

Transcript Details

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A Pre-Teen's Perspective on Living with IBD

Announcer:

Welcome to Crohn's & Colitis Perspectives on ReachMD. This series is produced in collaboration with the Crohn's & Colitis Foundation, providing updates and driving innovation in IBD research, education, and clinical support.

Dr. Caudle:

If I were to ask you to think back on your teenage years, I think we can all agree that being a teenager and having to balance things like school, and friends, and sports, and other hobbies, isn't always easy. But what if I were to ask you to imagine doing all of that while coping with the effects of inflammatory bowel disease? For the 80,000 children living with inflammatory bowel disease, this is a reality, which is why it's so important for us to not only help ease the physical pain our patients experience, but also the emotional and psychological stress that often accompanies that disease.

Coming to you from the ReachMD Studios in Fort Washington, Pennsylvania, this *is Crohn's and Colitis Perspectives* on ReachMD. I'm your host, Dr. Jennifer Caudle, and joining me today are Caroline and her parents, Preston and Rachelle. Thank you all so much for joining us.

Preston:

Absolutely. Happy to be here.

Rachelle:

Thank you for having us.

Dr. Caudle:

Absolutely. So, Caroline, we're going to start with you, okay? You know, I'd really love to hear a little bit more about your story. Tell us how old you are and how old you were when you were diagnosed with IBD, specifically Crohn's disease.

Caroline:

So, right now I'm 12 years old and I was diagnosed at the age of 4 and started showing symptoms at 3. So, I've had Crohn's, from what I know of, for almost 10 years now.

Dr. Caudle:

Yeah, and it sounds like you've – I mean you've really had it for most of your life, right? Most of your life has probably been – Crohn's has been in the picture. Is that correct?

Caroline:

Yep.

Dr. Caudle:

Yeah, I mean how does that feel? What is that like? Maybe that's what you know?

Caroline:

Yeah, I don't really remember life without knowing I have Crohn's, because from what we know, I could've had Crohn's since I was born. But, I'm lucky to know that mine isn't as bad as others.

Dr. Caudle:

That's a very positive way of looking at it, right? You know, we know that watching a loved one in pain is never easy, especially when it's

your child. So, Preston, let's go to you and what can you tell us about Caroline's diagnosis from your perspective? The whole process of that. What was that like?

Preston:

Um, you know, when we were leading up to the diagnosis, she was having bathroom issues. She was going frequently. It was clear that there was something wrong, and it was happening regularly, and that was the number one concern. So, at first, it was just very light – okay, maybe she's a little ill or something like that. And we go to our regular pediatrician and that leads to wanting to go to a specialist and, at that point, we started to get a little bit nervous. But, through the whole process working into this, you know, we started to understand that there were treatments, and so on, as we were leading up to the diagnosis because they were saying it might be this, it might be that, and Crohn's was one of them, IBD in general. So we were nervous and confused because most people aren't aware of what all is involved with anyone, whether they be a child or an adult who has Crohn's disease – you've heard of it before, but weren't really sure all it entailed, and the more we looked into it, you know, still a decent amount of confusion. We weren't sure how she was going to respond to medication, what the options were. We had, you know, started to do a little bit more research into it and realized that yes, this could get very serious and something to be, you know, reckoned with. So, it was scary. Certainly, there are things that are more scary, so we were kind of happy that it wasn't anything worse than that but, thus began our journey into this world that we knew was going to be a long one. So, as we started to find out more about it, we started to ask the right questions and associate ourselves with other people that were having similar issues and maybe see what we could learn from them. But it was scary at first and, of course, like you said, seeing your child in pain, which we were starting to see, is not easy at all. Especially for somebody like me, because I'm the one that goes, oh you cut yourself? Yeah that's pretty bad. Let me see that. That might be broken, you know? I don't know how to comfort properly. I've gotten better at it. She's the expert at it. So, learning to be a proper caregiver parent is part of the process as well. But there's a lot to learn when you find out about a diagnosis like this.

Dr. Caudle:

Right. You mentioned so many really good points and I think a lot of our listeners and watchers will sort of understand that and appreciate that, right? Some of the fear involved in what's going on, and also talking about how much there was to learn. This would be for any patient. And, once again though, I also have to bring it back. You know, you said something similar to Caroline, which both of you seem to have an appreciation that it could have been worse, which, you know, there's a sense of gratitude, even despite the fact that you're dealing with Crohn's and it can be tough, that you seem to have, which I think is remarkable and probably, at times, hard to have, you know?

Preston:

Yeah. Very much so. And we've learned, the more we've gotten involved in organizations and met more people that have IBD issues that sometimes it's – and what I wasn't aware of was the pain can be so severe that they really think about some drastic things that I didn't even consider. So, it can get to a certain level. So, that's always in the back of our mind as well. We're doing fairly well now. We're responding well to treatment, but it might not always be that way, so we're always on this, you know, eggshells, walking on eggshells type of mentality.

Rachelle:

Well is it, is it, you know, you don't see the disease, but you also don't see the psychological aspects of the disease that people don't want to talk about Crohn's to begin with, much less the psychological part of it.

Dr. Caudle:

Right, right.

Rachelle:

So being on top of that has been key for us.

Dr. Caudle:

Sure, sure, and I'm just going to go off topic for a little bit because I think that's a really important point, and we're going to talk a little bit more about the psychological stuff, but why do you feel that people don't want to talk about Crohn's? What has been your experience? Is it that it makes them uncomfortable? Is it that –

Rachelle:

Poop isn't fun.

Preston:

Well, and listen, it's also, you're talking about feces and things like that that people can snicker about and find funny if they don't know much about it, about how painful it is. Or it's, you know, it's a part of the body that some people still feel uncomfortable talking about,

you know, about bowel movements and things like that. So, I think that the awareness over the past few years since we have come into this has absolutely, positively gotten more serious and people understand that it's not a joke, and that people live with pain and are looking for treatments and cures, and that – and I think these charity events, these walks, and the more people that get involved – and you see people in mass coming out and saying, yeah, we're here to support and help find a cure. People are either being hesitant to talk about because of its sensitive nature or aren't finding it funny because of some of the subject involved. You know?

Rachelle:

Well, I also think the awareness of the whole autoimmune umbrella.

And that there's so many branches of that that, you know, oh you have that, I have this, which falls under the same invisible –

Dr. Caudle:

We're looking at it maybe differently or more holistically, maybe – and more awareness, so many things.

Rachelle:

Correct.

Dr. Caudle:

I'm glad that you mentioned that because I think as physicians and healthcare providers, we should be addressing that issue. That for patients it's got to be hard because, you're right, for some people this may be uncomfortable. You know? So, Caroline, I want to come back to you because your parents have set up a really good description of some of the process and how they were feeling, and maybe how you felt, too, going through the diagnosis. But I'd like to hear about what your life is like. Tell us a little about your social life and school. What are some obstacles that you faced because of your Crohn's disease that you've actually been able to overcome?

Caroline:

So, anxiety is like, hurts my stomach a lot, depending on how anxious I am. So, I would be anxious to go to school because is my stomach going to hurt today? Am I going to miss a lot of class today because of my stomachaches? How long am I going to be in the bathroom and miss a lot of classwork? And a big one for me was am I going to pass? Luckily, I got pretty good grades this year.

Dr. Caudle:

Excellent. Congratulations.

Caroline:

But I went to see a therapist for quite a few months to help, and I was able to finally be more happier and actually want to go to school.

Dr. Caudle:

That's really excellent. I appreciate you sharing that because that's something that we might not think about, right? Is the anxiety that you and many other patients may feel with like going to school, as you said, are you going to have stomach pains? Or someone who's working, are they going to be in the bathroom half the day? So, I really, really appreciate you talking about that. What would you say to doctors or healthcare providers out there listening, besides what you've just said, which is very powerful? What advice might you give us regarding that? Any suggestions you have with things we can do so we can help our patients?

Caroline:

Um, be patient because they could have a lot on their mind that they want to get out, but they can't always. So, you need to be patient, but you also need to have permission for a lot of things because they may not be comfortable with certain tests.

Dr. Caudle:

Ah, interesting, interesting. Give me an example of what you mean. Like, what kind of test are you thinking about?

Caroline:

Like they may not be comfortable with getting their blood drawn. Stuff like that.

Dr. Caudle:

The stuff that you have to do as a part of the condition that you have. Yeah.

Caroline:

So, they would have to be understanding and try to help them feel better about doing the tests.

Rachelle:

We definitely have other – we definitely have places that we prefer to go that are more gentle with blood work and tests than other places.

Dr. Caudle:

Yes, and I'm sure you've gotten really savvy about that, right? You kind of know where to go and how to go and who to see and probably have your favorite phlebotomist, and things like that. You're favorite lab techs. No, I appreciate that. So let's stick with you, Rachelle, okay? You know, you and your family are very active members of the Crohn's and Colitis Foundation, but you're also a board member of A Mother's Wish, and a big supporter of Camp Oasis. Could you explain your participation with these organizations a bit further and, you know, how did you find out about them and really how have they helped you and your family?

Rachelle:

So, for A Mother's Wish, it was a web search. They were – She was just diagnosed and we were searching the web and found they had an event coming up, so it was great because I got to connect right away. But being able to connect with other parents to be like, this is what we're going through now. What did you go through? It was hard.

Dr. Caudle:

What was it like for you and how did you deal with this?

Rachelle:

A lot of sleepless nights. Um, a lot of phone calls.

Dr. Caudle:

I really appreciate you guys opening up. You know? It's going to help so many people.

Rachelle:

So, I think the psychological part as a parent is, I can't fix this.

And we all have to go through the process – the journey – whatever that is for each individual because not one person's Crohn's is the same as the next. So, I think that makes it hard for the medical professionals is well what worked for this child doesn't work for this one, and all we can do is try. Initially, we weren't sure if her Crohn's was a food allergy. So, we were taking things out of her diet and monitoring her and keeping a journal before we ever made it to the pediatric gastroenterologist. So, when we got there, we had months of things that we had tried. And so, she was scoped within the first week.

Dr. Caudle:

Wow. I just know that all the work that you guys did in preparation really helped that GI really say, okay, let's move right to plan B. Let's get right to this next step, and really kudos to you all. You talked about the support, you know, do you recommend that for other families and is there a way that as healthcare providers we can facilitate that? And, you know, what are your thoughts? Are there suggestions for us, I guess is what I'm asking, in what you have found helpful?

Rachelle:

I think for me it was connecting with other parents. There are support groups for adults who are dealing with it themselves, but having other parents is a different aspect of it.

Preston:

I think maybe if physicians, you know, have these – like the Crohn's and Colitis Foundation and the Mother's Wish and the other organizations – have that information at the ready for the patients and say, here are some resources that you can use – because I'm sure, as a physician, you probably don't recommend, but we do, going and Googling these conditions and symptoms, because that can make things worse because you see the entirety of it all when there are some sections that pertain to your child, more specifically, and maybe speaking one on one with people might be a better way to do that. People who have gone through it as well might have some suggestions, some coping things to recommend as a parent. Not saying that a physician would know these things, but somebody might connect a little bit better with a parent who has a child who is going through the same thing, so I think having those resources at the ready and passing those along.

Rachelle:

Or maybe not necessarily the doctors, but you spend so much time with the nurses. And educating them on here's what's available in the community. Because they're the ones that are having those longer conversations.

Dr. Caudle:

And often taking phone calls and things like calling back. Those are great suggestions. Not just saying, okay, here's your prescription. We'll see you in a month. But we're saying, here's your prescription. These are the instructions and here's some resources that might be helpful for you and your family until I see you next time. So, I do like that suggestion.

Dr. Caudle:

Caroline, of course, you're the star of the show today – a couple more questions because we definitely want to hear a little bit more about your life and all of that. So the last two questions are for you. The first thing is – and I know we talked about this a little bit before we got started and you guys have all been helpful with giving us docs suggestions, but is there anything that your doctor says or does, in particular, either in the visits that you had when you were younger, or even today, that has just been really helpful for you and you like and that maybe something other doctors should consider doing?

Caroline:

Well, he's very kind to me. He always keeps like a softer voice, which is calming. And my mom is always in there with me and helps me out if I can't have – if I don't really have an answer, so she's allowed to be in there and it's not like my doctor, Dr. Kelly, is not allowing her to say anything. And, he's just a really great doctor to me and he's very nice.

Dr. Caudle:

That's awesome. So, listening is really important, it sounds like, and also sort of the way that doctors come across. He does things that help to make you feel comfortable, right? With the way he speaks and the way he asks questions and he allows your mom to participate, and that makes you comfortable.

Caroline:

He gives me a lot of time to talk. Of course, he has like a time frame where he needs to get to the next patient, but he lets me have a voice.

Dr. Caudle:

I like that phrase. He lets you have a voice. Now, that's a humdinger, right there. He lets you have a voice. I really love that. Do you guys have things to add to this? Because I think this is a collective experience, too, that you notice –

Rachelle:

Well, in the appointments, we try to sit back and allow – she needs to have control. This is her disease and so she needs to communicate and be her own advocate. So, when she gets stuck, then we help her but until then, we try to sit back and allow her to drive the car.

Dr. Caudle:

Well, you drive your car very well. Let me tell you. Because you're communicating how you feel very well and I think a lot of people are going to benefit from this. And then, let's go into another topic, okay? Because I know sometimes this can be a little bit of a tricky subject, but, you know, what would you tell other girls and boys your age to make them feel comfortable with IBD? You know, especially someone who might be just getting diagnosed or things like that, what would you tell them to make them feel more comfortable and help them feel more comfortable talking to their doctor? What advice would you have for them?

Caroline:

Well, to feel more comfortable, find good friends, not just friends who are just there to like take advantage of you. I would also – if you're – don't let your IBD take control of you or any emotions that cause it to hurt or any symptoms. The sooner that you can get out how you're feeling to somebody who can help you, like your parents or siblings or friends that you trust or a therapist or doctor, et cetera, the better – the sooner you could feel better. The sooner you can be treated and it's just – if you don't tell somebody sooner or later, then it will just go downhill.

Dr. Caudle:

Right, so you're saying don't be afraid to talk about how you're feeling and the sooner the better because hopefully that will help you sooner. That's very, very, very wise advice and I can't thank you guys enough. This was unbelievably amazing. So, one more thing I'd love to talk about is how doctors and physicians, healthcare providers, we can help support the whole patient more. You all have been very open in talking about sometimes what made you nervous or anxious and how you were able to overcome this, so what are things that we as healthcare providers can do to help our patients in how they feel about what they're going through. What would you say?

Rachelle:

I think really treating the whole patient and the family through therapy also in different coping skills and things that you may not handle so well or trying to understand their perspective. A teenager dealing with the disease, and I think really getting into therapy early on can avoid crisis down the road.

Preston:

Yeah. Anxiety coping skills and things like that. Which is, you know, it was Rachelle's idea to have her speak to a therapist, and it's been wonderful. And we, in turn, ask her if there's anything that she spoke to her therapist she'd like to speak to us about, and so there's a privacy issue if she wants it. I think physicians could recommend that, especially if they see not alone just Crohn's or IBD being an

issue, but maybe there's been a personality change, social change, or something along those lines, and maybe these things that are held inside because of this or is directly affected by this, meaning IBD, or they may be experiencing some backlash from friends or acquaintances or things like that, and it's really helped Caroline out, especially with school and having these issues and missing some school because of it. So, I think having that outlet certainly can help a lot. And if physicians can recommend that or maybe, you know, point them in the direction of some therapists that may be able to help out.

Rachelle:

But, as a parent, you have to understand that when your child goes into therapy, you're not in the driver's seat anymore. And if they don't want you to know something, you have to be okay with the fact that they're telling the therapist. Because the session isn't about you, as the parent; it's about your child. So, they need to know, whatever I say to the therapist, I may not want you to know about. So, you're not going to know unless they give permission.

Caroline:

Or the therapist thinks that the parent really needs to know.

Rachelle:

Like self-harm. Things like that.

Dr. Caudle:

Absolutely, well you know what, I think you're a remarkable, remarkable young woman. You've given so much – you've given therapy advice to us all during this interview, I have to say. And I feel so good that you've come to talk to us. All of you – it's been so helpful and you're going to help so many people. So, thank you.

Preston AND Rachelle:

Thank you.

Caroline:

Thank you.

Announcer:

The preceding episode was brought to you in collaboration with the Crohn's & Colitis Foundation. If you have missed any part of this discussion, or to find others in the series, visit ReachMD.com/foundation. To learn more about the Crohn's & Colitis Foundation, please visit crohnscolitisfoundation.org.