

**CROHN'S &  
COLITIS UK**



# UNSTOPPABLE

OUR STORIES OF LIVING  
WITH CROHN'S AND COLITIS



# THE LONG RUN

Hi, I'm Paul. I may look fit and healthy but I know how frightening and painful Colitis can feel – and what it takes to come out the other side.



**I was 23 when I got my diagnosis.** I was working as a teacher, and those first few months were the hardest time of my life. My 20-minute drive to work had to be planned to the second to avoid any accidents. Every morning at the school was awful.

**It's hard being a young man.** My friends were supportive, but they didn't really understand. I was very body-conscious and I stopped going out for a long time.

Everyone gets dealt different cards in life. I got Colitis. It's changed who I am, but it doesn't define me.

**Taking steroids** just masked my symptoms – they are not a long-term option. One day I realised I needed to tackle the Colitis head on. I found a nutritionist who created a special programme for me. I didn't have the best diet and we started changing that. Still, nothing improved at first and I nearly stopped. But we kept going, and after six months it started working.



**Exercise has always been important to me.** And even during a flare-up, I found I didn't need the toilet as much when I was active. So I kept going to the gym and – when I was taking steroid medication – I began running and doing Spartan races. I've run the Rotterdam, Paris and London marathons in the last three years. But it was never about proving anything to myself – like 'I've got Colitis and I can run a marathon'. I don't need to do that. I've never seen myself as not normal.



Making my move

**I should really thank Colitis for helping me meet Ella, my fiancée!** She liked a video that I'd shared on Facebook about how nutrition had helped my symptoms. We got talking, and it went from there. This year, I proposed to her in Paris. I actually asked a photographer to follow us around at a museum taking pictures secretly. And when we got to the clock-tower, I got down on one knee.

**I'm not embarrassed to say I have Colitis.** Why should I be? Yes, it's a condition I'll have to live with for the rest of my life, but I can cope with it. It's felt like a nightmare at times, but I've got more mental grit and resilience because of that. I'm not bitter either. As hard as it sounds, if I had to go through it all again, I would. I think the most important thing is not to let it define you. It can feel all-consuming, but you need to tackle it head on. There is life beyond Colitis. I wish I'd realised that sooner.

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Us at Machu Picchu



**I have a very close-knit family, and they've been really supportive.** I'm very grateful but sometimes you don't want to talk about it. I didn't want them to ask "how are you?" all the time – it's like they were talking to the condition, not me. That's why I think the Crohn's & Colitis UK community is really important. Even if you have friends and family, it can still feel very lonely. No one really understands unless they've been through it. I would sometimes lock all my feelings away, but it's really important to find the right people to talk to.



**Why Machu Picchu?** It sounds funny but the first time I talked to my nutritionist, he asked me for a goal. I said it was to stand in a field with no toilets around and just feel comfortable. I'd had a long time where toilets were like a security blanket – I always had to know where the nearest one was. So the idea of going to Peru and doing the Inca trail – that once felt like an impossible journey. But that's where we've just gone on holiday. I'm not worried at all now.

# RAISING

# ARIZONA

I'm Arizona. I was diagnosed with Indeterminate Colitis two years ago, but I've had symptoms as long as I can remember. Today, drugs are keeping the disease in check and I'm starting a brand new adventure.



**I always knew something wasn't right.** It's not normal to bleed or feel like that. Initially, I felt scared and didn't want to tell anyone – but being diagnosed helped me come to terms with it and get on with life.

**It took me a long time to get a diagnosis.** I now just take one drug (Octasa) and am symptom-free most of the time. I don't really think about it now. My friends sometimes say: "Wow, you take so many meds!" But it's just normal – it's like remembering to brush your teeth.

**My membership to Crohn's & Colitis UK is really important.** I use the Radar Key and 'Can't Wait' Card a lot. I also follow them on Instagram and find *Connect* magazine really useful.

**This photo is with my sister, Willow.** She doesn't make a big deal out of my Colitis – and that's great. If I'm not very well, she'll ask if I want to have a rest. Some family members mean well but they're always asking about my tummy. I want to say, "Stop!" When I'm feeling healthy, I don't need to be reminded.



**This photo of the giant termite mound is us in Australia.** One of the things I was worried about on the flight was needing the toilet on the plane. We spent about a month travelling, which was really nice.

**There's me and my dad on the bikes.** That was back in 2013. I hadn't been diagnosed yet. The doctors thought I was constipated and prescribed me laxatives, which didn't help.



**This was a few days before my prom.** It was a difficult night. I was in a flare-up and couldn't really eat or drink – and I couldn't go out clubbing like everyone else. I was disappointed but I could have been ill with a sickness bug and it'd have been the same. It's annoying but I don't blame the disease.



**I've been doing some film work with a friend recently.** That's one of me making a documentary about street art. Now I'm stable, I don't have to worry as much about toilets and using trains. This year, I'm also starting a degree in sociology at the University of Hull.



Making a splash

**What would I say to my 15-year-old self?** Educate yourself. Know the symptoms, eat well, stay hydrated. And keep talking to your doctor or specialist nurse. At the start, lots of people said it was serious but I didn't know anything about it. No one in my family did either. Now I've read into it, I know it's not the end of the world.



# TAKE FIVE

Hi, I'm James. I was diagnosed with Ulcerative Colitis ten years ago. I want to show you five photos that tell the story of my life with the disease so far – and share some advice for anyone recently diagnosed with Crohn's or Colitis.



1



**That's me with my mum.** I was studying sports science at Brighton University. I'd also been diagnosed with coeliac disease, and it clicked that the right diet wasn't just important for sportspeople. I began reading more, started cleaning up my diet and exercising. And I felt a lot better for it.

Before that, I'd read an article about what to eat during a Colitis flare-up and I thought that's what I should be eating all the time. So I had only plain, bland food for a few years! My studies helped me understand more about nutrition – and I went on to do a Masters degree in Liverpool.

My mum has been there with me every step of the way. I live with her and she's been fantastic. Recently I've started going to my Local Network in Essex, which is run by Crohn's & Colitis UK volunteers – and she came with me to the last meeting. She always reads everything in *Connect* magazine too, bless her.

**Wow, this was eight years ago.** You wouldn't know it but this was probably my worst time. I'd been diagnosed with Colitis a few years earlier, was being bullied at school and feeling very anxious. I didn't ignore the disease, I couldn't. But I didn't really want to know about it. I was in denial really. I think I was just so embarrassed about having diarrhoea and blood in my stools.

This photo is actually quite rare as I didn't take many when I was ill – I didn't like how I looked. I lost a lot of weight and went down to 6 ½ stone. It was draining emotionally too. I found it hard going to new places and hoping there was a toilet nearby. I remember this concert though. I was with my best mate Andrew. He was always great at understanding.



Me and my mum on graduation day

2



**That's just last month at an Ed Sheeran concert.** Can you see that's my mate Andrew again on the right? He's been through it all with me. I'm at a good point now. Exercise has made a huge difference. And I'm glad I started going along to my Local Network. It's nice to talk to other people with Colitis who totally understand where I'm coming from.

**I thought this was a funny one.** On the way back from a sports nutrition conference, the only place open was a McDonald's. I think I just had the chips. Where I'm at now is that I know what food does and doesn't affect me, so I can maintain things pretty well. I've got myself into a really good routine.

**That was my first lads' holiday.** We went to Kavos in Greece – and I didn't drink alcohol the whole time as it made my Colitis worse. The reps were great and said I'd still enjoy the holiday. I had a few symptoms but nothing major – and had a great time. I was sharing a flat with four other guys and, by the end, I thought my bowels were in better condition than theirs!



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Revving up for Ed Sheeran

**What would I tell my 15-year-old self today?** I'd say don't get too overwhelmed. When I was diagnosed, I panicked. It felt like my world was falling apart. So I'd tell myself not to spend time worrying about what may or may not happen. Instead, listen to the doctors, read up on it yourself, and know that you will find a point where it all feels normal. It'll become so day-to-day that you won't even think about it.



Out with the boys in Kavos

4

# MOEED ON SCREEN

Hi, I'm Moeed. I've always dreamed of working in the media. I thought my Crohn's might stop that, but I'm back and living my best life.



**I remember my diagnosis vividly.** My consultant was drawing lots of little diagrams to explain what Crohn's was! That was nine years ago and I'd become really ill. I guess it was a relief knowing what it all was – that day was the first step to getting better.

It wasn't easy. Life spiralled out of control for a while. I had to leave university, struggled to work, and I became really isolated and sick. One of the hardest things was becoming intolerant to lots of foods. I had to avoid so much – imagine being 19 and not being able to eat fried chicken or pizza!

By 2014, it was clear none of the medications were really working. I'd already had surgeries but this time I needed a stoma. I was upset but then I realised I wasn't enjoying life and thought 'What's the harm in trying?' It's reversible and I just wanted to get back to a normal life.



Nothing to hide

**It's all about adaptation.** It took me about four months to get used to the stoma. Now I've adapted to it completely. No one else is bothered by it either. I find that if you're cool with it, other people are too. If you make a big deal of it, they will as well. That's why I've always been very open about my stoma. Everyone reaches that level of comfort in their own time, but I think there's no need to hide anything. Everyone goes through their own stuff in life. This is just what you've gone through and, if you embrace it, everything becomes a lot easier.

**I've always been into making videos.** The night before my stoma surgery, I decided to record something. It was midnight and I had to be up at 6am to go to hospital. The video was just meant for me – something to look back on – and it was pretty raw emotion about how I was feeling.

I ended up making a few more videos at the hospital after my surgery – and it's nice because you can see the physical improvement in me each week. I sent them to Crohn's & Colitis UK and they shared them on social media. It went crazy – I think thousands of people have watched them now!

Today, I'm part of the Instagram community in London. I don't take myself too seriously though. That photo of me in the tub is when I was out bath shopping with my mum. I jumped in and said 'Mum, take some photos of me!'



**Today, I'm feeling great and living the life I want.** My career in the media is taking off. I've got an agent and done some modelling, and some sponsored brand shoots on Instagram.

I also present a live weekly breakfast show on Sky for [ethnic satellite channel] BEN TV. It's a fast-paced, high-pressure environment in the studio, but having Crohn's has helped me develop a pretty cool mentality. Nothing really fazes me now – I find it very difficult to get stressed.

I also don't think I'd be as open-minded if I hadn't been through this experience. I'm much more appreciative of the small things in life. It's helped me build character.

My plans are to have my own TV show one day where I interview people. I want it to be funny and inspiring. To show that no matter what you've gone through, or where you've come from, you can get to where you want to be.

My surgery video diary



**Today things are about 8 out of 10 healthwise – and there are no issues I can't deal with.**

Being able to do more than one thing in a day is great. I go to the gym in the morning, go to work and then play football in the evening. I've never been able to do that before.

I even forget about it now. It's so far in the back of my mind that it's not important. I don't want to sound unappreciative but I'm just focused on living my life.

**What would I say to my 19-year-old self?** I remember being so terrified before the stoma surgery, but it's chill. The main thing is to understand that it will be fine. If you start doubting yourself, you become your own worst enemy. It's something that you'll have to learn to adapt to – and you will. Don't let your mind run riot, and know that things will get better if you let them.

Search for 'Moeed Majeed' on YouTube to find my stoma diary.



# A LIFE LESS ORDINARY

I'm Helen and I was diagnosed with Microscopic Colitis five years ago. I've accepted it and moved on with my life in the best way I can.

## When did you get Microscopic Colitis?

I only began getting symptoms when I was 73. I wasn't working or bringing up a family, but it was still very frightening. I'd have diarrhoea sometimes all through the night.

## Where did you turn?

Nobody told me some of the things I might experience, like fatigue or joint aches. That's when I contacted Crohn's & Colitis UK. The information they gave me was invaluable as it meant I finally knew what was going on.

## What happened next?

I desperately tried to find dieticians and nutritionists who could help, but didn't get too much support. Finding the right diet was really a question of trial and error for me.

## What's worked best for you?

I think the key thing for me has been to recognise that I know my body better than anyone. If you know your body, are aware of the research happening and read all you can about the disease, you can also help yourself.

I have a huge respect for medical professionals but it's about working in partnership.



Autumn 1964 - on a ship to Montreal

London

Sydney, Australia when the children were little - 1976

## Tell us a bit about your life before Colitis.

Well, I've lived all over the world. I was in London in the 1950s and emigrated to Canada for work in 1964. Then I moved to Sydney, Australia, in 1971 before coming back to the UK. I suppose I haven't led a very ordinary life!

## How much help have your family been?

I can talk to my daughter about everything. She's seen the worst of it, especially in the early days. And my son is very supportive too.

## What advice would you give someone newly diagnosed with Microscopic Colitis?

Be self-aware and have respect for your body. Find out everything you can. If you can, try to help yourself. It's easier if you can simply see it as part of you - and deal with it in a positive way.

My children





# Jag's Journey

My name is Jag and I was diagnosed with Ulcerative Colitis in 2005. I had a major flare-up the following year and the doctors performed an emergency ileostomy. This is my story.

### I felt isolated when I was diagnosed.

I didn't know what it was, who to talk to or where to get information. When I felt pain, I didn't know if it was normal or if I should ask for help. Now I'm much more confident.



**Before my surgery,** I was on IV steroids for a few months. They caused me to put on so much weight – and totally changed the way I looked. I used to stand in front of the mirror and not recognise myself at all. When I look at these photos, I think 'Oh my god, is that even me?'

**The surgeons said** I may not be able to fall pregnant naturally, as the ileostomy could leave scarring on my ovaries. But in 2011, six years after my stoma, I became pregnant. I had no complications – in fact, it was the best I've ever felt. My little boy Jeevan was born in October 2012. I just couldn't believe this miracle had happened!



**My grandfather** passed away two years ago. He was a big part of my life, and I started bleeding again. I couldn't do a supermarket shop and needed to have children's changing mats on my car seats. I ended up shopping online and isolating myself.

I wanted to avoid more surgery because I didn't want it to affect Jeevan. But then I realised not having it was affecting him more. To make life better for him and myself, I had a total proctectomy (surgery to remove all of the rectum). Now I've left all of those bad episodes behind me. I have control of my life again.



**My colonoscopy** showed that my bowel could perforate. The doctors tried medication but I didn't respond. The next thing I knew, the surgeons had to operate on me immediately. I just had time to call my mum, and she got a taxi to the hospital. I only had a few hours to get my head around having an ileostomy.

**Not everyone was supportive.** I had a lot of people in the community tell my parents, 'It's a good job she's married because she wouldn't have found someone with her bag'. My mum and dad were just happy that I was alive!

**How do I stop feeling angry** about what's happened? My technique is to put any negative feelings to the back of my mind – but to recognise when they're building up too much. Every three or four months, I'll need to have a really good cry and then I'm fine again. That's how we deal with it.



At my sister's wedding

**When I came round** and I saw the stoma, I actually fainted. I wasn't ready to accept it in my life. It took me a long time but I did get used to it, and I realised it was making me feel better. Now I know there is no stigma in having a stoma. It doesn't hold you back – it gives you strength to carry on.



**In the Asian community,** people don't tend to talk about these things. It was only after my stoma that I discovered this disease has been in our family for years. But no one ever spoke about it...

**I only got married** six months before my flare-up. It was an arranged marriage, so we were still getting to know each other. My husband has gone through this whole journey with me – and I wouldn't have been able to do it without him. He deserves a medal!



**If you can find someone** who's gone through the same thing, it's so much easier. My family really care but I know they feel helpless, and I feel bad that I've put them in that position! It's hard to speak to someone who hasn't been through it because they don't understand.

**If I could speak to my younger self,** I'd tell her to think positively after the stoma operation. I'd promise her it's not the end of the world – and say you will go on to live a better life.

If someone had said I'd become a mum, go swimming with my boy and have holidays, I wouldn't have believed them. But anything is possible. So it's really important to stay positive, and surround yourself with positive people. If I ever felt down, my mum would give me a reality check. She'd say there are people out there a lot worse off than me. I'm grateful for those stern talks as they've helped me get where I am today!

# WHERE NOW?

If you've been diagnosed with Crohn's or Colitis, you may be feeling anxious about what comes next and how your life will change.

The good news is that you are not alone. There are many ways to find support, comfort and strength from people who understand what you're going through. And we're here for you every step of the way:

## Go online

Have you joined the Crohn's & Colitis UK Forum? This closed-group community on Facebook is for anyone affected by Crohn's or Colitis. You can share your experiences, connect with others and get support: [facebook.com/groups/CCUKforum](https://www.facebook.com/groups/CCUKforum)

## Get outside

Our Local Networks of volunteers across the UK are always busy organising events. These are great opportunities to get to know other people affected by Crohn's and Colitis in an informal setting – and get involved with educational, awareness-raising and fundraising activities. Your families and friends are also very welcome: [crohnsandcolitis.org.uk/local-network](https://www.crohnsandcolitis.org.uk/local-network)

Find more opportunities to raise money to fund vital research and make life better for people with Crohn's and Colitis: [crohnsandcolitis.org.uk/fundraising](https://www.crohnsandcolitis.org.uk/fundraising)

## Have your say

Use your experiences to help improve healthcare services. Our Patient Panels are groups of people with Crohn's or Colitis who work collaboratively with their IBD healthcare team to drive up standards for everyone. Email: [patientinv@crohnsandcolitis.org.uk](mailto:patientinv@crohnsandcolitis.org.uk)

## Find the knowledge

Get instant access to over 50 practical, reliable and up-to-date information booklets and guides about all aspects of Crohn's and Colitis. All free to download: [crohnsandcolitis.org.uk/publications](https://www.crohnsandcolitis.org.uk/publications)

For quick answers to many common questions, check out the award-winning Crohn's and Colitis Companion: [companion.crohnsandcolitis.org.uk](https://www.companion.crohnsandcolitis.org.uk)

## Talk to someone

We're here for you. Our helpline is a confidential service giving information and support to anyone affected by Crohn's or Colitis.

Our team can:

- help you understand more about Crohn's and Colitis, including 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 just 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](mailto:helpline@crohnsandcolitis.org.uk)

Talk to us online using LiveChat: [crohnsandcolitis.org.uk/livechat](https://www.crohnsandcolitis.org.uk/livechat)

## Join us

Be part of a powerful, active and supportive community. For just £15 per year, members can receive a free radar key for independent access to over 9,600 locked public toilets in the UK. You'll also receive information booklets and guides, a discreet 'Can't Wait' Card, our *Connect* magazine, access to Local Networks and many other useful benefits.

Find out more: [crohnsandcolitis.org.uk/membership](https://www.crohnsandcolitis.org.uk/membership)



# HERE FOR YOU

Every day, Crohn's & Colitis UK supports people just like you to feel more in control of their conditions, and get on with their lives.

So whether you're newly diagnosed or are experiencing a flare-up, we can help you.

From practical information about treatments and medications to emotional support, we can help you overcome the tough times and feel more positively about the future.

The stories in this booklet are just a few examples of ordinary people with Crohn's or Colitis who have overcome often extraordinary challenges.

They want to share their experience to show you that you're not alone – and that there are lots of people out there who understand what you're going through and can help.

Together, we give each other comfort, confidence and strength.  
Together we are unstoppable.

