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Released: 03/25/2024
Valid until: 05/31/2025
Time needed to complete: 50m

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Examining the Lifetime Impact of a 25-Year Misdiagnosis – Part 1

Announcer:
Welcome to CME on ReachMD. This episode is part of our MinuteCE curriculum.

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Patient:
My name is Marquis, and I am a Crohn's disease patient. And I just wanted to share a little bit about my journey living with Crohn's disease. So, I was diagnosed with Crohn's in 2009; that's when the diagnosis came, August 12th to be exact. And leading up to the diagnosis, I was experiencing all kind of symptoms that come with IBD; that's Crohn's disease and ulcerative colitis, collectively. I had weight loss, I had abdominal pain, I had nausea, I had a loss of appetite. All of these are common symptoms associated with IBD. And I would say that probably started early January is when I started feeling these symptoms. And maybe around March/April of 2009, is when I decided to go and see a GI doctor. That was the first doctor that I went to go see, like, I didn't go to a primary care doctor first, or I didn't even go to the ER, I went straight to a GI doctor. I'm not sure what exactly led me to a GI doctor right away, but that's just where I ended up.

And I was with his GI doctor for quite some time, at least maybe 3 months or so. And when I met this doctor, we ran all kinds of tests, we did colonoscopy, we did endoscopy, we did an ultrasound. We did a barium test, which is where you drink this white, chalky stuff and it coats your whole intestine, your whole digestive tract, and then they run you through like a CAT scan, or take x-rays, and then they can see your insides is coated with white, and they can kind of identify things through that. So, we did all of those tests.

And he's prescribed me medication for acid reflux, antidepressants, and all these medications that weren't treating my cause, right? I did not take the antidepressants, in case you're wondering, because I wasn't depressed. I was just a sick person that was wanting to know what was going on with me. And once I started taking the acid reflux medication, again, like it wasn't treating my symptoms.

And there was a point where I had to seek a second opinion and seek a different doctor, because the first GI doctor that I had didn't just have my best interest in him. He was pretty old school. And not only that, it was just the lack of compassion towards me that I received from his staff, as well. There was one time when I called to get my lab results, and when I called, the receptionist was basically like, you know, this doctor is very busy, so you just basically have to wait to hear about your results. And at that moment, I was like, you know, that might be true. And I don't doubt that that's not true. He's a doctor. Yes, he's busy. However, when you're dealing with sick patients, you're in a healthcare professional, that's not how you deal with somebody that's calling to get their results. It could have been handled a different way. And at that point, I was like, you know what, all right, I’ve got to go seek another opinion. I need to get another doctor that knows how to interact with people, right? That knows how to interact and that's not dismissive. That's the word, that’s not dismissive.

And so, I met my second GI that made a diagnosis. So, the first doctor that I got referred to, after I decided to make a switch from my first GI doctor, he was actually a surgeon, which I don't know why I got referred to him, but it was a blessing because once I talked to him and went through all of my symptoms and went through that spiel all over again, he realized what was going on me that he was not the person for me, so he referred me to the GI doctor that made a diagnosis.

Now, this GI doctor had me diagnosed within a couple of weeks. The very first day that I met him, I took him all of my x-rays from my previous doctor, and he was holding them up to the light and he was looking at him. And he was asking me questions. And he was saying, ‘When this happens, you feel this right?’, ‘When this happens, you know, do you feel this?’ And every question that he asked me, I could only say yes, yes, yes. And he said, ‘I think I know what it is.’ However, he wanted to do a few more tests to be 100% sure. And what I really love and appreciate about him was that he didn't believe in prescribing medication if it wasn't treating a root cause, so he didn't prescribe me anything until he was 100% sure what it was. And by the x-rays, he thought he knew what it was.

And so, the test that I took was a capsule endoscopy, also known as a pill cam. And what it is, is it's a pill, where the front part of the pill is the camera. And what happens is, it connects to a device that you put on your hip. So, when you meet at a doctor in the morning time, they will strap you up with like little wires, about five or six wires all over your chest. And then they hook you up to a set like a device that cam connects to you, you put it on your hip. And basically, you have to be up for the whole day, like 8 hours so that the pill can go through your natural digestive tract. And what it does, is it takes hundreds of pictures a second, all color. And then at the end of the day, you go back to the doctor's office, and then they, you know, take the wires off for you. And then they take the, like the SD card outside of the device, plug it into their computer stuff, and then all of the color images from your digestive tract they can see. And that's when he made the diagnosis.

And he was a blessing, and this is why, because the doctor that did that, that made my diagnosis, he was the only doctor in the area where we were living at a time to do the test that I needed to make the diagnosis. And so, after he had did that pill cam, and he saw what he saw, he wanted to scope me one more time, right? He wanted to scope me. And I had went to the hospital that one day, the following Monday from when I got the pill cam results, and we did a colonoscopy. And I was there all day, I think I got there like around 8, I probably left like around 5 or 6 but I had to come back the next day. And then basically from Tuesday to Friday, I was in the hospital. Now, Tuesday when I got back, he did an endoscopy and he also told me that I needed to have two blood transfusions, because that's how bad I was at the time that I met him. I went from about 150 pounds to literally about 100 pounds soaking wet, might be slightly under 100 pounds. And so, when he told me, I needed those two blood transfusions, I was like, okay, let's do it. And you know, you don't know that you can refuse to have a blood transfusion, right? But again, I trusted him and I needed it, like I could feel that I needed it; that's how far gone I was.

And so, after that, the results came back and it was Crohn's disease. And the thing about it is my doctor that made the diagnosis, he was familiar with the other doctor, my first GI. And he was like, had he went lower with my scopes, he would have saw what he saw to make the Crohn's disease diagnosis. And so, I didn't have to go all of that time without having a diagnosis and getting started on the medication that I needed to treat Crohn's, had he went a little lower with his colonoscopy or the endoscopy, then I could have avoided all of that. But it was a blessing. You know, it was a journey.

What I would say is my journey living with Crohn's, I've always adapted a mindset and the model that I have Crohn's disease, it doesn't have me, right? What does that mean? When I say I have Crohn's disease, it doesn't have me, it simply means that I'm going to control the elements that's within my control, right? Exercise, nutrition, and mindset. And collectively, along with my medication, this is my treatment plan and how I get by living with Crohn's disease. I've had it for 14 years, August it will be 15 years, that I've been living with Crohn's. I take a monthly injection that I've been taking since 2010, once a month. And so, that combined with nutrition, really controlling what I eat, exercising 5 days a week, helps me to manage my Crohn's symptoms.

Now, that doesn't eliminate Crohn's, right? This is something that I’ll live with for the rest of my life. However, those measures, when I control those elements, it helps to manage symptoms, it helped to keep symptoms at bay. And the goal is to always have minimal flare-ups, right, when you’re living with IBD, I mean, it's Crohn's disease and ulcerative colitis. So, you want to have minimal flare-ups. And that's how I do it. That's how I manage it and it have managed.

And one of the things that I really love about Dr. Wen, when we first met, after he made a diagnosis, when I got started on my medications. And in the beginning, they load you up heavy on the meds. And then as the weeks go by, you start to come down. So, I was taking like prednisone, 6-MP, all of these drugs. And prednisone is a steroid. And so, they start you high and they start you low.

Before he prescribed all of those, he wanted me to do the self-injection that I do right now, because at the time I was diagnosed with Crohn's in 2009, this was a new biologic that was pretty much just introduced to the market in 2008. But I was like, no, I'm not feeling that, I'm not comfortable with doing a self-injection. And he didn't over push it. It was like, ‘That's okay, that's fine.’ And so, what we did, was we came to a mutual agreement that we would do the orals for a year. And when he scoped me the following year, so we're talking 2010, if there hasn't been any change and inflammation in my colon, then he wants me to start the biologic. And I said, that is perfectly fine. I'm okay with it. So, let's give it a try. So, we did it for a year. In 2010, when he did rescope me, even though I was feeling fine, there weren't much change in the inflammation in my colon, so I did start a biologic.

Now, after being on that biologic for 1 year, in 2011, when he scoped me, I saw the difference from 2011 to 2010. That 1 year being on the biologic, and my colon look impeccable. Like, it looked totally different, the inflammation was gone. And it was amazing. And so, that's what I've been on for the last about 14 years now I've been taking that. I would say that it helps keep it at bay. My condition hasn't gotten worse. And you know, it just kind of keeps it at bay. And so that's what I currently take. So again, that combined with just exercise and nutrition, and really having a positive outlook on this whole situation, is how I get through living with Crohn's disease.

And that's a little bit about my Crohn's disease journey, and my Crohn's disease story.

Announcer:
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