Hepatitis C and Waiting: Ten Tips to Help You Stay Calm

August 17, 2015 By Lucinda K. Porter RN

I had no idea that living with hepatitis C would involve a lot of waiting. I waited for lab results, insurance approvals, medication, and the ultimate wait--better hepatitis C treatment. With all that waiting, either I had to develop patience or I was going to be a hot mess.

In 1997, I muddled through 3 months of treatment for chronic hepatitis C virus infection. Treatment was interferon, self-injected three times weekly. Since I had genotype 1, my chances of eliminating the virus were low (less than 10%), so it was no surprise that I didn't respond. Waiting for better treatment was my best option.

In 2003, peginterferon became available. Used with ribavirin, I had a nearly 50% chance of success, so I took the plunge. I responded to treatment, and went through a 48-week course. I waited for 24 weeks for lab results to learn that the hep C was back.

I waited another 10 years for treatment. I participated in a 12-week clinical trial with Harvoni plus ribavirin. Like everyone else, I waited for results. The wait times were getting shorter now that we have post-treatment week 4 results that are strong indicators of success. We also have cures that can be declared at 12 weeks following treatment, rather than waiting for 24 weeks for the results.

Graceful waiting is an act of courage and patience. It takes courage to live with a virus that is gradually damaging one's liver. It takes even greater courage to live in peace with this knowledge. Here are my tips for developing patience:

Tip #1: Don't be a victim--be your own hero. Waiting is an active process. While waiting for better treatment, a frustrated patient once told me, "I feel like I am sitting around and doing nothing while the hepatitis C is eating away at my liver." Don't sit back and let this happen. Use this time to build your health.

Tip #2: Take care of your entire body. You may have a liver disease, but statistically you are more likely to die of an unrelated medical condition. While you are at it, take care of your mind and spirit too.

Tip # 3: Get a life. It's easy to dwell on hep C, especially when we are first diagnosed. However, after awhile, thinking about hep C all the time can become an obsession that may hurt more than help. Strike a balance between the need to stay current and the need to be free from thinking about the virus.

Tip # 4: Imagine health. Visualization, positive self-talk, and imagination are powerful tools. We can use them to our advantage or detriment. If all we can think about is how tired and befuddled we are, it doesn't leave room for much else.

Tip # 5: Stay connected. Find people, with or without hep C, who are vital and wise. I found it necessary to let go of unhealthy relationships, and surrounded myself with people who had gumption. Someone wrote, “Life isn’t about waiting for the storm to pass. It’s about learning to dance in the rain.” If I was going to dance in the rain, I wanted to be with other dancers.

Tip # 6: Strive for the healthiest lifestyle you can. This is courage in action. Lao Tzu said, “A man with outward courage dares to die: A man with inward courage dares to live.” Start small. I don’t smoke or use alcohol. I eat well, maintain my weight, am active, and I meditate. This took years to achieve. I gave up alcohol first, then cigarettes. Exercise came next. I am still working on meditation. It’s a process. If I tried to change all of me at once, I would have given up.

Tip # 7: Live in health, not fear. Hep C is scary, and it is reasonable to freak out about it. However, fear and worry don’t help, so when you are ready, consider giving up fear. Amy Tan wrote, “If you can’t change your fate, change your attitude.” Attitude can change everything.

Tip # 8: Surround yourself with positive messages. Mary Kay Ash, founder of Mary Kay Cosmetics said, “If you think you can, you can. And if you think you can’t, you’re right.”

Tip # 9: Live in gratitude. There is a Chinese proverb that states, “We count our miseries carefully, and accept our blessings without much thought.” Are you counting your blessings or your troubles?

Tip # 10 Keep your sense of humor. The English poet, Lord Byron wrote, “Always laugh when you can. It is cheap medicine.” In addition to scientifically proven health benefits, humor lightens even the heaviest load.

Developing patience is much like being in training. It is a declaration of intent to stay healthy no matter what. It is medicine without taking drugs. When we dare to live well, honor ourselves and inspire others to do the same.

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