The Importance of Taking Cirrhosis Medications; Hepatitis C Patient Interview with Suzanne, part 2

July 12, 2017 By Connie M. Welch

Connie: To Recap your last Hep C treatment; In December of 2013, you did treatment for Hep C with one of the new Hep C treatments Sovaldi & Ribavirin for genotype 2. You received very good results, becoming Non-Detected for the Hep C virus. You achieved your SVR12 and SVR24 (sustained virologic response-reaching 12 and 24 weeks post treatment and still remain Non-Detected for the virus.)

Connie: When did you receive the news that you were cured of Hep C?

Suzanne: Yes, I was fortunate to get on this combination of drugs. Dr. Muir said if the viral load test showed Non-Detected that would be encouraging but if the next test at 3 months post treatment showed Non-Detected then he would considered me cured. Dr. Muir doesn't make many calls so when I looked at the name and number I think I picked it up before it went to a second ring. The last test was done in September 2014 which showed Non-Detected.

Connie: We are thrilled you have been cured from Hep C. I understand though that you were under the impression once your Hep C was cured, your cirrhosis was cured or your liver would completely heal from cirrhosis, is that correct? If not, what did you understand?

Suzanne: I knew I was cured of Hep C but still had stage 4 cirrhosis. I was under the impression that the liver could rejuvenate but a lot of damage had been done. I now know the liver cannot regenerate from this stage of scarring.

Connie: I understand you had a dangerous experience with not taking your meds for your cirrhosis, can you share why you stopped taking your meds and the dangerous episode you and your husband Mark experienced?

Suzanne: I had 3 episodes that made me think I was going into liver failure. I felt completely normal when I laid down that night. The next morning when I woke up, as I got out of bed my legs were like rubber and I fell to the floor. Mark flew over to ask me if I was OK and help me up.

I walked to the office and sat down to put my contacts in. I was shaking so bad I couldn't do it. Mark said I wandered around the house and was headed out the back door to feed our cat but couldn't figure out how to open the door. I asked him to open the door for me and he knew

something was very wrong. My speech was slurred as well. This was my normal routine in the morning. Mark stepped out for a few minutes after he put me back in the bed and I began to cry.

He acted quickly and called Duke and gave the PA details about what was going on and took me to my primary care immediately, which was close to home. The PA immediately said it was high ammonia levels. I had STOPPED taking my Xifaxan and Lactulose because I thought they were Hep C drugs.

I had two more incidences similar to that. Today, I do not miss a dose and never want to go through anything like that again. Lactulose is an inconvenient drug to take because it is a laxative but the results if it isn't taken are far more complicated.

I do not drive or stay alone when I am confused or have neurological issues. Mark stays home with me when these episodes occur. The PA simply said my brain isn't actually telling my body what to do so it's best to always consult with a physician.

Connie: From the caregiver stand point, it was very important that Mark recognized what was going on and acted very quickly, and getting you medical attention. You mentioned he's very organized and keeps all your doctor's telephone numbers in his wallet which helps make a big difference. Great job Mark!

Connie: After this episode, what were you instructed by your medical team about symptoms of high ammonia levels, taking your cirrhosis medication and the importance of a special diet?

Suzanne: I was told to take my medications as prescribed and I can increase Lactulose if I feel foggy or confused. The only way to keep ammonia levels down is get them out of your system, meaning 3 to 4 bowel movements a day. I am checked every 6 months for elevated ammonia levels through blood work.

Connie: Has your cirrhosis meds had to be changed in anyway?

Suzanne: Yes, the Lactulose can be increased if needed.

Connie: Has your medical team instructed how often you are to receive blood work, and tests (what type of tests) are to be done due to cirrhosis?

Suzanne: I will receive the same blood work as they have been doing all along every 6 months, which is a blessing in itself. I will have additional ammonia levels checked at my request if I think I need them.

It is also important to note, Dr. Muir said an infection in the body, an example with a UTI (urinary tract infection) can also affect high ammonia levels so not every episode can be liver related. It's important to consult a physician immediately and get blood work and exam to determine if there is an infection in the body. If so, this needs to be treated with antibiotics immediately.

Connie: Is there something you'd like to share with others who have cirrhosis?

Suzanne: Yes, at my last doctor visit I asked them about my life span with stage 4. They told me I was doing everything right so this wasn't a death sentence. I am holding my own and after the recent Fibroscan I was still at stage 4. Dr. Muir only did the test this early after my Hep C treatment because I wanted it. He said he would have normally waited another year.

I would say to everyone, NEVER STOP taking any medications without your doctor's approval. Never make assumptions on anything and ask a lot of questions and write down the answers so you can remember what you were told.

Go over your medication list thoroughly with your doctor, not a nurse or medical assistant that checks your vitals before seeing the doctor. Most importantly give the praise to God that you were able to walk away from another visit.

Connie: Suzanne, Thank you for sharing your experience and important proactive information. You are a Hep C Hero and Mighty Warrior! We are thankful for all you and Mark do to help spread the news about Hep C and liver disease and the importance of a proactive lifestyle. God Bless you.

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