

About IBD Podcast Episode 112

How to Be Happy & Healthy With IBD: Discussing IBD With Family and Friends

People who live with Crohn's disease or ulcerative colitis don't want to feel like a burden. They may feel guilty about changing or canceling plans. Sometimes, people with IBD may not even want to make plans in the first place. A strong support system can help overcome these issues and help patients manage their new normal. Dr Alexandra Fuss, a clinical health psychologist and an Assistant Professor of Psychiatry in the Department of Psychiatry at Yale School of Medicine and Brooke Abbott, ulcerative colitis patient, founder of The Crazy Creole Mommy Chronicles, and co-founder of IBDMoms tell me how they have productive conversations with friends and family surrounding IBD.

Concepts discussed on this episode include:

- [What to Know Before You Eat Out When You Have IBD](#)
- [How to Share a College Dorm Bathroom](#)
- [7 Tips for Keeping IBD at Bay on Big Days](#)
- [Navigating Daily Life with IBD](#)

Find Alexandra Fuss, PhD on [Instagram](#), [LinkedIn](#) and at [Yale School of Medicine](#).

Find Brooke Abbott at [The Crazy Creole Mommy Chronicles](#), [Facebook](#), [Twitter](#), and [Instagram](#).

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

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[MUSIC: IBD Dance Party]

Amber Tresca (00:05):

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 112.

Amber Tresca (00:19):

About IBD is excited to be partnering on this new limited podcast series, How to Be Happy and Healthy with IBD. Talking with friends, family, and coworkers about IBD is not easy, and in some cases, that's probably an understatement. If you look at social media though, it might seem like there are many people who are comfortable discussing their IBD pretty openly. But even experienced patients can find it challenging to be vulnerable and honest with the people that are close to them.

Amber Tresca (00:49):

That's why I asked Dr. Alexandra Fuss, a clinical health psychologist and an assistant professor of psychiatry in the Department of Psychiatry at Yale School of Medicine, and Brooke Abbott, ulcerative colitis patient, founder of the Crazy Creole Mommy Chronicles and co-founder of IBDMoms, to tell me how they cope with everyday conversations surrounding IBD.

Amber Tresca (01:10):

While open communication is really a key part of creating a support system, stick around to the end to hear how Dr. Fuss and Brooke both also look to their pets as important members of their IBD team.

Amber Tresca (01:25):

Our topic today is how to discuss IBD with our friends and family. I have two guests with me to dig into this idea. First, Dr. Alexandra Fuss, a clinical health psychologist and assistant professor of psychiatry in the Department of Psychiatry at Yale School of Medicine.

Amber Tresca (01:42):

Welcome to About IBD. Would you please take a minute and tell us a little bit about yourself?

Dr Alexandra Fuss (01:47):

Yeah, absolutely. Thanks so much for having me. You hit the name. I'm Dr., very fancy, Alexandra Fuss. So I am the digestive health psychologist at Yale School of Medicine, assistant professor in the Department of Psychiatry there. Beyond all of that fanciness though, I am a ulcerative colitis survivor and thriver.

Amber Tresca (02:11):

Thank you so very much. I'm going to take that into my soul, survivor and thriver. So also with me, I have another ulcerative colitis survivor and thriver, Brooke Abbott, the founder of Crazy Creole Mommy and the co-founder of IBDMoms. And she also happens to be my friend, and in pre-COVID times, frequent traveling partner. Welcome back to About IBD, Brooke. I wonder if you'll take a minute to introduce yourself.

Brooke Abbott (02:38):

Absolutely. Thank you so much for having me again, Amber. I really love your podcast. I am Brooke Abbott. I'm a mom of one teen and a mom of one furry toddler. He's a dog. He's [crosstalk 00:02:56] a furry child, toddler. And like Amber said, I'm an IBD patient, but I also live with a J-pouch. So I'm a J-poucher and I'm currently a student hopefully transferring to UC, which is University of California because I am a California resident. And I'm a political junkie and a coffee person. All I do is drink coffee, I realize. Coffee and water, that's scary actually.

Amber Tresca (03:29):

At least you get the water in there. I definitely don't get the water in there as much as I should. Although, when I'm recording I do, because it does help to keep the voice a little fresher. So thanks to both of you for being here. I really appreciate it. You're going to bring different perspectives to this topic and I'm so looking forward to it. So I'm just going to jump right into it. And first I'm going to start with you, Dr. Fuss. You're a GI health psychologist, and you also live with IBD.

Dr Alexandra Fuss (03:56):

Yes.

Amber Tresca (03:57):

Can you talk a little bit about your journey as a patient and then how that has intersected with your career?

Dr Alexandra Fuss (04:03):

Yeah, happy to. So I also have a J-pouch. I probably should have mentioned that as well. Thanks for reminding me, Brooke. Just to kind of give a little bit of backstory, I was diagnosed with UC when I was about 13. And from there, I went through just a whirlwind of medications, drug trials, blood transfusions, TPN, Remicade, the whole nine yards until eventually we just came to the realization this wasn't going to be a matter of if, it was going to be a matter of when, when it came to surgery. So I had a three stage J-pouch procedure, with a temporary ostomy. And then unfortunately towards, I think it was right around my third surgery, I ended up going getting a pinhole leak. And so I was septic, went under the knife for 30 days plus in a row doing the full clean out. So definitely been through the ringer there. In college, I had to have an ostomy bag again, because of course, she likes to act up here and there. You got to get your 10,000 mile tuneups as I like to say too, with those J-pouches.

Dr Alexandra Fuss (05:10):

And so how that intersected with my career. So my team of medical providers was absolutely phenomenal. I could not have asked for better. And at the same time, there just wasn't a lot in terms of resources for how I was doing emotionally and handling this. And not just myself, but I even think about my mom who was my absolute rock. I say all the time, she's the reason I'm still here. So I knew I wanted a career where I could somehow give back and fill that need. I thought about going and becoming an MD. Calculus said no and then I really got thinking and it's yeah, okay, it's those emotional things. Like there's so many people who don't have the

Susie Fuss out there being an advocate and helping and giving you the pep talk and the tough talk.

Dr Alexandra Fuss (06:05):

And so again, that's where I started thinking about psychology. I loved those classes. And then I went on for my masters and I said, "Okay, this is what I want to do. I want to be in GI." And my professors, a lot of them said, "That's oddly specific, but okay." And so that's what I did. I got my masters at Marquette University in Milwaukee. I'm sure you can hear the Wisconsin native in every ounce of my voice right now. And then I went and got my PhD in counseling psychology at the University of Memphis.

Dr Alexandra Fuss (06:37):

And so every single thing I've done since then has been to move towards that career in GI, psychology and specifically working with gastroenterology patients. So in terms of also with career intersect, it's very interesting. I work in the department that's also the people who treat me.

Amber Tresca (06:56):

Yeah.

Dr Alexandra Fuss (06:57):

And so my fellowship was in rural medicine. And so sometimes it was getting referrals from a doctor who I just have to kind of look at him and go like, "Well, you've seen my butt and now we just have to set that boundary. We're going to pretend that didn't happen while we're discussing this professionally." And so, it intersects in so many different ways.

Amber Tresca (07:19):

Yeah. I love that. We're so grateful to have you because that's really fantastic. I just love it. I'm not happy at all that you live with IBD, but I'm very happy that you are here to help us. So Brooke, as we were just discussing with Dr. Fuss's wide range of capabilities and understandings, as she went through her studies, IBD affects everything. It affects our families, it affects our relationships, it affects our friendships. Can you talk about some of the ways that IBD has affected the relationships in your life?

Brooke Abbott (07:56):

Oh yeah. In so many different ways, both positive and negative, I think. I don't want to start off on a negative foot, but I didn't start off as a single parent. I'm currently a single parent. But I also have found that I've been a little bit more open with my friends and my family. I'm a little bit more transparent where I was pretty closed off before. I do see different relationships within my family. We have a very close-knit family and it's very large. But I find that those relationships that I had before I was diagnosed or before I started getting sick, have grown and matured in a way, because I think that this disease and my advocacy work has forced me to be more transparent, more talkative, more vocal about my feelings.

Brooke Abbott (08:57):

And it wasn't always like this. I think before my surgery, because I was keeping my disease to myself, I was still that keep it to yourself, close person. But after my surgery, when I started to tell my story and I realized that it was more important that I be about my symptoms and about how I was feeling, it wasn't so much of a burden as I thought that I was before. It really did help with my relationships, with my parents, with my siblings, with my cousins and my grandparents. And you said earlier, "I don't like that you have IBD but I'm grateful that Dr. Fuss is able to help us." And I feel the same way. I don't like that I have IBD but I think without IBD, I probably wouldn't have some of the relationships that I have now, especially some of the friendships, like you and some of our other friends. It wouldn't have allowed me to be as open as I am now.

Brooke Abbott (10:04):

It's also allowed me to be a better mom. It wasn't just so much that I was home more. I think I've taken more time to communicate with my kid about everything. We talk through things. I've allowed them to be a little more independent in certain ways, because I've almost had to rely on that independence because I get sick so frequently. So yeah, I think there've been some very good highs and some lows. But I also feel like I'm coming into my own and having a better relationship with myself too.

[MUSIC: ABOUT IBD TRANSITION]

Amber Tresca (11:04):

I think one thing that we have that comes up a lot when we're trying to cover, so when we're trying to go through our life around people who don't live with an IBD or a chronic illness, we are trying to do all the things that they're doing, and it doesn't necessarily work out. And maybe that's one of the reasons that we sometimes find it easier to have friendships with people who have IBD or live with another chronic condition. And so Dr. Fuss, one of the things that we can come up against when we're trying to live our lives is that we end up canceling plans. We cancel on people, or maybe we don't even make plans in the first place, especially if we're dealing with a long-term flare up. How can people feel less guilty about taking the time to take care of themselves when they do need to cancel plans and maybe are disappointing somebody?

Dr Alexandra Fuss (11:59):

Yeah, and that's a really great question. I love the word that you use, when we're trying to cover. Yeah, when we're trying to just be exactly like another person who, like I said, isn't dealing with this, who isn't going through all these things. The first go to strategy is really leaning into that self-compassion. So as human beings, we're often our worst critics. We're the hardest on ourselves. And it can be really easy to lean into that "Oh, I should be able to do this because all these people can do it. Why can't I do it?" And not to mention the fact, I think when we are in a situation where we have to cancel plans, when we have to just put ourselves first and say, "I'm not going out tonight," I think that also is difficult emotionally because it highlights that our bodies aren't working the way we want them to, it's highlighting those limitations.

Dr Alexandra Fuss (13:00):

And so you can see where that can even kind of perpetuate more of that shame and that guilt. And so taking a quick breath saying, "Okay, if this was somebody I loved and cared about and they had to cancel, what would I actually think?" Or, "Would I fault them for staying in?" Probably not, because we are so compassionate. We are such compassionate people and we're kind, and we care about this person. And so remembering that, okay, as much as we can be kind to others, we can be equally kind to ourselves. And keeping in mind too, we are worthy of caring for ourselves and openly communicating with others why we're canceling those plans.

Dr Alexandra Fuss (13:41):

I think Brooke, you hit it really nicely there with becoming more open and communicating these things with people, just so that they understand. It's not that I don't want to see you. It's not that I'm mad at you. This is what's going on with me. I have found the more vulnerabilities I've been in my life, and even sometimes with my patients, the better relationships are, the more people understand, the more I'm able to receive compassion from others, because they're able to voice it in a way that's authentic. Because even if they don't know and if you've ever gotten, they're like, "Oh, no, it's fine. Don't worry about it, girl. It's okay."

Amber Tresca (14:18):

Yeah.

Dr Alexandra Fuss (14:18):

And then you're sitting there going you have no idea. It's probably not okay. But when they know and you know they know, it's a little bit easier to take in that compassion and that reassurance that it's all right.

Brooke Abbott (14:33):

I feel like Dr. Fuss just went into my brain and just put it out there. Even though you can be transparent, even though you can be open, you still have those moments of guilt. Two things, my kid was supposed to go shopping for the dance, first dance, going shopping with their friends. When I went to pick them up from school, I had completely forgotten. I wasn't feeling well and I was on a tight schedule. And I told them no, after I had already told them yes. And then I started crying and I was like, "I'm sorry. I'm really, really sorry." He was like, "Okay mom, it's fine."

Brooke Abbott (15:13):

And I feel like sometimes even though you hear okay, you're still projecting that fear and that anxiety. And I did it with my sister the other day. She had a Zoom birthday and I was just not in a place to be able to be on Zoom with all of her friends. I just didn't want to distract from her birthday and her thing. And so I didn't show up. And she was not angry, she totally got it. And I just profusely apologized, not realizing she's seen you at your worst, she gets it. It's fine.

Amber Tresca (15:48):

Yeah.

Brooke Abbott (15:48):

But you do it automatically. And maybe if we just start trusting our friends a little bit and our family members and trusting that they understand, it could be better for all of us individually.

Dr Alexandra Fuss (16:00):

Yeah, absolutely. And I think even building on that, if there is somebody in your life who perpetuates that guilt and says the things like, "Well, you should be here" and "You always do this," it's not maybe a safe person to talk to or be open with, thinking about, okay, wait, is this a person that is a positive influence on my life? Is this an actual good friend? Is this a good support person? And allowing yourself to remember, you don't have to live to super high bar because that's unreasonable for any human. And it's my opinion that every human deserves a certain level of respect, dignity, and to be treated with compassion and caring and love. And if there is somebody in your life who isn't doing that chronic illness are not, that's not okay. And it's okay to acknowledge this isn't okay and set that boundary.

Amber Tresca (16:58):

Yeah. Let's pull at that a little bit more because IBD is really isolating. And yet, we need a good support system to help us through our challenges. So Dr. Fuss, I'm wondering, what are some of the way that we can focus on creating and keeping stronger bonds with our friends and family?

Dr Alexandra Fuss (17:22):

Yeah. I think we've talked about open communication plenty. We know that's a great way to start. One thing too is to think about your support system and really identify, there tends to be three kinds of supportive people. You've got at your distractors, who are your, "You don't want to talk about it. Let's just go out and not talk about it and go do anything else." Go to a movie, talk about what's on Netflix, good distractors.

Dr Alexandra Fuss (17:47):

You've got your emotions people who will sit with you with, I always imagine the hot tea and the blankies and just like, "Tell me everything. How are you feeling? Cry on my shoulder." And then you've got your doers who are the, "I'm going to bring you a casserole. I'm going to clean your house. You want me to walk your dog? I'll walk your dog. I got everything done. I did your grocery shopping. What you need?" Some people are combinations of two and then you have those lovely unicorns who can be all three. It's good to keep this in mind when we're asking for support of our support system. Are you asking a distractor to engage with your emotions?

Amber Tresca (18:25):

Yeah.

Dr Alexandra Fuss (18:25):

Well maybe that's why it's not going so hot. Or maybe leaning into, "Okay. I know so and so is the hot tea and cry person and that's what I need right now, that's my person." So that's one way of utilizing a support system, is recognizing who can do what and every person has good

strengths and weaknesses and being thoughtful of that. And also getting creative. And maybe going out is hard right now. We're in a global pandemic and you're dealing with an illness because it's just not fair. But you still want to be in touch with people. So maybe instead of getting up and going out and putting on clothes and having to put real pants on, gross, maybe having the Zoom movie date where you can stay home in your jammies, but you're still having some of that quality time together or having friends and family who are comfortable coming over to just do nothing.

Amber Tresca (19:25):
Yeah.

Dr Alexandra Fuss (19:26):
That's a good way of still building connections. And then phone calls, check-ins, text messages, even just sending a funny meme that just like boop, forward, just to let people know I'm still thinking about you. You're still on my mind. If you're finding your support group is kind of, no, this isn't quite getting it for me, finding other folks with IBD or with a chronic illness through support groups and support networks so that you can talk to other people who are in similar circumstances and who do really get it, and you can feel that genuineness from in that way. And maybe that's just the connection you need at that moment.

Amber Tresca (20:04):
I love that. I've never heard of this, three different types of people. But as you said, it was like everything makes sense now, like I get it now. I am that meme person. So that is how I will check on someone. I will send them a meme and just see what I get back because sometimes it leads to a larger conversation about whatever's going on with them because I've found that some people don't like answering the question, "Hey, are you?" Because I think I am that tea and emotion person at times, or I want to be. But some people are not at that place. You give them a way to talk to you that is not necessarily, "Hey, how are you?" It's just a different entry into the conversation.

Dr Alexandra Fuss (20:50):
Even for us, as soon as somebody I know, knows that I've been in the hospital, it's so well-meaning and it comes from nothing but love, but explaining to five different people what happened. I was actually in the hospital not too long ago and then I kind of fell off the face of the earth for a little bit socially, just for a little bit. I was off doing things for the holidays. And I got in touch with my girlfriend and a mutual friend of ours was like, "Hey, is Ali okay? We haven't heard from her since the hospital." And she goes, "Oh, well, we're getting memes. So she must be alive."

Amber Tresca (21:29):
Yeah. I think that's sometimes how people know that I'm alive as well as I just randomly send them a meme. Brooke, do you have any tips? Do you have anything that you do to keep in touch with people and keep relationships going, maybe when you are feeling like it's a struggle to keep up relationships or people might be worried about you at the time?

Brooke Abbott (21:48):
I love a good group text.

Amber Tresca (21:52):
Yeah.

Brooke Abbott (21:53):
Just a good group text. I also bombard my siblings and my mom with reels on Instagram, like funny animal reels or funny kid reels. I love creating a special time. Not too long ago, Amber, you, me and Ryan, we have a Zoom evening. It was just an hour and we just talked about really nothing but everything all at the same time. And it was so fantastic. I don't know that I can do that all the time. But to be able to once in a while, just have that connection with people who don't expect a lot out of me is very nice and reassuring. And then just the check-ins, I don't really do the, "Hey, how are you?" I will send an emoji, I will send a meme. I'll send a picture of the dog. So yeah, I use a lot of interactive things. I don't know that I'm like, "Hey, how's it going?" [crosstalk 00:23:03].

Dr Alexandra Fuss (23:03):
Are you okay?

Brooke Abbott (23:03):
Are you all right?

Dr Alexandra Fuss (23:04):
Would you tell me if you weren't?

Amber Tresca (23:07):
Oh, no. I do that.

Dr Alexandra Fuss:
My friends and I do that, but most of us are a psychologist. So you have psychologists, psychologizing in each other.

Amber Tresca (23:23):
That must be fun.

Brooke Abbott (23:23):
I learned that from my tween. Because when you ask a tween or a teenager a direct question, you don't get an answer whatsoever. But if I send my kid a clip, a YouTube clip, or something, that engages a little bit more.

Dr Alexandra Fuss (23:41):

Yeah. And what a great highlighting moment though of that self-compassion right. I meet him where he's at. So why wouldn't it be acceptable for people to meet you where you're at?

Amber Tresca (23:52):

Ooh, that might be asking too much of some people.

Dr Alexandra Fuss (23:58):

I know. I know. So easy to say, so difficult to practice sometimes.

Brooke Abbott (24:05):

True.

[MUSIC: ABOUT IBD TRANSITION]

Amber Tresca (24:11):

So I think something that happens a lot is that people with IBD feel like they can be a burden to their family and their friends, especially people that wind up as our caregivers, whether that's a partner or a parent or sometimes it can even be our kids that end up being our caregivers. So I'm wondering, Dr. Fuss, what do you say to your patients who come to you and say that they feel like they're a burden to other people?

Dr Alexandra Fuss (24:37):

Yeah. And that's definitely something I hear a lot. And it's something I've personally felt plenty of times being. Using open communication, not just to communicate, about the disease itself, but even just saying to a loved one or a friend, "I'm feeling a little like a burden" or "I could just use some reassurance right now," and just openly asking for it is one helpful thing.

Dr Alexandra Fuss (25:01):

And there was this amazing saying that I heard from a provider in palliative care. It's really stuck with me and I know I'm going to butcher it because I always do. But it's basically, if we think about when somebody we love is hurting or isn't going through a great time, we want to help, we want to do something, we want to support them. But sometimes we don't know what to do. And so when we allow other people to be there and to help us, we are giving them that opportunity to do that thing that we would want to do for them.

Amber Tresca (25:33):

Right.

Dr Alexandra Fuss (25:33):

And so that's one way of thinking about it is we're allowing somebody to feel like they are doing something that can help us when we ask for help or even when we don't have to ask for anything and it's literally just, "Thank you for your patience."

Amber Tresca (25:47):

Thank you for your patience is my new favorite phrase. I use it all the time. Thank you for your patience with me.

Dr Alexandra Fuss (25:53):

Thank you for your patience. Yeah. I think I read that somewhere. It was, instead of saying sorry for everything, start saying thank you.

Amber Tresca (25:59):

Yes. Yes.

Dr Alexandra Fuss (25:59):

And it's been a pretty big game changer.

Amber Tresca (26:01):

I think it has too. I have to say, I don't often have this burden feeling. I'm wondering how that resonates with you though, Brooke. Have you ever felt like that and how did you manage it?

Brooke Abbott (26:16):

This is a tough one because no one has ever actively made me feel like a burden. No one has said anything or been unsupportive. There have been times recently where my mom has tried to help me and I just feel so guilty. So I don't know that I really manage it very well. I'm not as bad as I used to be and I think that communication has really helped us a lot in my self realization that I haven't done this to myself, I'm not guilty of anything. We are a family, my friends love me and I'm not a burden to them. We are in an active relationship. I am an active member of my family and my group of friends and my community. But yeah, I still have that nagging thing in the back of my head. And I think too, I also just get tired of being sick and that's part of it too.

Amber Tresca (27:18):

Yeah.

Brooke Abbott (27:19):

And it sounds so irrational because there's no cure for IBD. I have extra-intestinal manifestations that will never go away. I will always have some sort of disease, some sort of form of fatigue or an ailment or physical pain. And I have come to an agreement with myself, logically, that this is the way it is. And then that makes me feel like a burden, because I feel like I'm restricting other people's lives or other people's access to me and my family.

Dr Alexandra Fuss (27:51):

Yeah. And as you were speaking, I think one thing that definitely struck me too, is we spend a lot of time talking about how do we not feel frustrated? How do we feel better? And at the same time, it's perfectly reasonable to be frustrated and to be sick and tired of being sick and tired. And so I think even just allowing yourself to feel that is really healthy, as opposed to trying to push it away all the time and finding that coping or whether it means that allows you

to it and acknowledge it and work through it. Because if we stuff it, if we push it and we put it in the box and the closet, eventually that box is just going to get really full and it's going to pop out one way or another. So I think that's as equally as important as it is to cope and to manage. It's also very, very important to acknowledge and feel those feelings.

[MUSIC: ABOUT IBD TRANSITION]

Amber Tresca (29:08):

Dr. Fuss, do you have any tips for patients on how they can open up a conversation with family or friends about IBD. And do you have a way of knowing when someone is ready to hear about IBD and what we have to say about it?

Dr Alexandra Fuss (29:23):

Yeah. The first thing, when it comes to talking with family and friends about IBD is ultimately, it's completely up to you how much or how little you want to share with who and when. And a lot of that is really based on your relationship with that person, how safe you feel talking to that person. I tend to lean also into humor. IBD can be really rough, and I find it sometimes easier to just use that humorous stance when I'm talking about it, to connect with other people. There's a lot of different little aspects to it, but it really in the context. So if, and let's say somebody, and it's more negative of they are saying "Well, why can't you do this? Just suck it up."

Dr Alexandra Fuss (30:12):

Whatever the saying might be, of just saying, "Okay, actually that really hurts me. Why don't we sit down so I can tell you why. Maybe if we had took us second and I was able to break this down and help you understand, I think that would be really helpful," which is like the most shrinky way to probably say that ever. Just even utilize a conversation with my partner more recently. He's obviously never dated somebody with IBD before, and I was a little flarey. And we went out somewhere to eat. I just told him what to order. He went up and he said, "Oh, they asked me a question and I changed it."

Amber Tresca (30:48):

Oh no.

Dr Alexandra Fuss (30:50):

And I was like, "Okay, we need to talk about that. When I'm in a flare, you can't change my order, and this is why." Or, he would say, "Oh, we're going to get dinner and things at this time," and then it wouldn't happen. I was like, "Okay. Again, I plan a lot of my day around when we're eating and what I'm going to eat."

Amber Tresca (31:07):

Yep.

Dr Alexandra Fuss (31:07):

And so sitting him down, being vulnerable, saying, this is why this is. And I think that also kind of segues nicely into, is there a way to know when someone's ready to hear it? I think it is being that safe person. There's kind of that sense. And sometimes, maybe they're not ready to hear it, but they need to hear it.

Amber Tresca (31:27):
That's a good point.

Dr Alexandra Fuss (31:28):
And that's also okay. We don't always need to tip toe around other people. We have needs. It's okay to say, "No, I think you need to hear this." And it's not going to be easy, but it's definitely going to impact our relationship in a really healthy way, if you know this.

Amber Tresca (31:44):
And maybe that's why my toes hurt all of the time. Too much tip toeing. Brooke, how about you? When you need to discuss IBD with someone that doesn't already know, and in our situation, it's sometimes a little bit different, it's kind of like, well, doesn't everybody know? But there are sometimes people, then you meet them for the first time and you need to disclose something. How do you start? What do you do?

Brooke Abbott (32:11):
So I usually start with Crohn's disease because most people know what Crohn's disease is. And I'll say have you ever heard of Crohn's disease? I have the sister disease to Crohn's disease. When I started talking to my family about it. We're really into normalizing everything. A big thing for us is Sunday dinner. And quite often, we would get together. And when I say I have a large family you all, our Sunday dinners were multiple tables of people having different conversations. And quite often, autoimmune diseases would come up. And it wouldn't be like, "Hey Brooke, how's your ulcerative colitis." It would just be like my aunt would say like, "Is this IBD friendly, this food?" Or, "Can you have coffee tonight with dessert?" We try to normalize them. And I've kind of taken that concept and I've used that in my advocacy work.

Brooke Abbott (33:15):
And I've done that in just talking to parents at the school with volunteering. Sometimes I will volunteer for things, but before I completely sign my life away to the school, I'll say, "Just want to remind everyone, I have a chronic condition. Some days I'm unable to do X, Y, Z. So I may need help with" blah, blah, blah, blah, blah. And that will lead into a very casual conversation. When I wasn't very educated about the disease, it felt very overwhelming. And I almost blocked it out for, not almost, I blocked it out for a time because it just seemed like a lot. And also, I don't know if anyone's ever stepped back, but when you start thinking about your symptoms and stuff, it's like, is this real? You're really feeling this way? Seriously? That's how it feels?

Brooke Abbott (34:10):
It almost seems fantastical. So I really try to keep it relative and casual. And I keep the door open for more questions. And the first 10 years of me having this disease, when I would be

flaring and we'd be at a restaurant and you know, everyone's like, "Well, Brooke, you pick the restaurant because you've got IBD." And I'd be like, "No, I'll find something." And we're all sitting there and everyone's ordering these amazing dishes. And I'm like, "Can I have a plate of fries?" And my mom's like, "You can't eat." I'm like, "This is all I can eat right now."

Brooke Abbott (34:46):

And that conversation would turn into, "Well, the doctor said, blah, blah, blah. But mom, this part works for me. This is why it works. This is why I need the salt." These are the conversations. And I also try not to get too defensive because it's coming from a place of love and a place of wanting to understand and a place of wanting to help. My mom's only asking that question because she wants to be able to be prepared the next time I'm in a flare to say, "Oh, I'm going to go out. Should I get you some sorbet and white rice?"

Dr Alexandra Fuss (35:18):

Back when I was first diagnosed, the idea of talking about it, and this happens with a lot of my patients as well, it's so overwhelming and scary because we don't really know how people are going to react. And so it got me thinking about, I explain anxiety a lot as sometimes it's kind of like a scary movie. The best scary movies are the ones where you don't see what the monster is, because your imagination can run wild and you can just, "Oh my gosh, it's got to be this crazy thing." And then they show it to you and it's usually bad special effects. It's usually pretty funny. So not only just by experiencing that conversation, it gets easier and easier and easier with time. But also, however scary you're imagining that it is, it's probably going to be about just bad special effects once you actually get to it.

Amber Tresca (36:07):

That was an amazing analogy. Thank you so much for that.

[MUSIC: ABOUT IBD TRANSITION]

Amber Tresca (36:33):

Dr. Fuss, I saw your cat just now.

Dr Alexandra Fuss (36:36):

Yeah.

Amber Tresca (36:37):

In the video, since we can see each other, although I only do audio. She?

Dr Alexandra Fuss (36:41):

She, yep. I have a cat and my dog is usually around here somewhere. So they're like my staff, sleeping on the job.

Amber Tresca (36:51):

I was on your Instagram and I did see a photo of your cat, but I didn't see your dog. Would you tell us a little bit more about your pets?

Dr Alexandra Fuss (36:57):

Oh yeah, sure. So Tyrion is my dog. He's a corgi. He is now eight years old. I've had him since basically, gosh, a couple days after I graduated from undergrad. He is very sassy, an absolute love. We have many conversations. I'm pretty sure he probably has at least a master's degree by now. I've had him all through school. So he's like my study buddy.

Dr Alexandra Fuss (37:21):

And he talks back to me like with the grumbles, not just in my head. And then I have Bernadette back here. She is a American Shorthair terror maybe is a good way. No, I joke a lot that she wakes up and chooses violence every morning. But no, she's amazing. Definitely probably one of my biggest emotional supports are these two. Whenever I'm not feeling well or sad or happy, anything, there's just like a big pile of fur all the time in this house. So I love them.

Amber Tresca (38:00):

I love that you have that support. Brooke, you have a similar type of support in your house, but also sometimes it can be a little tricky. Tell me about your dogs.

Brooke Abbott (38:10):

Okay. So I love them to death, but they are literally, I would say that they're Ethel and Fred, for sure. We had a pit bull, a red nose pit bull for 13 years. And he passed away 4th of July weekend, 2018. Then we got Betty who she's a Papillon and Poodle Pluto. She's only 12 pounds, but we got her at six weeks because she was born to a litter that my mom's really good friend had and that friend passed away suddenly. And so we took and Betty and Betty and bam, bam were super, super close. So when Bam Bam died, we were like, okay, we needed to find another dog.

Brooke Abbott (39:02):

So I thought about getting a small dog, but then a big dog, I thought, okay, that will kind of help with the balance. Well, so we got Winston. I got Winston at six weeks. Girl, this dog. First of all, he's a Cane Corso. Okay. He looks like Marmaduke. He's small for a Cane Corso. He's only like 100 pounds. And he is probably the goofiest dog, but also the neediest dog. Like if I could just carry him around in my shirt all day, he would be completely fine. But also, because whenever Amber and I are recording, Betty finds a way to bark and Winston finds a way to get in the camera shot.

Amber Tresca (39:49):

This is true.

Brooke Abbott (39:50):

Every single time. I don't know what the deal is today. And love them to death because even though Betty doesn't like to be hugged or touched or anything, because I think she's really secretly a cat, she's still like my best friend.

[MUSIC: IBD DANCE PARTY]

Amber Tresca (40:08):

Dr. Fuss, Brooke, thank you so much for your voices and for your perspectives. You have both said things that are really making me think differently right now and you've also provided so much information in short amount of time that will really help other patients. So I want to thank you both so much for talking with me today and for everything that you do.

Dr Alexandra Fuss (40:30):

Thank you. I was really excited to be on the show.

Brooke Abbott (40:33):

Thank you so much, Amber. I appreciate all your work in the community and thank you for bringing us together today. This was awesome.

Amber Tresca (40:45):

Hey, super listener. Thanks to Dr. Alexander Fuss for sharing her experience as both a clinical psychologist and as an ulcerative colitis patient, living with a J-pouch. She is busy at Yale creating programs for people with IBD and I'm excited to see the ways her activism benefits our community. You can find her on Instagram as @dr.AlexandraFuss. And Fuss is spelled F like Frank, U-S-S. Thank you also to Brooke Abbot, who has appeared on About IBD more than any other guest. And yet, she always has a fresh perspective to share with us on life as a single mom with IBD. You can find her all over the in interwebs as Crazy Creole Mommy. And you can find both of us together as IBDMoms. Links to a written transcript, everyone's social media handles, and more information on the topics we discussed is in the show notes. And on my episode 112 page, on AboutIBD.com.

Amber Tresca (41:45):

You can follow me, Amber Tresca, across all social media, as About IBD. Thanks for listening. And remember, until next time, I want you to know more about IBD.

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