

## West Midlands Network

### WHAT A YEAR IT HAS BEEN!

I don't think anyone was prepared for the impact 2020 was going to have on the world!

We had some very big plans for 2020 as a local network, very sadly we had to cancel all of them due to the Coronavirus Pandemic. Like many of you, we were instructed to begin Shielding by the Government. Some of us were put onto furlough and some of us were able to make adjustments to work from home.

2020 also has been tough on the charity as a whole. Income for the charity dropped significantly and [an urgent appeal](#) was launched. Throughout this the charity's support and guidance was in demand like never before with Helpline calls rising by 400% and website visits rising by 600%.

To help further respond, the charity's Trustees approved a plan to reduce some ongoing costs and to get it into good shape to take advantage of an improving situation when this happens - [rebuilding the charity](#) over time to deliver more for you.

The future beyond Coronavirus is uncertain, but we're all determined and focused to not give up. Hopefully we can start to offer some support locally again in some shape or form.

[www.crohnsandcolitis.org.uk/coronavirus](http://www.crohnsandcolitis.org.uk/coronavirus)

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### MY WALK IT

2020 didn't quite go to plan. Lockdown restrictions meant that this year, WALK IT was replaced with a new event - My WALK IT.

My WALK IT gave you the option to do a virtual 5k or 10k, as well as spreading the distance out into sections you wanted to.

Volunteer Dean walked 2k a day with his family for 5 days and raised £255. Volunteer Priya also walked 10k and raised £503.

More than 360 Crohn's & Colitis UK members and supporters registered to participate, raising nearly £70,000!

We would like to give a huge congratulations to everyone who supported My WALK IT this year and hopefully we can all get together in person for WALK IT 2021.



## MENTAL HEALTH AND WELLBEING

### 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.

When you have Crohn's Disease or Ulcerative 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 mental 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.

This higher likelihood is down to something called the 'Brain-Gut Axis'. Anxiety or depression can lead to new gut symptoms. Equally, experiencing symptoms in your gut has been linked to developing new psychological symptoms. Stress has also been linked to bringing on a flare-up.

### What you can do to improve your mental wellbeing

- 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
- Learn about the condition and treatments from good sources of information. Understanding the benefits as well as risks of treatment, and finding new ways to manage troubling symptoms, can help relieve some of your anxiety
- Talk about your Crohn's or Colitis with family and friends. The 'In My Shoes' App can really help them understand your condition
- Regular exercise, however small, can make you feel better and help you sleep
- Find a Mindfulness technique that works for you

Check out the full publication 'Mental health and wellbeing' from Crohn's & Colitis UK [here](#)



## SUPPORT

For psychological support; your GP or IBD team should be able to arrange this for you.

### Organisations that can help

[Samaritans](#) 116 123

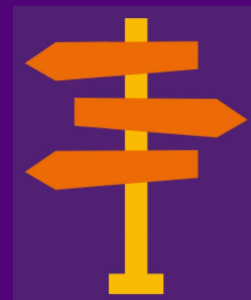
[MIND](#) 0300 123 3393

[CALM](#) 0800 58 58 58

[Every Mind Matters](#) 111  
[oneyou@phe.gov.uk](mailto:oneyou@phe.gov.uk)

[Birmingham & Solihull  
Mental Health Foundation  
Trust](#) 0121 301 0000

You're not alone, the charity are here to support you and provide information when needed. The 'It Takes Guts' ([www.ittakesguts.org.uk](http://www.ittakesguts.org.uk)) talking toolkit can help.



## VOLUNTEERS DURING LOCKDOWN

We thought we would share with you what our volunteers got up to and how they felt over the first lockdown of 2020.

*Davina McKenzie - Lead Volunteer*

### Did you work through the first lockdown?

I was working as a locum (agency work) when lockdown happened in March. I work as a solicitor buying and selling houses and as people were unable to move home, my work was put on hold.

**I worried how I would cope mentally being at home**, with no work to distract me. The only other times I have been at home for long periods of time without work was when I was flaring. I remember feeling very lonely and envious of others enjoying their lives when I was stuck at home. I do now see that experience, helped me cope with lockdown.

**I made a plan**, to each day go for a walk, even if it was just around the block. I ordered food online and planned meals for the week.

**I kept in touch with friends and family** by WhatsApp and FaceTime. I tried to check on friends I knew were living alone.

**At times I did nothing.** Before lockdown I practiced yoga at least once a week. I did not have the same motivation in lockdown and decided it was OK to do nothing and take this time to rest.

**At times I was anxious.** The news about the virus was and is never ending. I decided to watch only the daily briefing and I would not watch the news. I snoozed certain news pages I was following on Social Media. At times I just sat with the anxiety and wrote in my journal which helped.

**I had contact with my IBD team at the beginning of lockdown.** First a pre-arranged hospital appointment and they asked me whether I was happy to have a telephone consultation. I spoke to the IBD nurse who confirmed that because I was on Humira I was medium risk and had to practice stringent social distancing. I was told that my blood tests will now take place at New Street station or at the dental hospital, not at the Queen Elizabeth hospital in Birmingham as usual.

I also had my next hospital appointment over the phone with my consultant. I explained I was less tired, due to not having to commute to work and she said a lot of patients had felt the same way and felt their IBD had benefitted from working from home. I was due to have my 8 year IBD cancer check colonoscopy this year and I was told that this would be delayed due to the hospital trying to catch up with cancer patients treatment.

**The first lockdown taught me that I am resilient.** Although I am sad, we are in another lockdown, I will try and remember that I managed to cope before and hopefully will be fine again. I try and write down three things I am thankful each day, whether that is being able to go on a walk, listening to one of my favourite albums or receiving a thank you from a client at work.



**Leah Simons - Activities and Awareness Volunteer****Were you considered high risk? How did you find it?**

Yes, I was high risk due to taking the immunosuppressant Azathioprine and having infusions of Infliximab. I shielded from March until end of July. I don't think the situation really hit me until I heard Boris' speech announcing lockdown.

**Have you worked through lockdown? What did you learn from this experience?**

Although I had a laptop given from work, due to the nature of what I do I couldn't really work from home. Although my partner was at home with me, he was actually working from home, so I kept myself occupied during the day. I was lucky that there is lots of renovation work to do on the house. I learnt that routine and setting little goals are the key to getting through lockdown whilst shielding, from doing some yoga each day to tidying up one cupboard.

**Best activity (outdoor or indoor) during these times?**

Outdoor activity - Painting and putting up a fence! It hasn't blown down yet so it was a good job done!  
Indoor activity-running my Guide unit through Zoom. It's been great fun!

**Did you have any contact with your GP or IBD Team?**

I didn't need to contact my GP. My IBD team phoned with a questionnaire to see what my current situation was.

**What have you learnt from lockdown?**

I have learnt to value each day and that mental as well as physical health is just as important.

**Robert Sargeant - Activities and Awareness Volunteer****Were you considered high risk? How did you find it?**

Yes, I was considered at high risk. I found it difficult to cope with as I live on my own, however you just have to get on with life and cope as best you can.

**Have you worked through lockdown? What did you learn from this experience?**

I did work from home, I found you need to be more disciplined and focused to separate the home work/environment.

**Best activity (outdoor or indoor) during these times?**

My constitutional walks and limited responsible socialising.

**Did you have any contact with your GP or IBD Team?**

I have had contact with my GP Practice but not the IBD Team as I have not required their assistance.

**What have you learnt from lockdown?**

Take every day as it comes and there are many worse off than me.



**Priya Sharma - Activities and Awareness Volunteer****Were you considered high risk? How did you find it?**

I was not classed as high risk, although I am on immunosuppressants through the eye hospital and they said that my dose wasn't high enough to shield however to take social distancing very seriously.

**Have you worked through lockdown? What did you learn from this experience?**

I actually started a new job during lockdown. I have been fortunate as I'm able to work from home for both my previous and current job. Starting a new job was strange, especially as it was for the NHS. I was really anxious initially as wasn't sure if they would make me go into a patient facing area. At times like these, its usually all hands-on deck so even if you aren't clinical, you may be asked to help. Luckily there were risk assessments in place and I was deemed at higher risk so was told I could predominately work from home. For me, not having to commute was great however a few months in, I have really noticed how my working day has extended and I can easily work 10 hours a day, 5 days a week. Sometimes, it's due to the additional workload we have on at the minute but at other times, it's because there is no natural cut off point and people send emails all day (and night) long as they all have access to everything they need at home, but I've learnt it's up to me to put in those boundaries and switch off.

**Best activity (outdoor or indoor) during these times?**

Walking! I forgot how beautiful the canals of Birmingham are. With nothing to do, especially when we were only allowed out once a day, the only activity we could do was walk so we went exploring. I'll be honest and say at the start I was really anxious about leaving the house, knowing many of the public toilets were closed but it also helped to build up my confidence.

**Did you have any contact with your GP or IBD Team?**

I actually started flaring during lockdown, after being quite stable for the last 5 years, so that was a real surprise. Not entirely sure of the trigger but that was really scary. I contacted my IBD team via email and they sent me a stool sample pot to my home address and I was able to drop at my GPs. Much of the advice has been via email or telephone but they have responded quickly and helping me back remission (slowly but surely).

**What have you learnt from lockdown?**

That those without IBD really rely on toilet paper more than I realised!! That was an interesting few weeks for those of us with IBD, seeing the empty shelves! I have learnt how to appreciate the smaller things in life, I was always so busy and even though now I find myself filling my time with other stuff, I enjoy the walks outside and the tranquility over the hustle and bustle of city life.

**Dean Bennett - Activities and Awareness Volunteer****Were you considered high risk? How did you find it?**

I was, and was placed into Shielding. It was a big change not to be able to leave the house to visit the shops and rely on grocery deliveries for a long time.

**Have you worked through lockdown? What did you learn from this experience?**

I was furloughed for a very long period as I was unable to work remotely from home. It was very odd to spend such a long period of time within the house and find things to keep myself busy.

**Best activity (outdoor or indoor) during these times?**

I started going out cycling more. Initially in the empty car park over the road with my daughter, then every weekend with a few friends around the park.

**Did you have any contact with your GP or IBD Team?**

I have seen my local practice nurse but this was conducted within the waiting area of the surgery. I have had some phone appointments with my IBD team and started a new treatment that required a visit to hospital which was a very odd experience being so separated.

**What have you learnt from lockdown?**

I learnt how little we used to think about coming into contact with others whilst out and about daily, as well as how many things we would normally touch in a day.



On Friday 13<sup>th</sup> December 2019 I was invited to attend the Longbridge Camping and Caravaning Club Christmas Gathering. The meeting was held near Astley & Dunley Village Hall near Stourport on Severn-in-the-Wyre Forest. At the meeting, I was presented with a cheque for £2279.25 as a charitable donation on behalf of the club for Crohn's & Colitis UK.

The cheque represented a very generous donation from the club having been raised over the last twelve months during their 40<sup>th</sup> Anniversary year celebrations. I thanked the club chairperson John Burt and all of the members present for their generosity on behalf of Crohn's & Colitis UK, and a memorable festive evening was enjoyed by all attending.

We were in the middle of planning some events using this money, which due to lockdown meant we couldn't do.

Due to the unprecedented times, we gave his money to the main body of the charity.

Robert Sargeant  
Awareness and Activities Volunteer



*If you have received this newsletter by post and would be happy to receive future editions by email please provide your name, membership number and email address to [networks@crohnsandcolitis.org.uk](mailto:networks@crohnsandcolitis.org.uk).*

*This will save the network valuable funds which can be used to benefit all those affected by Crohn's and Colitis.*

*The West Midlands Network has made every reasonable effort to ensure the content of this newsletter is accurate, but accepts no responsibility for any errors or omission. The views of the contributors do not necessarily reflect the views or policies of Crohn's & Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.*

## CONTACT US

**CROHN'S & COLITIS UK**

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Crohn's & Colitis UK West Midlands Network



CrohnsColitisWM



Crohnscolitisuk\_westmidlands

### GENERAL ENQUIRIES

**Crohn's & Colitis UK**

1 Bishops Square, Hatfield Business Park, AL10 9NE

[www.crohnsandcolitis.org.uk/contact](http://www.crohnsandcolitis.org.uk/contact)

**Volunteer Enquires: 01727 734 475**

Charity registered in England Number 1117148 Charity registered in Scotland Number SC038632

A company limited by guarantee in England: company number 5973370

### HELPLINE

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

Our team can:

- help you understand more about Crohn's or Colitis, 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 Crohn's or Colitis and understands what you are going through

### CONTACT US BY:

**TELEPHONE: 0300 222 5700\***

Monday to Friday - 9am to 5pm

Email: [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)

**Live Chat:** [www.crohnsandcolitis.org.uk/livechat](http://www.crohnsandcolitis.org.uk/livechat)

\*Calls to this number are charged at a standard landline rate or may be free if you have an inclusive minutes' package.

Calls may be recorded for monitoring and evaluation purposes.