

Managing IBD and Its Complications Requires the Right Healthcare Team

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admin

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Football season has returned, and it feels like fall, despite the 100-degree weather.

Our lives revolve around the “Friday Night Lights” of high school games and waking up on Saturday mornings to watch Lee Corso put on a mascot’s head on ESPN’s “College GameDay,” followed by 12 hours of college football. Side note: I’m still giddy from the magnificent win my Auburn Tigers eked out over Oregon in the last nine seconds of the game. War Eagle!

Fantasy football leagues are forming as people draft the best NFL players to create super teams to compete for money or bragging rights. I don’t play, but my husband does. Once when he had to work late, I started his draft. The pressure made me so anxious that I refused to do it again.

Selecting a healthcare team can be as complicated and stressful as picking a fantasy football lineup. Since my Crohn’s diagnosis in 2006, I’ve assembled a solid team, mainly through referrals from providers with whom I’ve had long and trusted relationships. While some of the players have been replaced, the specialties have remained the same.

My reliable defensive unit includes my gynecologist, optometrist, and dentist. With my gastroenterologist (GI) as my quarterback, I have five other key players rounding out the team: my primary care physician, endocrinologist, hepatologist, dermatologist, and nephrologist.

Following my Crohn's diagnosis and considering my complicated medical history, I selected an internist as my primary care physician because I thought that she could provide me with the best care. However, I rarely see her unless I need a specialist referral for insurance purposes or for a minor ailment unrelated to my chronic diseases. Sometimes, if she's unavailable, I attend another physician at the clinic.

Last year, I had my first annual physical with her since she's been my primary care physician. She didn't recognize me even though we've met several times. Now that I don't see my specialists as often, I'm making an effort to develop a stronger relationship with her.

My GI first sent me to an endocrinologist in 2010 to manage my vitamin D deficiency, but I stopped seeing her after my levels normalized and because I was dissatisfied with her care. After I broke my foot in 2015, my GI referred me to a different endocrinologist who I attended until she moved a couple of years ago.

I have a new doctor at the practice, but the same clinical nurse specialist has been treating me for the past four years. At first, I would see either the nurse or the doctor every three months. Now that my vitamin D levels are stable, I go every six months. The results of a recent bone density scan were significantly improved from last year, so at my next appointment in December, I hope that my doctor will reduce my follow-ups to once a year.

In addition to treating my Crohn's, my GI had been managing my primary sclerosing cholangitis. When my liver enzymes suddenly spiked, he referred me to a hepatologist. I was scheduled to have an initial liver transplant consultation with her on Sept. 15, 2017, but I met her 17 days earlier than planned when I was admitted to the hospital with sepsis, liver failure, and acute renal failure. Although I had several hepatologists on my transplant team, she is the one I see for my semiannual post-transplant follow-up.

My hepatologist recommended that I see a dermatologist and a nephrologist regularly to manage complications caused by the anti-rejection medication tacrolimus, which I have to take for the rest of my life.

While I've always had skin issues, I consulted a dermatologist only when my chronic dermatitis didn't clear up. As tacrolimus puts me at higher risk of skin cancer, I now have annual dermatology checkups.

Tacrolimus can impair kidney function, and as my kidneys are damaged from renal failure, I face the possibility of a kidney transplant in the future. I wrote about my first nephrology appointment in May, when I was concerned about the possibility of a third autoimmune

disease diagnosis. Fortunately, after tests showed no abnormalities, the nephrologist gave me the all-clear and asked me to follow up with him in one year.

I hope that I won't need to add any new providers to my healthcare team anytime soon. After this week, I'll have a short breather from seven straight weeks of doctor's visits, bloodwork, and tests before my next appointment at the end of the month. Unlike football, taking care of my health is a year-round sport, and it takes the entire team to help me reach my goal.

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