

About IBD Episode 97

Wine, Biscuits, and Drinking Water With Author Kathleen Nicholls

Life with inflammatory bowel disease (IBD) brings challenges and many life changes but it can also sometimes bring unexpected opportunities.

Kathleen Nicholls, author of "Go Your Crohn Way: A Gutsy Guide to Living with Crohn's Disease" and "My Flare Lady: a handbook for today's (diseased) dame" was diagnosed with Crohn's disease in her 20s. She started a blog as a way to process her disease journey. She was stunned when people started reading it and when publishers became interested. Two books later, she shares the lessons she learned along the way.

Buy Kathleen's Books:

- [Go Your Crohn Way: A Gutsy Guide to Living with Crohn's Disease](#)
- [My Flare Lady: a handbook for today's \(diseased\) dame](#)

Find Kathleen Nicholls on [YouTube](#), [Twitter](#), [Facebook](#), [Instagram](#), and on her web site, [KathFantastic.com](#).

Find Amber J Tresca at [AboutIBD.com](#), [Verywell](#), [Facebook](#), [Twitter](#), [Pinterest](#), and [Instagram](#).

Credits: Mix and sound design is by [Mac Cooney](#). Theme music, "[IBD Dance Party](#)," is from [©Cooney Studio](#).

[MUSIC: About IBD Theme]

Amber Tresca 0:04

I'm Amber Tresca and this is About IBD. It's my mission to educate people living with Crohn's disease or ulcerative colitis about their disease and to bring awareness to the patient journey.

Welcome to Episode 97.

My guest is Kathleen Nicholls, author of "Go Your Crohn Way: A Gutsy Guide to Living with Crohn's Disease" and "My Flare Lady: a handbook for today's (diseased) dame." Kathleen was diagnosed with Crohn's disease by way of arthritis. She began a blog as a way to process her disease journey.

A publisher expressed interested her writing a book. But as she'll tell you, her books are not like the others you'll find in the self-help section. Rather, she approaches chronic illness with a rare sensitivity and humor.

Because we're writers with similar tastes in music and TV, we talked for a while, and this is the first of two episodes with Kathleen. You'll be treated to more of her story in episode 98.

One content note: In the UK, people who were considered clinically vulnerable to serious illness with the novel coronavirus were asked by the National Health Service to take strict measures to avoid illness. They called that "shielding," Kathleen shielded in 2020, but as restrictions eased, she's resumed her life again.

And now, from Scotland, let's hear from published author, Kathleen Nicholls.

Kathleen Nicholls 1:26

Hi, thanks for having me. I'm so excited to to speak to you.

Amber Tresca 1:29

I I don't know how many get through this interview without totally just stopping every time just to listen to your accent. Which I've told you before because I lovingly follow you on social media. And every time you post your videos.

Kathleen Nicholls 1:47

Thank you. I'm flattered dsms. It's a unique accent. Yeah, but yeah, as long as you understand me, that's the main thing. That's, that's all.

Amber Tresca 1:57

So I wonder if you would start by giving me an overview of your Crohn's journey. And I use that word journey because it can be so twisty and windy. And it's been different for everybody. But maybe a little bit about your diagnosis and maybe some of the symptoms you've had over the years. I know you're a long term patient and any of the complications that you want to talk about

Kathleen Nicholls 2:19

first started exhibiting some sort of Crohn's related symptoms when I was around 25. So I think I've always been quite a sickly child. I've always been kind of unwell since I was as far back as I can remember, just issues with food and never have an appetite or always losing weight quite rapidly and never able to keep weight on. But yeah, when I was around 20, in my mid 20s, I started to have extreme pain in my joints and my legs. And I was back and forward to the doctor who told me to try frozen peas. And there was maybe just growing pains. I don't know how big they were expecting me to grow at 25.

Kathleen Nicholls 2:57

So it was I was quite frustrating to get to a point of being diagnosed with initially arthritis. So then, quite quickly after that, I started to have symptoms in my stomach, where every time I

ate it or drank absolutely anything that was an extreme pain. I was losing weight rapidly. And I couldn't I just couldn't eat at all without almost passing out from the pain. So again, back and forward to doctors and hospitals. And initially it was decided that I had appendicitis. And I was literally about a day away from getting my appendix. So when a doctor suggested it may be prawns, so then they started the usual tests, colonoscopies and endoscopy. And it was actually a medical student that accidentally told me I had Crohn's.

Kathleen Nicholls 3:45

They hadn't given me the official diagnosis. He just let it slip. I think he was trying to be helpful, but it probably got sacked. But so that was horrendous for me because they're not sure what to do with Google. So no one in my life, or or myself knew what Crohn's was. So I went straight on the internet. And that was the worst thing I could possibly do. But yeah, so after that I've been through that's that's over a decade ago know that I got my Crohn's diagnosis. And I'm, I've been through a myriad of treatments. And none of them have really worked for very long periods of time. But um, now I'm on Stelara injections. And that's been the first thing that's got me to a point where I'm feeling relatively normal, which is amazing.

Amber Tresca 4:27

Yeah, what does normal because you were 25 and it's like, like you're barely even adult you barely even know what's going on. So like, I always feel like how does a person diagnosed so young even know what it's like to be normal?

Kathleen Nicholls 4:47

Yeah, I suppose it's not the right. the right word. Really, I don't. I don't really know what a normal body should function like. Even that's such a thing, to be honest. But I suppose for me, the normal morality is and I'm able to eat and drink most things without passing out or clutching my stomach like I'm in a Victorian drama, or him constantly be in the toilet or, yeah, just just able to go to work and not have to think about a bit too much or my symptoms have been under control, I suppose is what I would consider to be normal.

Kathleen Nicholls 5:20

So my symptoms have been relatively under control for about two and a half years now. Which is incredible for me, because it's, it's been a constant decade of pain. So it's just No, no, I've just got the anxiety and the constant bubble and anxiety that this is going to stop working at some point. And then it's going to be on to something else. But that things have moved on so much since I was diagnosed that there's these treatments weren't even around when I was first diagnosed recording. So I know that things are changing all the time, and it will eventually hopefully, we'll maybe get cured or there'll be some other treatments down the line. But for no normality for me is just being able to eat without, without question.

Amber Tresca 5:58

Yeah, I think that's right. There's always more stuff in the pipeline that's coming along. And it sounds really bonkers to think about it that way and say, Well, if this stops working in a couple

of years, maybe something new will be approved. And I can say that, but I mean, sometimes I feel like that's like that's all we have, you know that you have to hold on to.

[MUSIC: About IBD Emotional Piano]

Amber Tresca 6:31

So we are hopefully I'm not really sure how it is for you in Scotland right now, with the pandemic, I haven't really been keeping up. internationally. I wonder if you would tell me more about what this past year has been like for you. And I know recently, things have started to change. And you all have been able to do more activities and things have started to opening up. But tell me what it has been like during the pandemic in Scotland. And then what life is looking like for you today?

Kathleen Nicholls 7:05

Okay, well, even in Britain as a whole, we're all we're separated and the rules around em restrictions here. So Scotland has been a little bit behind England and Wales, I think, because we've been very, very cautious and moving things forward. So we've I've been shielding for around a year. So I've been in the house by myself. And so that shield an ended for me, but 3-4 weeks ago. So that's me back to like my office now.

Kathleen Nicholls 7:32

And I mean, we'll leave the house and leave the cat which he's devastated about but um, yes, it's been for me personally, when we first went into lockdown last March time, my long term relationship had just ended. So I'm having a bit of though it's not funny at all. But it's not as funny because it's ludicrous. It's the way it happened. So we separated it and then the whole world went into lockdown. So we were stranded together. And this Heartbreak Hotel, which was some some strange form of torture for both of us, but and because of the shield, and I was kind of relying on him for everything that I needed food, drink everything.

Kathleen Nicholls 8:12

So yeah, it was horrendous for the first few months. And then I was able to move out. And July time. So I've been on my own and my flow flat since then was just the capsule has been has been horrendous for everybody. I know, I'm not trying to make out like, worse than anybody else. But for me, it was just it was just a bizarre situation. But since I've been on my own, it's been quite helpful for me to have this time to learn about myself and learn what I want for the rest of my life. And I look inward rather than distracting myself or the usual cliches you have to do and you're heartbroken, go out and go over your friends wherever else. I've not had that.

Kathleen Nicholls 8:52

So I've had a kind of FaceTime calls or Yes, yeah, it was it was horrendous at first. But no, no, I realize it's probably been a blessing for me to have time to kind of grieve everything by myself. And while the rest of the world is grieving for other reasons. It's it's like this constant has been this constant kind of I don't want to say comfort because that sounds horrendous. But I suppose it's it's comforting to know that everybody's feeling sad in the seat at the same time in

the same way and know that things are starting to calm down. It's such a relief and it feels like everybody's shoulder ease and because we know that the cases are going down and people are getting vaccinated and it's every you can feel a sense of relief everywhere over the globe is amazing. No, but it's been a long, long process for everybody.

Amber Tresca 9:38

Yeah, that's a very bizarre thing to go through in the first place. Yeah, breaking up and then having it happen the way that it did.

Kathleen Nicholls 9:48

See, it's funny.

Amber Tresca 9:51

I mean, it is and it isn't. I do, I lovingly follow you on social media. So I knew that you were going through this and I just couldn't imagine having to deal with this in that way, having the breakup, and then also dealing with everything surrounding, you know, having to stay at home, we didn't know in the beginning how people with IBD would be affected. It was pretty scary.

Amber Tresca 10:19

But as I was, I was reading your first book, I was reading Go Your Crohn's Way. And it was a, you know, a strange experience to read how you were writing about your relationship, and then knowing my knowing that that relationship was over for you. And then also, did you kind of feel like, Well, of course, it would happen to me this way.

Kathleen Nicholls 10:46

Yeah, absolutely. There has to be some element of comedy. And it happened like this. I think we both thought it was funny. But we could all laugh at it together, because we're both heartbroken. But yeah, I've had that thought myself that my books dedicated to him as well. So it's kind of bittersweet to know that that's still in the world. And people are going to read about my relationship as if it's this perfect, wonderful thing. And it's not non existent. No, but but that was a snapshot in my life and life moves on. But yes, it's, it's been horrendous. But at the same time, it's a good story. for future generations to hear what happened in a pandemic.

Amber Tresca 11:25

Well, not only that, but maybe you might get a third book...

Kathleen Nicholls 11:28

Well eventually wrote it during the pandemic, because I wanted some way to get there was the same thing as writing the Crohn's book, I had to get my thoughts out in some way rather than just him tweeting, nor crying to my friends. So I've actually wrote a book about it. But I don't know if I'm going to do anything with it, because it might just dredge up again. And I don't know if I want to do that. So maybe in a few years, people are worried about heartbroken pandemic girl.

Amber Tresca 11:53

Oh, I think that's totally true. I, on the one hand, there are people that say that they don't want to consume any media for fun that has anything to do with a pandemic, or with viruses, or anything like that. But then there are other people that just can't get enough. And like, they're good with it.

[MUSIC: About IBD Transition]**Amber Tresca 12:18**

Let's talk for a minute about your writing process, though. And what it was like to write the two books that you have now. And we can even talk about the one that you've written that you're not really sure what to do with yet, which I hope will see the light of day. Personally, you know, I could edit it. Just throw that out there. But what was your writing process? What compelled you maybe to sort of write your first book?

Kathleen Nicholls 12:47

And well, first of all, it's great that you call it a process. And I suppose I started, I've always loved to write. And I started writing quite religiously, when I'd had my surgery for Crohn's. That was probably 2010, I think.

Kathleen Nicholls 13:05

And it was my ex partner, actually, and my brother, who is a very, very good writer, much better than me, Mark Nichols. And he encouraged me to write a blog, which had never done but that was a good way for me to write and kind of short bursts and get some feelings. Oh, and I had no idea again, what that was going to be. I just didn't think anybody would read it, which is probably why it was quite free. And because I didn't think anybody would look at it, other than maybe ham.

Kathleen Nicholls 13:31

So yeah, I started writing the blog. And then I kind of got hooked on that, and people started to read it, which was staggering. Then, I had written so much that a publisher contacted me and asked if I want you to write it in a longer form. So yeah, I kind of came together quite naturally, because I had done so much background writing I could tweak, tweak all those blogs and add to it, so it was really enjoyable. And then another couple of publishers contacted me, which was unbelievable, I think it was a great time. And because it is quite a niche topic. And there really isn't a lot of books about Crohn's. Or at that time, there certainly wasn't because it was just diet books or how to cure your gut or which just to drink to read yourself of the stuff in the next thing.

Kathleen Nicholls 14:19

So it was I think the publisher thought was quite a revelation when I was writing about it, because there's humor in there. And I try not to take myself too seriously as you might have crypt established. And I wanted to write a book that I would have wanted when I was diagnosed and scared and feeling isolated. Something that made me think that there is going to

be life beyond the diagnosis, which is something I didn't have at the time. I thought it was a death sentence. And everything I read was telling me it was a death sentence. So yeah, I just wanted something to give some people a bit of comfort when they are diagnosed and also people who have loved ones that are diagnosed that have been diagnosed or don't quite understand what the disease involves.

Kathleen Nicholls 15:02

So it's not a medical text, absolutely not a medical text. It's more about relationships and how to navigate your life after a diagnosis M, which I think has been missing for a while with a lot of conditions such as Crohn's.

Amber Tresca 15:16

Yeah, I think that's totally true. And that's exactly what I like about it is that it is not a how to eat the right things, or how to exercise the right way or do yoga. Not that not that there's a time in place for all of those things. But you are sifting through the the journey, and all of the different emotions, and all of the things that happen with your family and with medical personnel that you are dealing with during your diagnosis, and then after, and the treatments and all of that and, and literally just your personal experiences. And everyone's IBD journey is different. I've never talked to two people that had the same one. Although we usually have similar themes, similar threads. But I was so often laughing because there were so much in your books that really spoke to me, and did sort of resonate with my same experience. I was laughing particularly about how many times you say that you don't like to drink water?

Kathleen Nicholls 16:36

Well, actually, I hate to ruin things. But I've actually really started drinking water in this last week. absolutely furious to find it does make me feel better. So I don't want to ruin the facade. But yeah, unfortunately, I've stepped over the line. And I do drink water, unfortunately. But yeah, I think I was just I've always been quite averse to him motivational quotes and live laugh love stuff.

Kathleen Nicholls 17:05

So I kind of wanted to make annoyingly at the very start of the book I've wrote, there's not a self help book, just to give people an impression straight away that I'm not going to tell you what to do, or how to navigate your journey, or give you platitudes that could be looked nice on Instagram. But it's always in the Self Help section really drives me to distraction because I think people are going to buy this thinking I'm going to help them and I'm just, I'm just really not. But maybe it does help some people in some way, but maybe not in the way that you'd be by a self help book to help you.

Amber Tresca 17:42

Yeah, I think it does help absolutely to read someone else's experiences. And you lay pretty much everything out on the table, which I prefer. So but yeah, at the same time, you're not, you know, giving advice, which I also enjoy, because there is plenty of advice from all corners, whether we want it or not.

[MUSIC: About IBD Transition]

Amber Tresca 18:10

But tell me this though, when the people that are close to you read your book, and I'm assuming that they do and and but this is also a funny thing, because I also know from my own experience, like a lot of family and friends of my own don't consume my content. So. But when they but when they do, and they see themselves in what you've written, oh, yeah. What have the reactions been? Like? I'm so curious about this.

Kathleen Nicholls 18:41

Um, oh, that's interesting. I've not really thought about that too much. Usually positive, I think, I think maybe my mom would be the only one who was less so I can't say anything remotely negative. She's a wonderful person. But she, I think she was slightly concerned about how she was portrayed in the sense that she was a mega, whatever, which she is, unfortunately, there's nothing I can do about that. But I think a disclaimer in the book has treated me as if I was like, a precious vase that was going to break at any moment, but that is how she treats me and that's how a mother treats the child because they don't want anything to happen to them. So yeah, I think the only thing that was kind of flagged up was that I was maybe a bit this was about her too much but um, but none of it was negative I would never be negative ever. I don't think of her other than that. She's amazing.

Kathleen Nicholls 19:33

So beyond the whole I don't think there's been any, the only negative feedback I get is usually a bit my own face on the internet from strange men. Or, or occasionally I get in trouble if somebody is read the book, and they don't like that. Differentiate between IBD and IBS, which I do because there are different things. But I think people are can get offended if they have IBS. That is if I'm discounting the condition which f don't I think I don't think I've not read my own book for a while and maybe should go back and read it but, and somebody actually gave me some negative feedback the other day that when I was speaking about diet as suggested wine and biscuits really so you interpret it because I wasn't stressed and I could die. It's wine and biscuits. It's just magic. At least it was until I discovered water (TM).

Amber Tresca 20:26

Well, I think if you say at the beginning of the book, it's not a self help book. Yeah, come on, you know, and you've only got yourself to blame. You've only got you know what, read more carefully. That should be your answer to that. Maybe next time, read more carefully. I'm, you know, the section about IBS.

Kathleen Nicholls 20:45

Looking back, I can see it was probably a bit harsh.

Amber Tresca 20:48

But I understood where you were coming from, you know, at the same time, like, especially after you've been through surgeries, and with as much pain as you experience with your disease that sounds like that. You know, from reading your books, it sounds like that's one of the main things that that was really getting in the way of your quality of life was how much pain you were in that and how much you throw up. Like, you seem to just throw up a lot, actually.

Kathleen Nicholls 21:24

Yeah, you remember those happy memories come flooding back?

Amber Tresca 21:27

Yeah, you know, ever heard of it. She I like, I know, you're okay. So like reading, reading your your puking stories, like, I know that you are alright, and that you're doing okay, so, like, I felt like it was okay to laugh.

Kathleen Nicholls 21:42

Just know, realizing that when I wrote this book, I was in a long term relationship. And now I'm not so there's probably a few things. Maybe I wouldn't have put in there potential romantic partners may have seen the future. But no, but too much detail. But then you go.

Amber Tresca 21:57

Oh, that's a good point.

Kathleen Nicholls 22:00

Maybe if you can't handle me at my, vomiting and profusely best, then you don't deserve what I'm drinking water.

Amber Tresca 22:11

Now I'm gonna have to find somebody else that hates drinking water.

Kathleen Nicholls 22:16

Gosh, I just drank some water there for you. Life, right now.

Amber Tresca 22:18

I know. Right? You know why? And you know what? I'm drinking Diet Coke. I thought about getting some wine. I thought that might be fun. But, I just might screw up all the technical things, you know, so I got rid of that bad idea. So it's interesting, though, that you had publishers contacting you after reading a blog? And had you written very much before you were sort of blogging sort of therapeutically?

Kathleen Nicholls 22:53

And no, no, not for Like, since my school days. No, never. I just thought it was, I thought it was a wind up at first, to be honest, but a small publisher, but then yeah, so then I thought, well, if somebody is interested in I can try some other ones. So I sent away to every publisher under

the sun. And the response was really positive. Obviously, I've got plenty of rejections. But the majority of the feedback was that it was a great idea.

Kathleen Nicholls 23:19

So I just kept plugging on with that didn't ever think it was going to come up anything. So yeah, it was a complete whirlwind. It was so exciting. And I'm so happy it's in the world, and people are still reading it. The best thing is when people take the book library, and then send me a picture, because I get so excited. I'm so obsessed with libraries. And during the lockdown it was it was awful, because for the most shot so people were buying the book online, but yeah, it's wonderful. I just thought after one print and it would be pulped. I'm glad that still exists. didn't think it would be replenished again after the first time, but there you go. And it's everywhere in the world, which is amazing.

Amber Tresca 23:58

Hey super listener! Thanks to Kathleen Nicholls for sharing her story and for her work in writing her books about her journey with IBD. You can purchase "Go Your Crohn Way" and "My Flare Lady" both in print and as an eBook. You can also follow Kathleen on Instagram and Twitter as KathFantastic, as well as on YouTube and on her blog, KathFantastic.com. And I highly recommend you do.

As always, I will put these links in the show notes and on my Episode 97 page on AboutIBD.com.

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Thanks for listening, and remember, until next time, I want you to know more about IBD.

About IBD is a production of Mal and Tal Enterprises.

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