

About IBD Podcast Episode 98

A Week Spark of Inspiration

This is the second part of my conversation with 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." Hear the first part in Episode 97, where Kathleen tells us about her Crohn's disease diagnosis and how blogging became the way she process her disease journey.

We talk about how to answer when people ask us how we're doing. Which leads to another topic, and that's how providers can ask patients about whether or not they want to pursue parenthood. Kathleen also gives blogging tips, including a hard truth, and offers advice to anyone who is newly diagnosed. However, I think her wisdom is important for long-term patients as well.

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](#)

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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 98.

This is the second part of my conversation with 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." You can hear the first part in Episode 97, where Kathleen tells us about her Crohn's disease diagnosis and how blogging became the way she process her disease journey.

We tackle a topic that many people with IBD struggle with, and that's how to answer when people ask us how we're doing. For friends and family the answer is usually "fine," but that

probably shouldn't be what we tell our doctors. Which leads to another topic and that's when and how providers should talk to patients about whether or not they want to pursue parenthood, and what that might mean for IBD management.

Kathleen also gives tips for bloggers, including a hard truth, and offers advice to anyone who is newly diagnosed. However, I think her wisdom is important for long-term patients as well.

Once again, from Scotland, let's hear from author, Kathleen Nicholls.

Amber Tresca 1:22

Kathleen, thank you so much for coming on About IBD

Kathleen Nicholls 1:26

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

Amber Tresca 1:29

I have a passage from "Go your Crohn Way." Like I didn't tell you I was gonna do this. So you're like, Oh, no. But the amount of Crohn's puns that you come up with, like, I'm just like...

Kathleen Nicholls 1:43

I really cornered the market.

Amber Tresca 1:45

I'm never gonna come up with any new ones. It's just, yeah, but I like this part. So I highlighted it. So I'm gonna read it to you.

Kathleen Nicholls 1:51

Okay, I'll cover my face.

Amber Tresca 1:53

I won't, I won't look at you. "But to make another human feel that they are unworthy of a few moments of your time, when they are laying out their worst fears and feelings of utter hopelessness, right before your eyes. To me, just beggars belief."

Amber Tresca 2:11

Here's something that I often think about. And I think about in terms of the patient experience, and then having our healthcare providers understand more deeply about the patient experience, they may not get the deep and difficult things about our lives, just from the few minutes that they have with their with their patients. So I often think about how the content that we create could be part of a curriculum could be part of how you can better understand what your patients are going through.

Amber Tresca 2:46

I definitely think that your your books could be part of that. And I was thinking about that. And how the question that we get asked sometimes, like, how are you? or How are you doing? For instance, what is your response? When somebody says, Kathleen, how are you doing?

Kathleen Nicholls 3:05

Well, that's been a consistently difficult thing for me to navigate. Because my response is always I'm fine.

Amber Tresca 3:13

Exactly.

Kathleen Nicholls 3:15

I'm generally never fine.

Amber Tresca 3:17

No, I know, that's what I'm saying.

Kathleen Nicholls 3:21

It's, it's so backwards, because it's and it's also frustrating for people who do know you because they know you're not fine and all my friends will say, what's the real answer? Because I can...even sometimes by looking at me they know I'm not fine but. So now I think I've I still am guilty of saying that occasionally.

Kathleen Nicholls 3:39

I think I think I pick and choose who I'm who I'm sharing information with. So and sometimes you just don't talk about it as well. So it's easier just to say I'm fine. Or, or maybe I'll give an abridged version of just having a bad day or, or sometimes see I'm just talking about Crohn's day or.... But yeah, I think there's a levels of that as patients we know. It's as like a traffic light system. I don't know what you call it in America. So if it's, if it's red, then I'll tell tell people that, yeah, I'm really not fine. I need to go to the doctor, I need to do something. I need to take the day off. But generally, when it's green, or amber, I'll just either say I'm fine. Or I'll say, yeah, just having a bad day or a couple of days, I'll be feeling a bit better, or I'm just struggling today.

Kathleen Nicholls 4:22

But yeah, I think I'm still quite bad at not sharing as much as I really should. But sometimes it's just exhausting even talking about it. So I think it's more preserve my own exhaustion, because sometimes the full amount of energy is spent on just making it through the day. Because for me, the fatigue thing is the worst at the moment for symptom-wise. So sometimes you just don't even have the energy to experience...I've given you a really, really long answer to a really short question.

Kathleen Nicholls 4:55

So yeah, you can see when I usually go wrong, but yeah, usually I say I'm fine. Even when I'm not.

Amber Tresca 5:00

Yeah. And that's what most of us do, right? We just say I'm fine. And the passage that I read you was from a section you were talking about dealing with health care providers, and how this is a person that's asking you how you are and asking you about your symptoms. And you are expecting them to listen to you in a way that maybe you're not expecting from other people in your life. But you don't always get that, listening from them.

Kathleen Nicholls 5:30

I mean, I was I've been really lucky in the past few years, because I've had various consultants, but the one that I had, up until a few years ago was such a gentle kind man who really took the time to get to know me, and I know that obviously, every sort of medical professional has a schedule, and they don't have all day to listen to me rambling on about whatever's on my mind that day.

Kathleen Nicholls 5:54

But he could see through that I'm fine. And he would always say, No, no, you don't tell me the full truth. So can you tell me how you're feeling? And it's just as like a tap being switched on where you can go, right, okay. I can actually tell you because I don't have to... And as really bonkers to even want to conceal how you feel to the person who is meant to help you feel better.

Kathleen Nicholls 6:15

I've never quite understood why I do that, or anyone does that. But yeah, so it's almost like, I don't want to be a burden on anybody at all, even if it is the person that's meant to help me in the first place. But recently, I've had difficulty and in terms of I think it's my age, because everybody now assumes that I should be a baby making machine. And if I don't, I'm running out of time.

Kathleen Nicholls 6:34

So, and obviously, that's out the window at the minute because I'm, again, heartbroken. But um, so the last consultant I had was...seemed obsessed with me having a baby, and now is the best time to have a baby and was constantly telling me about how it would affect my treatment and so on. And it's never something I've even raised with her. So it was another kind of hurdle of why is this now a conversation? Why should Why should even be a conversation until I bring it up. So I think it's, again, I think maybe the issue lies with me not putting the foot down and an understanding that it's okay, there's a two way street, and I don't have to go along with whatever this professional tells me to do, or, or how the conversation should go.

Kathleen Nicholls 7:17

So I've tried to politely swerve to the bowels, and whatever else is going on at the time, rather than something that's not, this is a waste of time, a waste of time for both of us to discuss something that's kind of irrelevant to my life. So, um, yeah, it's been a mixed bag of doctors, and nurses. But on the whole, my experiences have been great. And I have had to be, and

especially in Scotland, we have quite wonderful, dedicated IBD teams, we have IBD nurses, I don't know how it is elsewhere. But obviously, if we can't get ahold of a consultant, and we need just some advice or worried about something, we can call these nurses anytime, and they're so knowledgeable and friendly. And more recently, especially in Scotland, there has been a lot more focus on the mental health aspects of IBDs, which is amazing for me. So you feel you can talk to them about absolutely anything, even if it's not "how is your stool?" or whatever.

Kathleen Nicholls 8:13

Because there's so much to it that's not just physical. So it's nice that that's been looked on some other way as well.

Amber Tresca 8:19

Yeah, the IBD nurses are not as common here in the States. I think some of the big IBD centers have them. But it's definitely more common for you guys in the UK.

[Music: About IBD Transition]

Amber Tresca 8:40

Your health care professionals were bringing up your wanting to have children or thinking about having children, which I think it can be a good thing to bring up. And I think at least here in the States that's not brought up with women often enough. But were you asked the initial question, though, like, is this something that you want to discuss? Or do they just start talking at you about it?

Kathleen Nicholls 9:06

I would say I would say they just started talking about it. I really want to try and be kind. Hashtag be kind, but um...

Amber Tresca 9:18

No, I know. I mean, I think it's good. It's it's a good conversation to have. But I also know people that have made up their mind that they're not interested in being a parent. So yeah, if if your gastro comes to you and says, Do you want to talk about you know, having kids like I feel like that should be the first question I guess is what I'm is what I'm getting at before they start telling you what you should and shouldn't do with your treatment plan when this is not even something that you are considering.

Kathleen Nicholls 9:47

It's kind of as a joke that between my friends but it got to the point where I almost felt like she was she wanted to be a surrogate or something looking for me to to loan out my womb the way it was so intense of know, your, your this age and you're in a relationship. So naturally, you must be thinking about starting a family. And I would kind of go "uh" then I would ever get so uncomfortable. Eventually just go. Yeah, okay. I mean, I think at one point I even said, Well, I'll talk about it tonight.

Kathleen Nicholls 10:21

As if I was gonna go home and see my gastro or told me that we should start a family and he'd say yeah, and we'd skip off through a field while I was heavily pregnant, but it got so uncomfortable that I thought we'll why, Why is it so? So pushy? I don't know. So maybe there's something maybe I give off some vibe of desperation, weathered, but yeah, I totally agree with that. And that's how I feel that should be the question should be asked and if the question is not responded to, and a positive reason it should be discounted and moved on. But and I've raised the baby question with my previous consultant, because when I started ustekinumab, I had asked, What are the side effects? What would happen if, if this and that, and he just calmly told me like he did with every other scenario, but I never read that, again, he never raised it again. So I don't know.

Amber Tresca 11:14

But I think this is a really great conversation to have, because I am a person as co-founder of IBD moms, who is often pushing physicians to raise that question with their patients.

Kathleen Nicholls 11:29

So it's your fault then.

Amber Tresca 11:31

It is totally my fault. And but to hear your side of it. And so we also need to consider that when people are not ready or have decided already, that they don't want to have children or it's far away, or their situation is complicated. Like we need to take that into account as well.

Kathleen Nicholls 11:54

I suppose it and think about it from what you say it of almost as a pre emptive to avoid any dangerous, dangerous situations If one fell pregnant. While

Amber Tresca 12:03

Yes, yes.

Kathleen Nicholls 12:04

I hadn't thought about that. Because I'm very, very sensible. That is absolutely that side of it as well. So I think for me, it just, it just got to a point where it was, it was almost, it was frustrating, because I thought I'm here to talk about this, and then it would put me off track because I still, even after a long, long time, I still get quite nervous when I speak to doctors, especially if I'm feeling particularly unwell and worried about what it might be or I've already thought about 500 things that could go wrong. So I think to be taken off track that quickly. It throws me every time so. But yeah, it absolutely should be, should be spoken about. So I'll just learn to be more patient and kind.

Amber Tresca 12:48

I appreciate your perspective, because it should be a conversation. And but I think that the conversations should start with. What are your plans? And then if you say, I have no plan, then it should be moving on to the next question. Which is how many times do you go to the bathroom every day? Right? So you know, that should all be...

Kathleen Nicholls 13:09

How much water do you you drink? No, I can see.

Amber Tresca 13:14

Oh, my gosh, thank goodness, I have never been asked that question because I would fail. I already fail at the first question. They ask me how many times I go to the bathroom every day. And I'm like, I don't know, I don't count. And then they get mad.

Amber Tresca 13:30

Do you have any advice for people who are starting out on their writing journey or thinking about writing about their disease or about something else?

Kathleen Nicholls 13:38

I suppose not. Any massively practical advice about getting a book published or all that other than there's absolutely no harm in approaching anybody and everybody because you have nothing to lose. So aim for the stars and see what happens. Because there will be something that's out there that appreciates your writing.

Kathleen Nicholls 13:58

And I think just don't try and emulate anybody else or any other style of writing. Just write what you feel that I'm trying to round a bit around right from the heart. But that's what I'm basically what I basically mean. Because the type of rate and I enjoy anyway is honest and open and makes you feel like you're talking to a friend or Yeah, obviously I know use a lot of humor to do that. So it's hard. These are hard topics to talk about. So if you can laugh at yourself, then this makes it easier for everybody involved.

Kathleen Nicholls 14:29

I think although doctors absolutely hate when I try and crack jokes if I'm speaking to a doctor, or especially if I crack upon that's just to get him off. And so yeah, sorry my advice would be to write honestly and as openly as you feel comfortable doing and just just approach no but if you think you're right and you want to push it further and write a book or write in any long form format and do it and then but then unfortunately the advice always as to write, because you can say till you're blue in the face that you want to be an author or you want to write a book or...but you have to actually do it. And if you don't enjoy actually doing it, then there really is no point. So you have to do the work first and then reap the benefits later.

Amber Tresca 15:14

Did you just say that you enjoy writing? What's that like?

Kathleen Nicholls 15:20

Yeah, that's not actually true. I mean, I do for the... Once I get started. I do. It's very, I still find it very hard to get motivated. And I don't write as much as I did now. But once I start, I really, really enjoy it. But sometimes I think, and I did this, even when I was blogging, I would think, what, I'm never going to have an original idea in my life. And I know every author does that or every writer does that.

Kathleen Nicholls 15:44

But I think it just takes a wee spark of inspiration. And sometimes that comes from strange places. But But yeah, once I get started to enjoy it, but sometimes it feels like the worst thing in the world. Especially the editing part. That's horrendous. But But yeah, I do, do still enjoy it, which is the main thing that's that's the only time that's the only thing that keeps me doing it is the fact that I love, I love it. And that seems to help people. So I don't think I would ever stop doing it because people do seem to get something from it. So.

Amber Tresca 16:11

Yeah, that's a nice bonus sometimes, especially when they let you know that it has touched them in some way that's really helpful and spurs me along to do more.

[Music: About IBD Emotional Piano]

Amber Tresca 16:33

Kathleen, I've never been to your country.

Kathleen Nicholls 16:36

Come on over.

Amber Tresca 16:37

It's, well, it's, it's on my list. But I want to ask you, though, I've looked this question up. And the answer that I found was so dumb, but I was trying to I was trying to understand what might be the best time of year to come to Scotland. I know right? You're laughing. Because when I looked this up, the answer is usually "whenever it doesn't matter, come whenever" and I'm like well that's not right. So I want to ask you what what is a good time first of all and then second of all, what are the things that we should see while we're there because you know, obviously only having maybe like a week or even less what would be some high points.

Kathleen Nicholls 17:26

And well in terms of when to I'm just looking at the window now and it's an absolute monsoon. So when to come if you're looking for good weather there really is no good...

Amber Tresca 17:37

No good time.

Kathleen Nicholls 17:39

I don't want to say summer because we don't really have a summer but usually we get few good days in maybe July August time. Last year unfortunately during the pandemic, it was absolutely scorching and July time when we were all locked indoors. But yeah, I suppose we would always suggest August for the festival we have a huge art festival here. Everybody loves to come there we get massive tourists come in in August.

Kathleen Nicholls 18:02

But if you want to see castles and all of that then you can come anytime of the year I would say probably maybe September time when it's still not...you're not going to get hypothermia but you'll still be able to see everything with a kind of mist around everything. If you go to Skye there's some beautiful castles on Skye beautiful and beautiful sights to see and Skye. So up in the highlands is absolutely gorgeous if you want a kind of authentic experience.

Kathleen Nicholls 18:27

And then you could come to Edinburgh and Glasgow and see what it's like to be knocked out after a pint. No, I'm sorry to my people. Yeah, it depends what you're looking for, I suppose. But yeah, I would say it's good to do a bit of both. If you're coming for a couple of weeks, and you can come visit me meet my cat and drink some water.

Amber Tresca 18:50

Well, I don't know about that last part. That's not really selling it for me. Okay, I have one more thing. I'm just showing you something I'm trying to figure out. I'm trying to figure out how much to show you because I didn't plan on doing this. Okay, this is this is gonna make for good. This is gonna make for good podcast.

Kathleen Nicholls 19:06

You're fiddling under the desk. I'm worried.

Amber Tresca 19:08

I am. I'm like, I'm removing clothing. That's what I'm doing.

Kathleen Nicholls 19:13

I didn't know this was part of the process.

Amber Tresca 19:15

I know, right?

Kathleen Nicholls 19:16

I'm not shaved.

Amber Tresca 19:19

I don't know if I can do this. Okay, wait, wait, wait, wait, wait. I'm trying to get my leg up.

Kathleen Nicholls 19:24

So Oh, wow. Oh, wow. It's a Prince tattoo. I love it.

Amber Tresca 19:30

Oh, yeah. So I have a I have the love sign on the inside of my right ankle. And so I actually got it a couple months after he passed. Oh, and so I think I knew that you are a Prince fan. But then I think I forgot.

Kathleen Nicholls 19:50

I think I talk a bit about David Bowie a bit more in my...I'm a huge Bowie fan. But yeah, I love Prince and Bowie.

Amber Tresca 19:56

Yes, you mentioned David Bowie about 5000 times in your books.

Kathleen Nicholls 19:59

I know.

Amber Tresca 20:02

Do you have a favorite album? Do you have a favorite song?

Kathleen Nicholls 20:06

I don't think I have a favorite album specifically, I just, I like a lot of the earlier stuff. But it depends. It's like David Bowie, there's so many different eras. So yeah, you can really use your mood to decide what era you're going to listen to. So sometimes if I really want a danc around the flat or listen to a really long winded song where it goes on a guitar solo for about five years, or like, there's a song that's got my name in it, which I love for selfish reasons. And "Starfish and Coffee" has got my name in it, which you'd never get a song with my name in it unless it's a really crass Scottish song.

Kathleen Nicholls 20:41

Yeah, I don't have a favorite album, but I just love the whole back catalogue. And I'll always love David Bowie and Prince and I'm so sad they're gone. I was genuinely took a day off when David Bowie died. I couldn't believe it. I was like, I lose a limb. Which I know sounds ridiculous. But if you've been a fan of someone for so long, it's was heartbreaking so and so unexpected as well. I think, same with Prince. Yeah, I'm so excited to see your tattoo. I've never I've never had the courage to get a tattoo yet. But maybe one day, I'm going to get a wee Bowie one on my hip. But I don't know.

Amber Tresca 21:08

I think you should do it. I totally think you should do it. It's it is bizarre to talk about because it does sound really weird to be so enamored and feel so close to someone that you've never met that they're a celebrity and whatever. But honestly, Prince dying was just so awful. And David Bowie the same. I had friends that were absolutely devastated by his death as well.

Amber Tresca 21:37

And I'll and I'll tell you what else too. Like you were talking about getting on your hip. I don't know how often you show your hip in public, but...

Kathleen Nicholls 21:46

Not in Scotland.

Amber Tresca 21:49

But whenever I'm out, and my tattoo is visible, occasionally someone will see it and it'll start a conversation. And yeah, and that was, you know, never something that I would have thought.

[Music: About IBD Transition]

Amber Tresca 22:10

Kathleen, do you have any advice for people who were recently diagnosed with Crohn's disease?

Kathleen Nicholls 22:15

But yeah, I think for me, if I was to give anybody any advice about being diagnosed with Crohn's, or any form of IBD, it's just to talk about it and talk openly and honestly, with people that love you. And people that don't, if you don't have anybody to hand that always medical professionals, who will listen, and never be ashamed of your illness, because shame thrives in silence. Talk about it. And people will listen.

Amber Tresca 22:43

Kathleen, thank you so much for coming on About IBD thank you so much for your work for your books. I've truly enjoyed them. I feel like I know you, which is probably weird for you...but I do.

Kathleen Nicholls 22:56

Oh, that's nice.

Amber Tresca 22:56

I'm glad you think it's nice and not creepy.

Amber Tresca 23:00

But let's go through your social media so that everyone can follow you and watch your videos and enjoy all of your puns.

Kathleen Nicholls 23:08

And okay, on Twitter and Instagram, and it's at Kath Fantastic. With a "K" not a "C" for everyone who thinks my name is Catherine. It's Kathleen. I'm on Facebook at Kathleen Nicholls Author, I think and I've got a blog page on Facebook called Chronological Order. That was the name of

my initial blog many years ago, and I still try and keep that up. I think that's it. Yeah, I think there's a you know, I've got a website sold as well called kathfantastic.com.

Amber Tresca 23:39

Thanks so much. And it has been a joy to talk to you.

Kathleen Nicholls 23:43

You too. It's been fun.

Amber Tresca 23:44

So thanks for coming on my show. And for all of your work. And gosh, I hope we get to do this again.

Kathleen Nicholls 23:50

Yeah, me too. Thank you so much for your podcast. It's such an amazing resource for people with IBD and I hope you keep it up for many years to come and have me back on many times.

Amber Tresca 24:02

Hey super listener! Thanks to Kathleen Nicholls for sharing her journey with us. 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.

As always, I will put these links in the show notes and on my Episode 98 page on AboutIBD.com.

You can follow me across all social media as AboutIBD. I'm an independent journalist so I rely on the community to spread the word about my work. You can help by rating and reviewing About IBD in your favorite podcast app or by liking and sharing my social media posts.

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.

It is written, produced and directed by me, Amber Tresca.

Mix and sound design is by Mac Cooney.

Theme music is from Cooney Studio.

Kathleen Nicholls 25:09

I'm a professional author who drinks water for God's sake...

Amber Tresca 25:12

Drinks water...

Kathleen Nicholls 25:13

I don't have time for this, yeah...

Amber Tresca 25:15

And can go like a whole 45 minutes without swearing, you're a goddess.