

About IBD Podcast Episode 80: Am I Forgiven?

Episode Transcript

Amber Tresca

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 80. I didn't look far to find my guest for this episode. It's my husband, Michael Tresca, who has been on my show twice before, on Episode 8 and Episode 20. It's been more than two years since he's made an appearance, though, so I thought it was time.

We found each other when we were in our early 20s and still in college. The twist was that I was living in Michigan and he was living in New York. We met over the internet but this was well before the days of online dating. After knowing each other for some time, I hopped on a plane and flew to New York to meet him. I stayed for a week and we decided what our next steps would be. Several years later that resulted in us being married in New Jersey and settling in Connecticut, where we still live today, 21 years later.

Many people with IBD have concerns about finding a partner because of how difficult it is to live with these diseases. It's true, having a chronic illness does put relationships in a different light. On this episode, we focus on communication and how important it is right from the beginning of a relationship.

Mike and I discuss how I first told him about my health challenges and how he responded. Turns out I remember it more vividly than he does. We then discuss a 20-year-old issue that occurred because he was a little more transparent about my illness with friends and coworkers than I was. I hope this gives you some insight into what it's like to have IBD as part of your marriage and a jumping off point to have similar discussions with the people in your life. Stay to the end for Mike's tips on how to be a better partner to someone who lives with IBD.

Amber Tresca

So have you listened to my last episode yet?

Michael Tresca

Yes.

Amber Tresca

That's good since it didn't come out too long ago. Here's the thing. I asked her a question that I've never really thought about a lot in regards to my own life. She was diagnosed when she was 11, [Jordan Diddy, Episode 79](#). And I asked her, how did she

tell people she was only 11 years old. And I just can't imagine how you would deal with that at that age. And she told me that basically, she didn't tell anyone, there was only one person that she told. And she really didn't know what other people knew. Her parents may have dealt with it. But people didn't directly discuss it with her. And it made me start to remember, I was a few years older. At my diagnosis, I was 16. But I didn't sit people down and talk with them about things. Obviously, my friends were constantly in and out of the hospital. You know, there was always somebody in my hospital room. But I don't remember having an actual conversation with anyone. Where I looked at them and said the words, I was diagnosed with ulcerative colitis, the only difference is when I told you, and I say told, even though I didn't actually tell you, I believe I emailed you.

Michael Tresca

Mm hmm.

Amber Tresca

Do you remember receiving this email from me?

Michael Tresca

Vaguely? Yeah.

Amber Tresca

Really?

Michael Tresca

Vaguely. Yeah, it wasn't a big moment. So I don't know if there was something I sort of knew what was up. But it didn't seem like a giant revelation to me when it happened.

Amber Tresca

So I went to the computer lab in Holmes Hall, went to send you an email, because we had met over the internet. And we're not obviously together. And that was a large part of our communication was either on the phone or email. Or we would get together on the different games that we played. So I remember going into this computer lab and sitting down to write this email to you. Because I think it was getting to the point where I was going to end it with the person that I was seeing. I don't think you were seeing anyone at the time or I wasn't aware, if you were. So we were getting to the point where we were going to have to figure out whether or not we were going to be able to meet physically, and then how we were going to figure all the rest of that out being that we were living in two different states and hadn't finished school and, you know, everything else that goes along with that. So I guess I just really wanted to make sure that you understood what my challenges were before, we were actually together in the same space. And you realized that my what my physical realities were. I think it was probably it may still be like the first and only time that I sat down to let someone that I was involved with know what was going on. And I don't remember specifically what I wrote. But I think I wrote what I understood to be true at the time, which is vastly different than what it is now. But at the time, I knew that I had a lifelong condition. That I was better than I used to be, but it wasn't getting any better from there. And that I didn't know what it would look like as

far as my future prospects in terms of a career in terms of having a family. I just couldn't tell you much of anything except what I knew to be true of the past five or six years of living with ulcerative colitis. And so I send off this email and I don't remember like, you know, after that, like what the day was like after that or whatever, but I do remember very distinctly the computer lab sending you this email. And you wrote me back whenever it was that you wrote me back. And I picked it up later. You say you don't really remember what I wrote to you. But do you remember what you wrote to me?

Michael Tresca

Not...not specifically other than I think in a lot of ways we didn't think it was a... It's funny because you made that comment where it was like what we understood at the time. So I thought, at the time it...I just took it at face value is just being another part of sort of your life and our life. And it didn't it...I don't think it fazed me. I don't remember what I said, though. No I don't.

Amber Tresca

You can correct me if I'm wrong. If you remember how this went. I believe that you wrote me back. Essentially, you were kind of like, well, none of this really matters. And you essentially went on to describe a coelacanth. Am I saying that right? I should know. And you said here was this thing that people thought was extinct. And lo and behold, they go and find one one day. And you're my coelacanth. And it doesn't really matter. Like all these other things. We'll figure it out. You know, and it was an interesting response. First of all, I had no idea how you were going to respond. Because I had had literally, almost no experience with telling anyone the realities of my disease. If they were around me, they might have seen it. But I certainly didn't describe it. And I don't think I'd ever told anyone that I was dating: no, I take that back. I did try one time telling someone that I was dating about my situation. And I don't know why. Because this was like, a summer boyfriend, you know, this was not going to be something that was serious. So I literally have no idea why I was trying to tell him anything, it kind of didn't matter. And he asked me a lot of really bizarre questions. And I was like, okay, so definitely, when summers done, I'm gonna go back to school. And we're done. Because this was fun. But no, thanks.

Michael Tresca

Yeah.

Amber Tresca

So your response was surprising. Now, on the other hand, it wasn't like this was an easy thing for us to try to be together, we had to do a lot of things in order to make it work. I guess I give a lot of advice and write a lot of articles and things about how you can talk to people about your disease, and I certainly do a lot more of it now. But interpersonally it just sometimes it just doesn't come up.

Michael Tresca

You know, I was all in obviously, I think my answer is consistent. Although it sounds weird, cuz I don't remember actually doing all that. But I think it's still applied, which was

sort of, I knew you, sort of as a person on the internet before we had been together. So there wasn't a lot of preconceived notions of like, how is this gonna affect how we date, because we didn't have any of that yet. So I feel like we had done a lot of getting to know each other sort of by communication. And whatever it was, I think it was part of, you know, I was just gonna accept that because that was who you were. And it didn't faze me at all. If anything, what we learned later was sort of some of the things we just took for granted, weren't the way we thought they were. So I sometimes blamed myself because I just, I sort of took it all on questioningly. And there's, that's not always great. And over time, I think we sort of re examined some of that. But for me, it was just that's part of who you are. It is funny to though, to talk about this and think about how we went from two kids, kids, even though we're in our 20s on different parts of the nation, to now we here have a 10 year old and a 13 year old, which is just crazy to think that we went through all that and came out the other side. Married for as long as we have so I think that's really astonishing because I can only imagine people who there are many couples who go through this and to think what challenges we they have to face and you know, that we had to face. We just ulcerative colitis being just one of them.

Do you remember work the fabulous work incident where it came up?

Amber Tresca

Which...which one? Give me a timeframe, a year.

Michael Tresca

Where you being introduced? When I was a consultant, and we introduced everyone and we were talking about and you made sort of a joke about somebody made a joke wasn't necessarily you about, oh, maybe your kids will be this way. And one of the contractors I work with said, I thought you said you couldn't have kids. Actually blurted that out at the dinner table.

Amber Tresca

You know what? That's coming back to me. But I don't remember where we were. Was it a holiday party or something?

Michael Tresca

Yes. This this is cathartic. Because it's haunted me for 20 years. Because the look, you gave me burned into my soul. So I'm glad it's nice to hear that it doesn't. It didn't stick as horrifying as it was for me, because, you know, this. So this is the discussion point, right, which is, on the one hand, I had brought that up in the context of, I'm not going to talk about it a lot. It's not it's sort of a sensitive issue. On the other hand, I think people in social settings didn't know how to approach it in any delicate/indelicate way. So it sort of came out. And it was one of those like, awful awkward moments, because frankly, it wasn't their business. But I was one of those things where when I would try to explain our situation. It just naturally it was part of the speech.

Amber Tresca

Were we even married? No, we weren't even married at the time.

Michael Tresca

No.

Amber Tresca

I only remember the incident. OK I do, I do remember that.

Michael Tresca

The traumas being relived.

Amber Tresca

I heard...I remember who said it.

Michael Tresca

Mm hmm.

Amber Tresca

I don't think it really wounded me. Except that it was apparent that this was a person that you were confiding in, and I didn't realize how much you were confiding in him.

Michael Tresca

And so and so here, well this was good, we'll have this out on the podcast. But what was happening was I didn't I didn't think of it as confiding because that was part of my speech on how I talked about us, and your situation.

Amber Tresca

It was part of your elevator speech?

Michael Tresca

Correct.

Amber Tresca

Why did you need to tell anyone about our situation? We weren't even married at the time.

Michael Tresca

Um, because people would talk about kids. And I'd be like, we don't know. It's a serious thing. Don't make jokes. That was sort of my feeling.

Amber Tresca

So you were trying to protect me?

Michael Tresca

Correct.

Amber Tresca

And this dude, yes. whose face is now...I can remember...decided to just -- kablam -- lay it all out. Okay.

Michael Tresca

Yes.

Amber Tresca

Okay.

Michael Tresca

People had alcohol.

Amber Tresca

Oh, yeah, no. And the reason why I remember it is...I do remember that now that you bring it up. I'm, it's not like I've ever sat down and really thought about that. I don't even know if we had a discussion about it. I remember it, because I was okay, this would have been a holiday party. So it would have been in 1998. I was not well. And I was on a lot of prednisone. And you could tell by looking at my face. So I was very self conscious. And my face look different. And there was no way to hide it. And then all of the sudden, it was like, people knew the thing that I moved away from and didn't discuss with anyone. So it wasn't necessarily about having kids, because I think I almost didn't let myself think about that too much. I was too sick. We were too young, and we didn't have any money, and I was gonna have to pay for this surgery. So, you know, having children was far and away from all of that. So I think it was more than here was a person that I considered to be tangential to our lives, who clearly knew things that I wasn't aware other people knew.

Michael Tresca

Yeah, and I think that well, that irreparably damaged the relationship with that guy. That was the end of that. Do you forgive me?

Amber Tresca

For for discussing it with other people?

Michael Tresca

Yes.

Amber Tresca

I mean, what's hilarious about it now is that I was very much a person who told others what they needed to know when they needed to know it. Therefore, no one at work knew of my challenges. I don't think even the people that we were meeting and that we were socializing with at that time, knew anything.

Michael Tresca

Right.

Amber Tresca

It wasn't...I didn't bring it up. I didn't...I didn't discuss it. So what's funny about it, now is that now I tell my story to anyone who will listen. And have done so many times and in many places and on video and audio and written and an interview form. It's kind of funny. Think about now to think about how private I used to be about it. And 20 years later, there's very few aspects that haven't been dissected in a public forum. So...

Michael Tresca

Am I forgiven?

Amber Tresca

Yes.

Michael Tresca

Thank you.

Amber Tresca

I don't...I mean, I don't know that there's really anything to forgive. It never bothered me in that...in that way,

Michael Tresca

Right. And so one of the things that I think is, it's, it's relevant to this discussion is I saw myself as your PR person in a lot of ways. We had talked about this was a joke, way before well, as this...

Amber Tresca

Well this continues to be the joke. Is that you're, you're PR.

Michael Tresca

Yeah, yeah. Um, but so what happened was, I did have sort of an elevator speech, which was completely crafted with no input from you that was sort of taking cues from you to sort of come up with this stuff. And I'm pretty sure you can bet your bottom dollar after that I left the other piece out and about, but it was one of those things that I was learning how to talk about it to other people. And what was personal and what was sort of off limits. And that was a harsh lesson to learn. And again, the person just blurted it out, because they were...everybody was drunk. And they were at a dinner party...

Amber Tresca

Well, I wasn't drunk.

Michael Tresca

You were certainly not drunk enough.

Amber Tresca

I don't even think I was drinking, I was way too sick.

Michael Tresca

Yeah, that's right, yeah.

Amber Tresca

But here's my question about that, though. Why did you have to have an elevator speech about my disease?

Michael Tresca

I think because I, there were some...I think there were times we didn't do things. And I wanted to be able to explain, you know, this doesn't make sense right now, or we can't eat this or that there were certain things that I don't if you asked me exactly what it was. But it sort of was a means of putting things in context. I also think, at some point, surgery was on the table where we knew it might affect availability of me and I don't know if it was at that job specifically, but I feel like that was a discussion point.

Amber Tresca

Well, actually, what happened was, is that you left that job, because you were in a brand new job.

Michael Tresca

Yeah.

Amber Tresca

In March of 99, when I had the first surgery.

Michael Tresca

Yeah.

Amber Tresca

Because essentially, you had to sort of finesse your way to be able to be with me at the hospital for almost a week.

Michael Tresca

Right.

Amber Tresca

While all of that was going on...

Michael Tresca

Right.

Amber Tresca

And you had just started that job.

Michael Tresca

I don't know that we knew when that was going to be exactly until later. So I think there

was a lot of ground laying that I was trying to do to sort of give me the ability to sort of say, like, I want I didn't want it to be as I got to go out all of a sudden, and people were like, why? So I think there was a lot of me sort of saying, I just want to let everyone know what the situation was. But I mean, look, I was young, the workplace we were at was pretty stressful. And one of the best way...I was pretty transparent, frankly. So it was a very good defense because there was a lot of sort of skullduggery going on in the world of contracting.

Amber Tresca

Skullduggery? What?

Michael Tresca

You heard me. You heard me. I used it.

Amber Tresca

Did you just see skullduggery on my show?

Michael Tresca

Yes. And I'm probably the only one. Am I the only one? I hope so.

Amber Tresca

Well, yeah.

Michael Tresca

Good.

Amber Tresca

And you might not even be the only one. I feel like I'm gonna cut that.

Michael Tresca

You better not cut it. I'm gonna own it.

Amber Tresca

What does that mean? Skullduggery? Like, what do you mean by that? Like, I know what the word means, but what do you mean by that?

Michael Tresca

I think there there was a lot of like, sort of backstabbing and a lot of sort of rumor mongering and a lot of that stuff, because people were jockeying for position. So part of that, for me was to be transparent. And that made it much tougher for people to sort of make things up.

Amber Tresca

But did people come to you and ask you about me? That's what I'm saying. Like?

Michael Tresca

Yes, you were a mystery for a long time. They hadn't met you, everybody else. Some of their spouses worked with them, or they were, you know, coming to work. So for a long time, you were a mystery. It was a big deal when you showed up. Like it was like a huge I don't even know what the phrase was, it was like a huge welcoming ceremony was like, oh, here is the the mystery woman that, you know, Mike's dating, and a lot of people will like, because I was obviously and still am a character. So there was a little bit like, what who could possibly date this guy? And what what is that like? So? Yeah, so a lot of this was to sort of put on the table who I was, and also, you know, make it make sense, hopefully make sense? Who you were in the background because again, they didn't know you. And then it went horribly awry, the first time they met, you so it was good.

Amber Tresca

Yeah but you know, the hilarious thing about this is that my response to the first 10 years or so with my disease was to not tell anyone, anything. And your response, after knowing me for three or four years, was to basically tell people everything

Michael Tresca

Yeah.

Amber Tresca

I think that continues to this day.

Michael Tresca

Yes, that's correct. Yep. I think you summed it up perfect.

Amber Tresca

I think that's a nutshell. That's that's our relationship in this why your PR, and I am tech support.

Michael Tresca

That's 100%. And operations too. Tech Support is minimizing operations, really...

Amber Tresca

And finance and a lot of other things. Yeah. But yeah, that's so funny.

Michael Tresca

Well, I feel better. This is already worth it. I feel like we've, we've overcome something. That's been haunting me for 20 plus years.

Amber Tresca

You ever think about anything like that? Don't you ever..because I feel like we talk about just like, everything. But like, Don't you ever...Didn't you ever get to a point where you thought about bringing that up and dealing with it? Or was it...was it the type of thing where it just goes on for so long that you're like, well, I can't bring that up now...

Michael Tresca

The look you gave me wounded me to my soul.

Amber Tresca

OK but to be fair, that's just my look. Like, that's just my face.

Michael Tresca

No, I know your face pretty well. I was fairly...I was mad at myself. I mean, I wasn't mad at you in any way. I felt it was unforgivable. Because I didn't understand obviously, right was the sensitivity of it. And again, it's so funny. Here we are. 20 years later, we're talking on a podcast about it, which is the least personal and private way you could discuss it. So it's clear, we've come a long way. But yeah, it was one of those things where it was like I had miscalculated. I had not. I had in my attempt to protect you, I had inadvertently been made it vulnerable, I think. So it was one of those things that um, you know, I, it was more a harsh lesson for me to change how I thought about some pieces of how we talked about it.

Amber Tresca

So let me ask you this. Why other than the idea of wanting to protect a person that you love, why did you feel the need to protect me?

Michael Tresca

I don't feel like you had a lot of people on your side advocating. Full stop. And because we had moved, and we were in a different environment, a lot of that, so I felt it was my responsibility. That simple. And certainly that...when we were in the hospital, it was really came home.

Amber Tresca

Yeah. Yeah. Well, I mean, you were my voice in the hospital.

Michael Tresca

Yeah.

Amber Tresca

You know, you can do a lot for yourself. But...

Michael Tresca

I mean, I'm a pain in the ass Anyway, now put me in a hospital setting. It was really interesting to see how little voice...and I'm not talking, you know, big picture stuff. I'm talking about like talking to a nurse, talking to someone at the front desk. Because it gets drowned out by everybody else.

Amber Tresca

Oh, yeah. And I'm not a squeaky wheel. Really. Or I wasn't.

Michael Tresca

Yeah. But let's be honest.

Amber Tresca

I wasn't then.

Michael Tresca

You were not then, yes.

Amber Tresca

I was not, then. Yeah, I had been hospitalized so many times for so long, that I kind of knew the ebb and the flow of things. But surgery was new. Being on pain medications was new, having things like a drain was new. And even though I was exceptionally well prepared by my team, no one can explain to you in a way that lived experience shows you. So there were things that we were dealing with in the moment that no one could have told you it was going to go that way. So you being there in you know, being able to I mean, I just literally remember when I was finally cleared to have clear liquids. They heard bowel sounds so okay, you can have clear liquids now. And they weren't bringing them and they weren't bringing them and they weren't bringing them and it wasn't mealtime that was the problem. It wasn't mealtime at all. But we were like somebody bring some jello, like literally some jello, some broth, some something. Otherwise, I'm gonna have to go all night, you know, and not have anything to eat. And then that's going to delay my recovery and going home and everything. And I remember I don't I don't even know how many times you went and bothered somebody about getting me a tray of clear liquids.

I think the tray of clear liquids was when I finally got to the point where I was like, Well, I'm just gonna stay here. Because I would I would go to the desk, ask and they say okay, and then I leave and then what would happen of course, is there be a shift change or whatever people would be moving around so it wouldn't be the same person and after I talked, I think three times it basically like I'm not leaving. I'm just gonna hang out here and that made everybody super uncomfortable. And then you got the jello.

No, I remember that tray. Very well. I've eaten many meals in the hospital. Don't remember a lot of them quite frankly. That one, I remember quite well.

How would you give a person living with IBD hope about finding a long term romantic partner.

Michael Tresca

Do not let a moment in time define you in such a way that you feel it's going to be forever because nothing is forever, no...even situations come and go, even if they're still physically the same. So though it feels like it's gonna be a long time, and they're, especially when you're in a dark place. There's somebody for everybody.

Amber Tresca

So we probably should have done this last year on our 20th.

Michael Tresca

I know, it's like, this is really intense. And why are we doing it on our 21st anniversary. Feels like it should be a 20th.

Amber Tresca

I don't know. It's just um, I don't know why we didn't do an anniversary episode last year, I guess. Well, last year, because we could go places. We actually took a fun anniversary trip.

Michael Tresca

That's right.

Amber Tresca

So we weren't around. We took two trips. Really.

Michael Tresca

Mm hmm.

Amber Tresca

We took a local trip. And then we decided to celebrate again, when we went down to Florida for advances in IBD.

Michael Tresca

That's right.

Amber Tresca

I was sick...again.

Michael Tresca

That's also right.

Amber Tresca

So I think I get more upset about my being ill during a special event than you do.

Michael Tresca

I was drinking and eating great food. It was fine for me. It was harder for you.

Amber Tresca

Yeah. But then I get upset and mean. So...

Michael Tresca

I was probably too drunk.

Amber Tresca

Well, Happy 21st

Michael Tresca

Oh, Happy 21st baby. That's wonderful. Hopefully we haven't horrified everyone trying to look for hope in being married for two decades plus.

Amber Tresca

Well, I'll just cut all the weirdness.

Michael Tresca

Yeah.

Amber Tresca

That's the joy of editing your own show.

Michael Tresca

I'm sure I'll come through, and I'll sound way more intelligent than I know.

Amber Tresca

Well, I'm not a miracle worker.

Michael Tresca

Way more than the wine makes me think I sound.

Amber Tresca

You know, I think I've been trained pretty well but there's a limit.

Michael Tresca

I think you're PR now.

Amber Tresca

Oh boy.

Mike Tresca

A relationship with someone who has IBD is going to have its ups and downs. It's not much different than any other relationship, but Crohn's disease and ulcerative colitis can bring some unusual situations. That's why I'm offering advice on how you can work together to create a rewarding partnership.

1. **Know when to tell others about your partner's IBD.** This is a tricky subject to navigate. First, check with your partner that it's OK to bring the subject up to others; you don't want to say the wrong thing. Most of the time, IBD will likely not come up. But there are times when it might be easier to explain, such as when there's a hospitalization. Be prepared for some off the wall questions, but

remember that it's a chance to educate someone who might not know anything about IBD.

2. **Be helpful during flare-ups.** Flare-ups are going to happen and when they do, you can be your partner's best advocate and helper. However, it might be hard to manage the household while your partner's recovering. Take a deep breath and be patient with yourself. Flare-ups don't last forever and the sooner your partner can receive treatment and rest, the sooner they'll be on their way to recovery.
3. **Be aware of potential body image issues.** IBD brings so many insecurities and worries involving the body, including the ability to be attractive and physically intimate. Some of the things that can impact body image include fatigue, medication side effects, and weight loss or gain. The key to staying on top of these issues is to communicate about them, even when it might feel like an embarrassing subject. If the problems become too complex to deal with on your own, seek out professional help.
4. **Create an emotional support network for yourself.** IBD is complicated and difficult to manage. As the well partner, you're going to have challenges that are unique and for which your partner may not be able to offer any help. Connect with friends and family about your emotional needs and seek out other people who are partnered to someone who lives with IBD for support.
5. **Take time for yourself.** Everyone has their own way of dealing with stress and it's important to nurture the hobbies and friendships that you enjoy, both with your partner and without them. Your identity goes beyond being a well partner and you deserve the time and space to cultivate the things that you love.

Amber Tresca

Hey, super listener! Special thanks to my husband, Michael Tresca for sitting down with me over a glass of wine to record. The episode you just heard was not the episode I'd initially intended, but honestly it probably turned out better in the end.

One thing I want to call attention to is the discussion of women with IBD having children. When I was diagnosed it was during the era when women were counseled against becoming pregnant, and I had to advocate for myself on that topic for many years. Today, I have two j-pouch children, both born via vaginal delivery, and they are ridiculously healthy.

Women with IBD can have healthy pregnancies and babies and do so all the time. If you're a mom with IBD or a mom of a child with IBD, be sure to connect with IBDMoms, which is a non-profit that I founded with my friend and frequent traveling partner, Brooke Abbott of The Crazy Creole Mommy Chronicles. You can find us on all social media as @IBDMoms and at ibdmoms.org.

You can also follow my husband, who is a fiction novelist and content creator for tabletop role-playing games, on all social media and on his Patreon as World of Welstar. I will put all his information in the show notes. You will also find links on the

episode 80 page on my site aboutibd.com and remember that you can also find me, Amber Tresca, on all social media as about IBD.

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

Amber Tresca

Okay, you expect me to edit that back into the rest of the episode.

Michael Tresca

You better believe that I do.