing me to connect with others affected by the same condition and be part of an organisation determined to raise awareness and funds to improve the lives of others in similar circumstances."

If you'd be happy to share your story, please email us at
ecwd@networks.crohnsandcolitis.org.uk
or message us on our Facebook page

SUPPORT & ADVICE FOR CHILDREN AND YOUNG ADULTS

If you have a child with Crohn's or Colitis, or you're a young adult who lives with one of these diseases, there's lots of information, advice and support available for you on the Crohn's & Colitis UK website. On this page, we highlight some key areas for you.

Whether you're a young person with Crohn's or Colitis or someone wanting to support them, you can find information ***here*** or head to ***www.crohnsandcolitis.org.uk*** and search for 'Children, young adults and students'.



Films for young people with IBD

by crohnsandcolitisuk

Playlist • 5 videos • 519 views

1 Leaving Home - University with Crohn's and Colitis
crohnsandcolitisuk • 4.1K views • 7 years ago
3:11

2 Relationships with Crohn's and Colitis
crohnsandcolitisuk • 12K views • 7 years ago
2:36

3 Schooling with Crohn's and Colitis
crohnsandcolitisuk • 5.3K views • 7 years ago
2:45

4 Transition into Adult Care with Crohn's and Colitis
crohnsandcolitisuk • 3.1K views • 7 years ago
3:58

5 Telling People About Your Crohn's and Colitis
crohnsandcolitisuk • 1.6K views • 7 years ago

There are short films on schooling, transition to adult services, relationships and more in ***this playlist on YouTube*** or head to ***www.youtube.com/crohnsandcolitisuk*** and search for 'Films for young people with IBD'.

There is a whole set of ***blogs*** for those thinking of going into further education, including tips for freshers, how to tell others about your condition, and how to put your studies on hold. Head to ***www.crohnsandcolitis.org.uk*** and search for 'Student blogs'.

The Unstoppables are a group of six young people aged 8 to 18 who share their ***inspiring stories*** of living with Crohn's or Colitis. Head to ***www.crohnsandcolitis.org.uk*** and search for 'The Unstoppables'.

It's not just Crohn's & Colitis UK that provides support and advice for children, parents, and young adults. Other organisations, highlighted below, also have lots of useful information.

CICRA was formed in 1978 by a group of concerned parents of young children with Crohn's. Now CICRA specialises in supporting children and families with Crohn's or Colitis. Head to ***www.cicra.org***

supporting CICRA

14 ways you can support children with IBD and their families

"Being part of E-Pals has made me feel less alone, and isolated. We all have similar experiences and chatting to others has made me realise I am 'normal' but my own kind of 'normal'."

One of the services CICRA provides is called ***E-Pals***, which allows children living with Crohn's or Colitis to chat with other children in a similar position. Head to ***www.cicra.org*** and search for 'E-Pals'.

Over The Wall Camp is a charity for children and young people with health challenges. It allows them to build friendships and gain confidence through fun activities. Head to ***www.otw.org.uk***

A place where children with long-term health conditions can rediscover the mischief and magic of childhood!

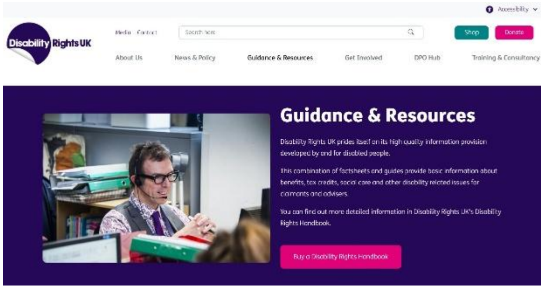
Free helpline: 0808 801 0343 Mon to Thur, 10am - 2pm

Supporting children and families with bowel and bladder issues

Find trusted information and support online

ERIC is a charity dedicated to improving children's bowel and bladder health, e.g. providing information about managing continence challenges at school and college. Head to ***www.eric.org.uk***

Disability Rights UK provides information on benefits you can get in further education (some students with Crohn's or Colitis may be considered disabled). Head to ***www.disabilityrightsuk.org***



Guidance & Resources

Disability Rights UK prides itself on its high quality information provision developed by and for disabled people.

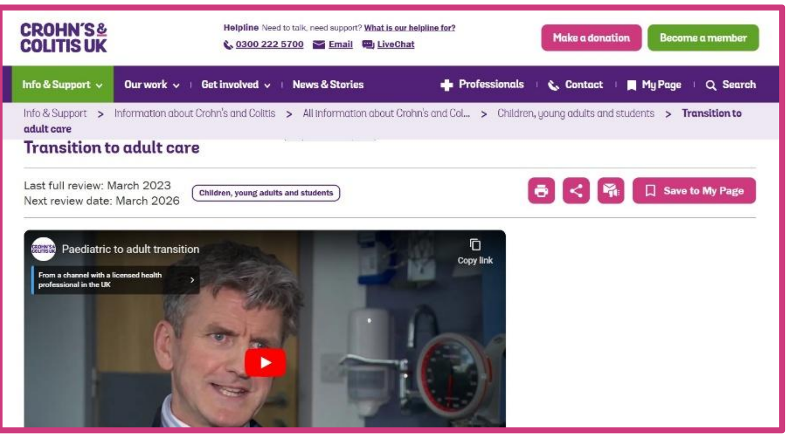
This combination of factsheets and guides provide basic information about benefits, tax credits, social care and other disability related issues for claimants and advisers.

You can find out more detailed information in Disability Rights UK's Disability Rights Handbook.

There is such a wide range of information on the Crohn's & Colitis UK website that it's easy to miss useful and important topics that may affect you as a young adult or a parent or carer. Here are a few more web pages that you or your family and friends may find interesting.

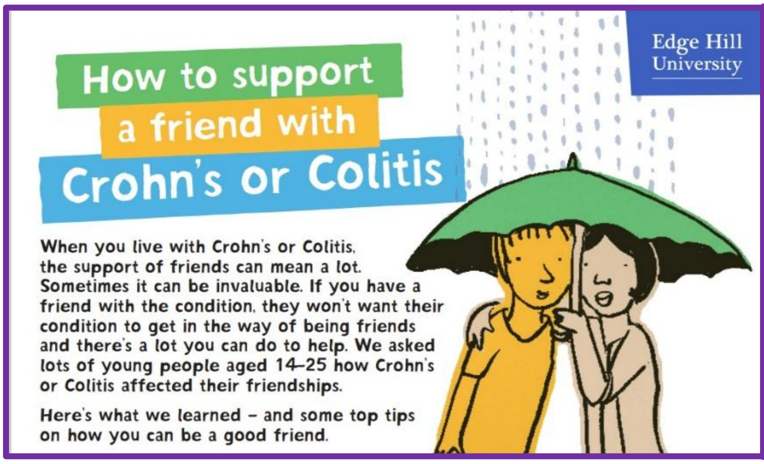
Crohn's & Colitis UK runs regular *Virtual Social Events* and some of these are specifically aimed at *parents and carers*, giving them the chance to chat with others going through similar experiences. The next one of these events should be *coming up in March*, so please head to *www.crohnsandcolitis.org.uk/vse* as this page will be updated once the event is confirmed.

Transition is the process of moving from children's or paediatric services to adult care, which usually happens between 16 and 18. This can be daunting for young adults but most families find that the change is positive. Head to *www.crohnsandcolitis.org.uk* and search for 'Transition to Adult Care'.



Transition to adult care

Last full review: March 2023
Next review date: March 2026



How to support a friend with Crohn's or Colitis

When you live with Crohn's or Colitis, the support of friends can mean a lot. Sometimes it can be invaluable. If you have a friend with the condition, they won't want their condition to get in the way of being friends and there's a lot you can do to help. We asked lots of young people aged 14–25 how Crohn's or Colitis affected their friendships.

Here's what we learned – and some top tips on how you can be a good friend.

Be a good friend!

Having the support of your family and friends during times when your Crohn's or Colitis is getting you down is really important. This *information sheet* was created from the things young people said were important in the 'Being Me with IBD' Study, funded by Crohn's & Colitis UK. Head to *www.crohnsandcolitisuk.org.uk* and search for 'Being Me with IBD'

If you're raising money locally for Crohn's & Colitis UK please get in touch with us so we can promote and support your event at ecwd@networks.crohnsandcolitis.org.uk or message us on our Facebook page

JOIN US at the PLYMPTON MAY FAIR!

We'd love to see you at this year's *May Fair at Harewood House in Plympton*. It's being held on *Saturday 3rd May from 10am till 3pm* and we plan to have a stall there selling our usual knitted characters as well as other items.

You don't have to buy anything - we're just as happy to have a chat with you so do come along and join us!

Right and below: Photos of our stall at previous May Fairs.

IBD NURSE CONTACTS

AT DERRIFORD

TEL: 01752 439224

EMAIL: plh–tr.ibd–advice@nhs.net

YET AGAIN, THANK YOU KAREN

We were so disappointed when *Dickensian Evening was cancelled due to the storm* back in December. Since 2016 this has been the most successful annual event we've been involved in, entirely due to the *generosity of Karen Kestell*. Her scrumptious mince pies and delicious warm mulled wine were always the highlight of the evening and many people returned year after year to sample Karen's cuisine.

Karen is planning on retiring this year (her fully-licensed restaurant, appropriately named Karen's, is currently up for sale and you can find details here - *RESTAURANT DEVON - Buy or Sell a UK Business with Daltons Business*) so December would have been the last time she hosted us at this event. Meanwhile, she has continued to keep a charity box in her restaurant and she recently handed over yet another full tin *containing over £234*! Thank you once again Karen 💜

Below left: Karen has kept a charity box in her restaurant for many years and regularly contacts us to let us know it's full again! Lead volunteer Dani collected one of those tins from her back in March 2019.

Below right: In August last year we held a coffee morning at Karen's and presented her with a plaque to thank her for her *amazing fundraising over many years which runs into thousands*. Pictured are Gwennie, Shas, Karen, Linda and Margaret.

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CONTACT US

EAST CORNWALL & WEST DEVON NETWORK
Leads: Shas Chilcott and Dani Brown

☎ **0300 222 5700 (via Helpline Service)**

✉ ecwd@networks.crohnsandcolitis.org.uk

www.crohnsandcolitis.org.uk/ecwd

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CONTACT FOR LOCAL IBD NURSES
Derriford Hospital, Plymouth
☎ **01752 439224** ✉ plh-tr.ibd-advice@nhs.net

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HEAD OFFICE CONTACTS
1 Bishop Square, Hatfield, AL10 9NE
✉ helpline@crohnsandcolitis.org.uk
Website:www.crohnsandcolitis.org.uk
HELPLINES ☎ **0300 222 5700**
Mon-Fri & 9am-5pm (except English bank holidays).
Answer phone service outside these hours.

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Charity registered in Scotland Number SC038632
A company limited by guarantee in England: 5973370

If you have received this newsletter by post and would be happy to receive future editions by email please send your name, membership number and email address to networks@crohnsandcolitis.org.uk This will save the Network valuable funds which can be used to benefit all those affected by Crohn's or Colitis.

DANCING ON ICE AMBASSADORS

We wish continued success to Crohn's & Colitis UK ambassadors *Sir Steve Redgrave and Mollie Pearce* who are appearing in the latest series of *Dancing on Ice*.

Sir Steve was *diagnosed with Ulcerative Colitis back in 1992*, just before the Barcelona Olympics in which he still managed to win a gold medal for rowing! As he says, "*I'm an Olympic rowing champion, but Dancing on Ice is a whole new challenge*".

You may remember *Mollie Pearce as runner-up in the second series of The Traitors*. She was diagnosed with Ulcerative Colitis as a child and had her colon removed and a stoma fitted when she was 18.

Happily, both Mollie and Sir Steve made it through the first 3 weeks. Fingers crossed they make it right to the end!

The East Cornwall & West Devon Network has made every reasonable effort to ensure the content of this newsletter is accurate but accepts no responsibility for any errors or omission.

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