

## About IBD Podcast Episode 111

### Colitis Conversations: Shared Decision-Making

Ulcerative colitis and Crohn's disease are complicated. There are choices to make along the treatment journey, which means that patients and their healthcare providers need to work together to find the right path. That's where shared decision-making comes into play.

Healthcare providers can help patients learn about their options but patients need to speak up and help their doctors understand what they want from their treatment options, because it's not always obvious. To better understand shared decision-making in IBD, I speak to Dr Rajeev Jain, a gastroenterologist in private practice in Dallas, Texas and Caitlyn Smith, ulcerative colitis patient and editor at The Mighty.

Concepts discussed on this episode include:

- [IBD Parenthood Project](#)
- [Shared Decision-making in IBD](#)
- [IBD Surgery Shared Decision-Making Toolkit](#)
- [Shared Decision-Making: Benefits to Care](#)
- [Shared Decision-Making: Being Prepared](#)
- [American Gastroenterological Association GI Patient Center](#)

Find Rajeev Jain, MD on [Twitter](#), and at [Texas Digestive Disease Consultants](#).

Find Caitlyn Smith at [The Mighty](#), [Facebook](#), [Twitter](#), [LinkedIn](#), and [Instagram](#).

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

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Episode transcript and more information at <https://bit.ly/AIBD111>

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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 111.

This podcast is part of the American Gastroenterological Association Colitis Conversations program.

Shared-decision making is a part of treating any chronic illness. For a condition as complicated as inflammatory bowel disease, it is vital. Every person living with Crohn's disease or ulcerative colitis is unique, not only in how the disease is expressing itself but also in how it responds to treatments. In addition, therapies can include anything from oral medications to infusions to surgery, and people with IBD will make different choices based on a variety of factors that includes cost, lifestyle, and safety.

To understand how healthcare providers and patients can come together to use shared decision making, I speak to Dr Rajeev Jain, a gastroenterologist in private practice in Dallas Texas, and Caitlyn Smith, ulcerative colitis patient and editor at The Mighty.

**Amber Tresca (01:01):**

We get into how healthcare providers can help patients learn about their options and how patients can speak up and help their doctors understand what the roadblocks are in receiving treatments, because they're not always obvious. We also discuss the importance of trust and the treatment that brought Caitlyn and her husband closer together in more ways than one.

Our focus today is shared decision making in IBD including how patients can be prepared and how it can be beneficial. To get into this topic, I have two guests with me. My first guest is gastroenterologist Dr Rajeev Jain, Dr Jain, welcome to about IBD. And I wonder if you'd take a minute to introduce yourself.

**Dr Rajeev Jain (01:43):**

Amber, thank you for having me again on your program. It is the delight to be here. My name is Rajeev Jain. I'm a gastroenterologist in Dallas, Texas in Private Practice and Texas digestive disease consultants, which is part of the GI Alliance, and I have the pleasure of working with the American Gastroenterological Association or AGA as their patient Medical Education Advisor. And so it's a real joy to work with our GI societies and with patients and to be with you and Caitlyn today.

**Amber Tresca (02:12):**

Also with me is Caitlyn Smith, ulcerative colitis patient, and editor at The Mighty. Welcome to about IBD Caitlyn, would you take a minute to tell us a little bit more about yourself?

**Caitlyn Smith (02:24):**

Yeah, thanks for having me. I'm excited to be here. I'm Caitlyn, as you said, I'm an editor at The Mighty that's kind of my side gig to my full-time job. So it's something I spend my weekends doing, which includes writing and editing the IBD newsletter that goes out every Tuesday. So it's kind of a passion project of mine. And I write a lot of articles on IBD for them as well. I just love writing my other job. I'm also in marketing doing a lot of writing and editing and I'm happy to be here.

**Amber Tresca (02:52):**

Thank you. You're a busy lady. I love your newsletters. They're so fantastic.

**Caitlyn Smith (02:56):**

Oh, thank you. I appreciate that.

**Amber Tresca (02:58):**

I learn a lot from them. Yeah. So I want to start with you, Dr Jain, how do you define shared decision making in the context of your practice and your IBD patients?

**Dr Rajeev Jain (03:10):**

Well, IBD there are formal definitions to this, but what I like to tell my patients is that we're in a shared journey of creating good health for you. And to get to that place first, I have to earn your trust. And then as part of that trust building, I need to make sure that I'm taking into context your life and your life experiences and what you want. Your goals are to make sure I'm putting those as my North Star, as I try to help you and your family navigate to the right place or right treatment decision intervention, whatever that might be. It could be as simple as blood test or as invasive as a surgery.

**Dr Rajeev Jain (03:52):**

You know, sometimes it's easy to make a decision for both of us patient and the physician or provider, but sometimes it's much more nuanced. So again, it's about finding a place where you have the right information and a truly evidence-based information. But not that I'm just throwing out a bunch of pictures with ratios, but rather explaining the pros and cons and going with you and finding what your perspectives are and desires are so that we reach that goal.

**Amber Tresca (04:20):**

So, Caitlyn, what does shared decision making mean to you and what do you think it means to IBD patients in the community?

**Caitlyn Smith (04:31):**

I think what Dr Jain said is spot on in particularly the part about just kind of throwing information at the patient and not really explaining why it's relevant or why it might help or may not help you. I think having an open dialogue for me is what shared decision-making means. So when you do get to those roadblock, so it's time to switch to medication or try something new, or even just diagnose the condition, whether it's Crohn's or colitis or some something in the middle, just having that open dialogue with your doctor and making it a conversation rather than going into their expecting the doctor, just kind of tell you what to do. So I think that's what I hear most from other patients is they feel like their doctor just isn't hearing them, or isn't asking them questions about how they feel about what they've talked about.

**Caitlyn Smith (05:20):**

Isn't kind of treating them like a teammate in this. They're kind of doing like a coach player type relationship and you really should be teammates. So to me, shared decision making is having that open dialogue and for the patient to not be afraid to bring up uncomfortable questions. And I don't want to say challenge your doctor in a negative sense, but don't be afraid to ask those questions. And in a way actually do challenge them like if you feel strongly that a decision they're presenting is not right for your body, then speak up and you guys can kind of talk it out, decide if it's still okay to go with, or if there's another option.

**Amber Tresca (05:57):**

I love that analogy, the coach player versus the teammate. That's fantastic. That's really a great way to put it and I think that everybody can understand it when you say it that way.

**Caitlyn Smith (06:07):**

Yeah. It's the lifelong athlete in me, I think.

**Amber Tresca (06:11):**

Yeah. You're probably right about that. It works well though. Dr Jain, do you think that a lot of patients have heard about shared decision making or is it something you probably fall into it naturally with your patients, or is it a conversation that you actually discuss this concept?

**Dr Rajeev Jain (06:31):**

Yeah, that's a great point. I think patients that either listen to your podcast or get Caitlyn's newsletter, they probably know about it. And my guess is that the average patient may not know formally what it is, but certainly wants it, I think. And so, and I love Caitlyn's comment. I mean, I think, we're all going in the same direction. We're in the same boat. We're not a captain or as you mentioned Amber, it's all about working together to get to that right goal. We may not get there right away, but as long as we're all going in the right direction, I think that helps. And I also think Caitlyn, you mentioned about challenging your provider. Absolutely. I didn't get permission from my mom to say this, but I'm going to say it. If my mom doesn't get the right vibe with the doc and she gets a new doc, and I think that's the way to go.

**Dr Rajeev Jain (07:17):**

So when one goes back to what I was saying earlier, you need to have trust with your provider. And so you can't have a conversation about shared decision making and decide which therapy to do if you don't trust your provider. So again, you build that trust and that is the runway that helps you then have those deeper, more difficult conversations. I find sometimes if the patient is tense and I can read the room right, I'm I might make some corny line, like stool is cool. If they're telling me about diarrhea and just to demystify it, de-stigmatize it because it's a real problem. And we shouldn't be afraid to talk. And so, yeah, Caitlyn you're the patient should challenge the provider if they're not going to the right place.

**Amber Tresca (08:05):**

That's fantastic. I love that. Caitlyn how about you? Does this come into play with your own physicians? Has there been a time when you've used shared decision making either you knew what you were doing or just sort of naturally happened?

**Caitlyn Smith (08:21):**

Yeah. I think a better question would be, is there a time where I haven't used shared decision making?

**Amber Tresca (08:26):**

That's good. Yeah.

**Caitlyn Smith (08:28):**

I've been fortunate that I've had really good a medical team, gastroenterologist primary care physicians, just everyone has always been really good from my diagnosis. I was diagnosed in 2001, so over 20 years ago now, so I haven't really had to struggle, I guess with getting shared decision making into my care plan. It's kind of happened organically and I'm really fortunate about that, but if it didn't, I think it is important for the patient to be an advocate for themselves. And I know that when you're first diagnosed, especially me, I was a teenager. It can be really scary, but I think it just comes with practice. So if you're walking into a doctor's office and you've never sort of engaged in shared decision making, like Dr Jain's said, it's not an official term that I've ever heard, but I think it's just something that happens organically over time between a doctor and a patient.

**Caitlyn Smith (09:23):**

So I would just recommend to the patient to get comfortable being uncomfortable, essentially, which is easier said than done, but doctor's office really is a safe place and it's the one person that's not going to make fun of your symptoms or poke fun at anything. And it's hard to, I think, transition from the real world where people do make those jokes, they kind of poke fun on it and then suddenly you're in this doctor's office and this doctor's telling you that everything's fine they're saying stool's cool. And you're like, what? So I don't know if that answers your question. I think it's important too if you're trying to establish that for the first time with your doctor to just, don't be afraid to speak up. Just rip the Band-Aid off, ask the question you're thinking because there's probably a thousand other patients that are also thinking it.

**[MUSIC: About IBD Transition]**

**Amber Tresca (10:27):**

Dr Jain knowledge is a really important part of having better outcomes in IBD and I'm wondering, are there ways that shared decision making presents an opportunity for patients to understand more about their disease?

**Dr Rajeev Jain (10:43):**

Absolutely. When a physician or provider employs, shared decision making in the right way if I'm going to explain a menu of treatment options to a patient, and let's just say for discussions

purposes, we're going to talk about biologic agents and immunosuppressive or a combination of the two. If you don't explain the benefits, the potential harms, the way that medication is delivered, what the cost might be is covered. I mean, there's so many angles that one can look at that, but if you don't explain many of those nuances, then the patient may or may not have all the information they need to be truly informed and make an intelligent shared decision making because, they need to have the right evidence base. So if, again, if they're not going to your podcast or Caitlyn's newsletters and are on some other rabbit hole that may not be providing them accurate information, then those misconceptions may lead them not to choose what could be a good treatment option for them.

**Dr Rajeev Jain (11:51):**

Remember the best one is the one they choose. But the good one that I may think is better than the other ones based on the information I have, it's critical for them to understand that. And it's our job as physicians to provide that education. And sometimes we're not the best way to do it and it takes time to think about it. And so I don't expect the patient to many times give me the answer at that spot. In fact, I'll say, "Hey, we go to the AGA website, go to the Crohn's and Colitis Foundation website. There are these different tools and decision aids that are there or additional information, or I'll send you a message on the portal. Think about it, ask me some more questions shoot me some questions on the patient portal and, or call me and we'll talk about it. And then we can arrive at that shared decision on what's the best treatment or intervention or whatever that question we have that we're trying to address."

**Amber Tresca (12:43):**

Caitlyn I think it's fair to say that not everyone has a physician like Dr Jain.

**Caitlyn Smith (12:49):**

Yeah.

**Amber Tresca (12:50):**

How do you think we can help the patients that you and I communicate with better understand what shared decision making is?

**Caitlyn Smith (12:57):**

That's a good question. I always, when I have a lot of friends that really struggle with their GI and they're looking for an GI or they've seen four GIs and no one's a good fit. They're just really struggling with finding someone that's working with them and not against them. So think the main thing I tell people is trust your gut first of all, like if your current GI doesn't feel right, they probably aren't right in your gut. I mean, this is all about the gut, right? Like your gut is very telling in this disease and it's telling in our instincts. So I think if it's not a good fit, you're going to know it and it's time to find someone new. And then I think it's also really important for the patient regardless of their GI or when they find that good fit and they're trying to sort of build that rapport and build the shared decision-making model with them is to do your own research.

**Caitlyn Smith (13:47):**

I think shared decision making goes really well with being an advocate and doing your own research on what's out there for example, if your doctor's throwing out a new biologic for you to try to get into remission, go look it up, write down five questions that you have about it and bring it to your next appointment. And just kind of taking that proactive approach in your own condition, can kind of organically lead to shared decision making because now you're prompting your doctor with these questions and maybe you're asking them something that they've never even considered, even though they are the professional and the expert in the disease, you're the professional and expert of your body. So I think that's a really good thing that I say in a lot of friends that I have. I think there's a lot of conversation around how much the doctor needs to keep doing to be there for the patient, with the patient also needs to show up and do all the same things for themselves.

**Caitlyn Smith (14:39):**

I don't want to sound like I'm blaming the patient or anything like that. Absolutely not, but it there's seminars and there's there's websites like AGA, Crohn's Colitis and there's support groups there for a reason to help us kind of all come together and learn from each other.

**Amber Tresca (14:55):**

Right, because we need to be partners in this situation because why go down a path that doesn't make any sense for you.

**[MUSIC: About IBD Transition]**

**Amber Tresca:**

When you're working with patients, Dr Jain, what are some of the situations in which you find shared decision making to be helpful?

**Dr Rajeev Jain (15:17):**

Most important decisions, be it treatment, diagnostic things like that in some way, shape or form you're using shared decision making it may be very minimal in terms of the questions you need to ask, but it could last several office visits. Something that comes to my mind is a situation that occurred a couple years ago. It just shows you that the provider can have a bias because they don't know something and that would be mean and so an example would be, I had a young patient guy that works needs a biologic therapy had been on an injectable biologic before my assumption was, as I was going to transition into a new biologic agent that, "Hey, this guy is young. Let's look at another alternative that's uninjectable." And I was just mentioning that to him. And so this is again coming at different angles and it was very interesting. He mentioned to me, "Hey, wait doctor, I don't want an injectable anymore because I'm the one that has to deal with the insurance company.

**Dr Rajeev Jain (16:18):**

I'm the one that has to make sure it gets shipped to me. And I don't want to ship to my office for my privacy. So I got to make sure I can get home to get it." It was just a number of different things I had never, ever in my life thought about from my perspective, because I'm not the one

living it. And so, it was just me kind of throwing it out there saying, I assume you want an injectable and he was like, "No." And then explained it and so it's those kind of conversations where you can learn from your patient what's best for them. And that's the kind of I think, two way partnership. I think Caitlyn is talking about that needs to happen for, because again, when patients are fully invested in what they are doing together with their provider, they're more likely to take their medicine. They're more likely to have better outcomes and both the provider and the patient are happier. So it's like a win-win.

**Amber Tresca (17:15):**

Yeah, that sounds right. And it's such a personal decision, Caitlyn, when you are considering your options in terms of treatment and in understanding IBD, do you feel like talking it through with your providers and using this model is something that really helps you in understanding the path that you want to take?

**Caitlyn Smith (17:34):**

Yeah, I think so. I think shared decision making is probably the number one thing that keeps me working with the same gastroenterologist that I have. I mean, the only reason I switched to a new one several years ago is because my old one retired.

**Amber Tresca (17:49):**

Awesome. That's the worst.

**Caitlyn Smith (17:50):**

I was very hesitant for the new one. I was like, you don't know me, and then I got to know her now. We're great friends and she's wonderful, but I'm in a new city now. So I have to kind of do it all over again. So I think, it will be really helpful for me in this point in my life kind of reestablishing that relationship in a new state with new medical guidelines and new hospitals and all that stuff. But I think it's probably the number one thing that impacts my treatment. I mean, there's a medication that helps me stay in remission and there's the bi-annual colonoscopies or however often you're getting them, but having those conversation with the doctor and especially those in between, I think one of the positive things about COVID is that it's really highlighted the necessary like telehealth and virtual options.

**Caitlyn Smith (18:41):**

So I think that having the portal to be able to message your doctor continue that shared decision making in between appointments, or maybe you're in remission and you just see them every six months, like just being able to pop in there and be like, Hey for me, since I'm pregnant, I talk to my OB and then it's like, oh, I need to run this by my GI before we do this. So just being able to like have shared decision making, not only with my gastroenterologist, but also span it with all my other doctors, because this isn't just about your gut. This is the medication you take here impacts this impacts that, and just kind of being able to span that from the GI and just see that it's also impacting primary care and OB and even therapy and everything. I think that's the key component to having a good relationship with your doctor.

**Amber Tresca (19:32):**

Yeah. And if you were less empowered and had less knowledge about how to do that, coordinating all these people would be really difficult.

**Caitlyn Smith (19:40):**

Yeah. And I think it can be for if there's newly diagnosed people listening, it can feel really overwhelming because now you have this new disease it's chronic, it's lifelong, you've probably had all the scary stuff thrown at you right away after that diagnosis. So it takes time to establish, I think the shared decision making and get into your own groove and your own communication style. But I think it's worth the time and it's not going to happen overnight just don't I would encourage people just don't be afraid to bring up concerns, any concerns to your GI, if you're concerned about body image has been huge for me with mine and depression, like don't even be afraid to bring that stuff up, just bring them in. They want to know everything to treat you correctly.

**Amber Tresca (20:25):**

Right. And I think that also gets into the idea of trust, which is another thing that I wanted to discuss in terms of shared decision making. And I'm wondering Dr Jain, how this all works into building trust and having good communication with your patients because discussing stool, let alone things like intimacy and mental health is really challenging. So have you seen that the shared decision making model helps you improve that trust and the communication that you have with your patients?

**Dr Rajeev Jain (20:55):**

Absolutely. As we mentioned in the beginning, trust is the foundation to a good relationship. And I think in a patient-physician relationship, one of the things I try to do is, I have to be vulnerable to them as well. They're being vulnerable towards me. And so I'm open to share little tidbits about my personal life that makes it look I'm just another person like you, I don't have inflammatory bowel disease. I'm not going through what you're going through, but I'm a person and I feel those things. And so I try to connect with them where I can connect in where there's something similar or interesting that we share. That always facilitates that. I think those little things and I don't do it just to do it. It's just, kind of, I don't know, it's a habit I like talking obviously, as you can tell.

**Dr Rajeev Jain (21:49):**

And so it's a good thing to connect with people and then when you have that connection, then you are willing to talk about those uncomfortable things, go to uncomfortable places otherwise, for example, Caitlyn mentioned that she's pregnant and as IBD, Amber interviewed me a while ago on the IBD Parenthood Project. So if you want a patient to be better educated so they can facilitate shared decision making, one option would be if there's something like that has more information about your particular circumstance, read about it ahead of time there's checklists that you can then take to your visit to make sure you're getting the best care and then go through these different options so you really are having that shared decision making. So I think the Crohn's & Colitis Foundation on their website even has a link for patients to understand

what this is. So I think having the ability to review those things before a visit or a new you're seeing a new provider, somebody different, it's probably good to brush yourself up on that. If you're a patient.

**Amber Tresca (22:56):**

I interviewed Dr Bernasko a few episodes ago. And she said she actually puts little flyers around her clinic. So it says things like, are you considering starting a family, things like that. And then she's found that is sort of a little entryway and helps patients bring things up when they come in to see her. And so it can start those conversations that people might have thought that it's not something to bring up when they're working with their gastro team. But actually it really is.

**Caitlyn Smith (23:28):**

I'll add to that. My GI was so excited for us to start a family, like two years before I was ready to start it. She was already asking me, she's like, "So you guys going to try to have kids?" And I was like, "Oh, I don't know. Not yet." And it was kind of like our joke for a little bit, but she was very proactive and like, let me know, and this is what we'll do to monitor your ulcerative colitis while you're pregnant. So it's fun too when doctors from another practice, like it doesn't have to be so siloed when they're excited like she wants us to send pictures when they're born. It's fun to have that relationship too with your doctor.

**[MUSIC: About IBD Transition]**

**Amber Tresca (24:27):**

We already heard about a few tools and resources. Caitlyn, do you have any more that you can think of that patients might use that can help them understand shared decision making or to have that conversation with their doctors?

**Caitlyn Smith (24:43):**

Yeah. I think some of things I mentioned before, for sure. I mean, for me, the number one tool, I would say it's not an app or anything like that is just have that support system and kind of find other people that have Crohn's or colitis, or are familiar, have a loved one with Crohn's or colitis, and just ask them questions and ask about their experiences in the doctor's office and ask their thoughts on something that a doctor said, obviously we're not doctors, we're patients, but I think just getting that validation and being able to have like an empathetic conversation with someone who gets it is a good tool. And you could even... I've even practiced shared decision making on friends, like pretending they're the doctor, I'm the patient when I'm nervous. This was way back years ago when I was flaring and we were kind of transitioning to a new treatment.

**Caitlyn Smith (25:35):**

I just practice because I don't like confrontation of any form. So even though I love my GI, I was so nervous and she's like, "Oh my gosh, absolutely, thank you for bringing this up with me." But anyways, I practice on friends and practice different sorts of outcomes that the doctor was forward or against it. So I think that's a really good tool that I use. Another one is sites that

we've mentioned, The Mighty.com has so much information on Crohn's and colitis. And a lot of that information is from patients such as myself that are writers and they just want to share their tips. They just want to share the hard stuff, the funny stuff, the gross stuff, the happy stuff, like it's all on there. So I think there's just so much you can find if you just go to the site and just type in inflammatory bowel disease or Crohn's disease or ulcerative colitis, or even irritable bowel syndrome, there's so much on there, to just see how other people are talking about it and get tips like something you might read.

**Caitlyn Smith (26:31):**

And you're like, I've never even thought of that. That's a good idea. So that would be another tool I would say I use a literal tool. I use the notes app in my iPhone. So if I have an appointment and there's a question that came up or anything else that I just want to bring up, I do that with all my doctors, not just my gastroenterologist. So I would say write things down, ask questions so you don't forget, especially when you're pregnant, pregnancy brain is very real, so I do that a lot. I think those are the main things and just kind of an internal tool is just, trust your gut and be your own advocate. It's not weak to ask questions, it's not weak to challenge your doctor it's shows strength that shows you're being proactive. It shows that you really want to get better and you want to reach that middle with shared decision making with them.

**Amber Tresca (27:32):**

So I'm going to tell you something, Caitlyn, the pregnancy brain never goes away.

**Caitlyn Smith (27:41):**

I denied it the first trimester, but here we are almost done. And I'm like, it's real. It's super real. I can't remember anything.

**Amber Tresca (27:50):**

Then it's just morphs into mom brain, sorry. I'm sorry to be the one to break it to you, but that's just how it is.

**Caitlyn Smith (27:58):**

Dang it. Well, now I know.

**Amber Tresca (28:00):**

So well now you're already in the practice, you're in the habit of writing things down and trying to keep track of these things. And I love this idea of role-playing with your friends. Did you find someone else that lives with a chronic illness or did you just ask one of your healthy friends to help you with this?

**Caitlyn Smith (28:19):**

I do a lot of sort of like role-playing practicing with my husband. He's my biggest supporter. My biggest I advocate. So I do at everything, like whether it's preparing for podcasts or role-playing conversation, I need to have with a friend that might be hard. I do a lot with him, but I also have

a lot of friends that live with IBD. So we kind of, I wouldn't say that we do so much like literal role-playing, but we bounce ideas off of each other. And I have two friends that actually have the same doctor as me. So we'll kind of check in after appointments, "Oh, how's Dr K?" And what they say, like, "Has she said this to you?" So it's just nice to have that support system and be able to ease the nerves, because it's easy to just swirl around in your own brain and think you're the only one feeling this you're the only one with this question and all that. And it's not true. It's never true.

**Amber Tresca (29:12):**

Right? It's never true. I think sometimes, I mean, I know that I forget to ask questions when I'm in to see my providers, because sometimes I'm going in there and since we've been working together for so long, it becomes a little bit of a catch-up session. And then I walk out of there and I realize that I didn't actually get my questions answered. So I'm wondering Dr Jain, what are some ways that we can help other providers understand that we like the shared decision making process and we want to be part of it. I think maybe sometimes we fall into it naturally, but it might be worthwhile to bring it up and actually have a real conversation that this is the tactic that we're going to use. So how do we get your colleagues to move in the same direction and start using the shared decision-making process more formally?

**Dr Rajeev Jain (29:59):**

Amber that's a great point and I think I can speak from my own experience. I completed my GI fellowship in the summer of 99 and we didn't have a construct it was probably out there, but it wasn't formally taught to us on how to do that. We were in a safety net hospital, just resource constrain, just trying to keep our head above water. So I think this requires input from our societies to further educate our physician colleagues and nurse practitioners and PAs, everybody up and down the provider chain. I think it requires even, should these be the kind of questions that percolate into board certification questions and what not? I don't know, but these are the kind of things that in one aspect, the organized part of medicine needs to push it. And for example, the affordable care act has language about shared decision making in it and we're supposed to in certain instances, document it in such a way.

**Dr Rajeev Jain (31:01):**

So that'll get some provider's attention, but I think what ultimately will get the provider's attention will be the patients. So when your patient comes in and says "You're just telling me to take this medicine. I want to tell you about my perspective. Here's my lived experience with Crohn's or ulcerative colitis or other any disorder it might be. And, I want to understand why that treatment, why not other treatments or no treatment? What are my options?" And so I think I can speak for myself and most of my colleagues to say we enjoyed talking and working with an informed, educated person who asks probing questions. We all learn from.

**[MUSIC: About IBD Transition]**

**Amber Tresca (31:46):**

Caitlyn, do you have any funny or embarrassing stories to tell about your ulcerative colitis?

**Caitlyn Smith (32:10):**

Of course I do.

**Amber Tresca (32:13):**

Of course you do.

**Caitlyn Smith (32:14):**

Who doesn't, which one do you want? My husband actually encouraged me to share the story because I am still embarrassed by it. But when I was flaring a little bit in 2018 before we got married, it was like six months before a wedding and it was presenting as proctitis. So one of the things that I needed to do was do the mesalamine enemas like every three days in the beginning or something like that. And I was really nervous because I hadn't done one in a really long time and I just couldn't do it. So my husband did them for me for like two months. And I was like, absolutely mortified I still am. It's so like uncomfortable sharing this, but I know that I'm probably not the only one that has to do that.

**Caitlyn Smith (33:04):**

And of eventually I started just doing them with myself and now everything's dandy and I don't have to do them anymore, but that was embarrassing. I mean, we're about to get married and that was the first time because I had been in remission for so long, that the first time he was really experiencing a flare with me. And so it was all those things of like, you're getting married and now I'm sick and like what's he going to think? And all those types of insecurities we have when we're sick, but I mean, he's wonderful. He's my biggest supporter. And he just said it's attractive when you're taking care of yourself and that's what we were doing. So yeah, that's probably the top one and then I got a whole bunch of like poop accident stories. You want those.

**Amber Tresca (33:44):**

Everybody has those.

**Caitlyn Smith (33:47):**

I have a dime a dozen on this.

**Amber Tresca (33:48):**

Yeah, kind of. I'm curious to know though. So he was finding the idea of taking care of yourself attractive. Was there anything else that he said about that experience? Did it help him understand what you're going through better or did it bring you to closer as a couple? Like how did that all play out?

**Caitlyn Smith (34:11):**

Yeah, I think we talked about it. A lot of it was me just being, I mean, I was nervous because we were getting married and I was my first flares in like 11 years. So, and it wasn't as bad as my last one, thank God. But yeah, I think it just had us have different conversations. I mean he

obviously knew I lived with ulcerative colitis, but to see like the running to the bathroom and I was seeing blood for a part of it. I think it opened his eyes a little bit more to this, it wasn't just like a chronic condition where I take my pills and move on. Like it can flare and it probably will flare again.

**Caitlyn Smith (34:51):**

And I think it did bring us closer. We both have our own health things and we've had to work through them together. So I was actually glad that it happened when it did it. When I look back on it, it was kind of like the universe is like, this is the last thing you need to see before you guys get married. Not that we were going to break up over it or anything like that, of course not, but I think it was a humbling experience for both of us.

**Amber Tresca (35:20):**

He sounds like a keeper. I think he should hang on to that one.

**Caitlyn Smith (35:23):**

He is a keeper. Yes.

**[MUSIC: IBD Dance Party]**

**Amber Tresca (35:27):**

Thank you both so much for coming on About IBD and discussing shared decision making with me. I think this is a conversation that will really help a lot of patients and also providers too, who are thinking about how they can implement this in their practice. So I want to thank both of you for speaking with me today and for everything that you do for IBD patients.

**Caitlyn Smith (35:48):**

Yeah. Thank you for having me.

**Dr Rajeev Jain (35:49):**

Thank you for having me and Caitlyn, thank you for sharing your story.

**Caitlyn Smith (35:52):**

Yeah. Thank you. It's nice to catch up with you. I know we talked before, so it's good to hear from you again. Stool is cool.

**Amber Tresca (36:06):**

Hey, super listener. Thanks to longtime friend of the pod, Dr Rajeev Jain for sharing his perspective and experience in shared decision making. You can also hear him all the way back on episode 39, help for parents with Crohn's disease or ulcerative colitis, where he discusses the IBD Parenthood Project, which is a source of information on IBD and pregnancy throughout all stages of family planning. Thank you also to Caitlyn Smith editor at The Mighty, who at the time of this recording is pregnant with her first child. You could follow her journey on Instagram, Caitpilk Smith, which is C-A-I-T-P-I-L-K S-M-I-T-H. 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, 111 page on about IBD.com. You could follow me across all social media as About IBD. Thanks for listening and remember until next time I want you to know more about IBD.

**Amber Tresca (37:05):**

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