

Reading the Fine Print: Discovering I Have Ulcerative Colitis

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I was purging paperwork the other day when I came across follow-up notes from my last gastroenterologist appointment. I never read these notes when I check out. I usually only look at them when I'm about to throw them away to compare the history of my bloodwork. I hardly ever look at the front page, which contains demographic information, weight, blood pressure, and pulse, and the running list of diagnoses for medical coding purposes to bill my insurance.

As I was about to toss the papers into a pile to be shredded, something caught my eye. At the top of the list of diagnoses was "Ulcerative Colitis; Active 12/2016." When I saw it, I remembered receiving a call from the nurse with the biopsy results from my August colonoscopy.

She said my ulcerative colitis was still active and that my doctor wanted me to set up an appointment with him the following month. I was confused because I had Crohn's (granulomatous) colitis, not ulcerative colitis, and I had orders to see my doctor every six months. I told her that I had scheduled my six-month follow-up a few days earlier and I didn't understand why the doctor wanted me to see him so soon. She insisted the instructions were in the notes, and she would have the scheduling department call me back to reschedule my appointment. When I never received a call to reschedule, I presumed she had cleared everything up with the doctor and had misread the part about my having ulcerative colitis.

But staring back at me in black and white was the ulcerative colitis diagnosis. I couldn't recall my doctor discussing a new diagnosis with me after my colonoscopy in 2016. At the time, I was seeing him on a quarterly basis, and he never brought it up. Then again, at my first appointment after the diagnosis, my liver function blood test numbers skyrocketed and took center stage. Even when I started seeing him on a monthly basis in 2017, all of my appointments focused on my worsening liver condition. My IBD symptoms were put on the back burner until after my liver transplant.

Since then, every time my doctor mentioned colitis, I thought he was referring to Crohn's colitis. Maybe all this time he was referring to ulcerative colitis. Unlike the other types of Crohn's that can occur anywhere along the gastrointestinal tract, Crohn's colitis affects only the large intestine, or the colon. Also, skin lesions and joint pain are more common symptoms in this type of Crohn's than the others.

Like Crohn's colitis, ulcerative colitis affects only the colon. However, with ulcerative colitis only the innermost lining of the large intestine is affected. With Crohn's, all layers of the intestinal wall can become inflamed. Another difference is that with ulcerative colitis, the entire colon has continuous inflammation. The colon may have healthy areas interspersed with inflammation with Crohn's.

The Crohn's and Colitis Foundation specifies three types of ulcerative colitis, depending on where the inflammation occurs: ulcerative proctitis, left-sided colitis, and extensive colitis. With ulcerative proctitis, inflammation occurs only in the rectum, typically in less than 6 inches of the area. Left-sided colitis affects the descending colon, extending from the rectum up to the splenic flexure, where the descending colon meets the transverse colon. The Mayo Clinic refers to a type of left-sided colitis, when inflammation is limited between the rectum and the sigmoid colon, as proctosigmoiditis. The entire colon is inflamed with extensive colitis, also classified as pancolitis and acute severe ulcerative colitis by the Mayo Clinic.

I plan to ask my gastroenterologist more about the type of ulcerative colitis I have when I see him in December. That way, I will know more about the symptoms I could experience and should make note of if I do. Although I don't know much about my diagnosis now, I'm not too concerned because my current Crohn's treatment also treats the symptoms of ulcerative colitis.

What I do know is that from now on, I'm going to pay more attention to the treatment notes I receive after my doctor appointments.

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