Patient Experience Living With Cirrhosis With John M., Part 2

September 5, 2018 By Connie M. Welch

Patients living with cirrhosis after being cured from hepatitis C often deal conditions and complications associated from cirrhosis, yet they live full lives with fighting spirits full of hope. We continue today to hear John's patient experience living with cirrhosis. See this link to read part 1 of John's experience living with cirrhosis.

Connie: John thanks for being back with us today. We're looking forward to hearing how you're doing. Let's pick up where we left off yesterday.

Connie: What medications did your physician prescribe for you?

John: I've been prescribed multiple vitamins, one for each letter of the alphabet. I did take Lactulose at first, but couldn't deal with the side effects as a result of the pharmacist doubling the dose by mistake. I've since learned to read the small print. I also take Xifaxan, Pantoprazole, Spironolactone, Bupropion Furosemide, Simvastatin, and Hydrocodon as needed. I have no idea what these drugs do, I just take them to help me. At the present my blood test showed me to be anemic so the doc put me on iron pills. Hopefully that will help in the battle with lethargy.

Connie: Do you experience symptoms like brain fog (HE), fluid retention (ascites), portal hypertension, or any others?

John: I fluctuate in the severity of my brain fog (HE), although it isn't as bad as it used to be at the first. I went through a time where I was retaining fluid in my chest cavity. I was undergoing a parentheses procedure about every other week. This procedure drains fluid by inserting a needle into the chest. They usually drained around 3 liters of fluid. Not any fun. This did preclude my having a portal vein procedure.

Connie: Are you on a special diet for cirrhosis? Example, a low-sodium, balanced protein, etc…? Can you share what specifically you do and what you avoid eating or drinking?

John: I've been placed on a low sodium diet, which is a struggle at times, being the salt addict that I am. I do watch the dairy products, and eat vegetables like a rabbit. I also consume all the fruit I can get my hands on. I eat fish and chicken, with an occasional steak slipped in. I drink 1-2 cups of coffee a day and lots of water and juice.

Connie: Can you recognize when you're having difficulty with symptoms or does a family member or friend, help alert you to symptoms?

John: For the most part I know when I'm having an episode, as I like to call it. My wife is in tune as well, and she can see the changes and knows how to address the situation.

Connie: It's great that your wife is there to help you and jumps into action. She's definitely an awesome Hero Helpmate.

Connie: How often do you see your doctor?

John: I see my doctor at least every 2 to 3 months unless something is going on like the radiation treatment of late to address the tumors in the liver.

Connie: Do you go for regular tests? How often and what type of tests are run?

John: Yes, I go for regular blood tests every 3 months like clockwork. I also have a CBC panel and tumor marker test as well.

Connie: What is your best source of encouragement?

John: My best source of encouragement is my relationship with God. My wife is also a marvelous cheer leader, friend and touch point to reality for me.

Connie: Do you have something to share with other cirrhosis patients and their families?

John: I don't know anybody else going through this trial at this time. With the exception of the forum members on Life Beyond Hep C, no one can speak to these problems unless they've been down in the trenches. That's why I'm thankful I found this website, Life Beyond Hep C.

Connie: John, You are a courageous and mighty Hep C and Cirrhosis Warrior my friend. Thank you again for sharing your experience with us. By sharing your experience you're helping other patients and their families feel not alone and encouraged. Our thoughts and prayers continue to be with you.

Can you relate to John's experience with cirrhosis? Do you have a question or comment about Cirrhosis or Hepatitis C? We'd love to hear from you.

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