
Living with Hepatitis C

Neil Van Dusen

Greetings from Halifax, Nova Scotia. My name is Neil Van Dusen. I am a 41-year-old hemophiliac, Factor IX deficient. I've been married for 19 years and have 4 children – 2 boys and 2 girls, ages from 7 to 16. At some point in my life, I acquired the hepatitis C virus and have since been growing progressively sicker.

At first things weren't too bad. The weariness and feelings of constantly being tired I put down to working a full-time job and helping to raise 4 children. I coached hockey and spent weekends at the local rinks. I was active in the community and pitched in at home when needed. Life was busy – with the 4 kids there rarely was a dull moment. I began falling asleep on the couch while watching movies with my wife. It became too frequent and staying awake was more work than it was worth. I lost concentration easily and would forget things that normally I wouldn't (losing the car in a parking lot was a scary experience – I thought someone had stolen it!).

In 1995 during my yearly visit to the Haematology Clinic, I was informed that I had tested positive for the hepatitis C virus. My wife and I felt that the best way to deal with this news was to learn all that we possibly could about it. We asked questions and surfed the Internet for any and all information. I was examined by a gastroenterologist, who recommended a liver biopsy to determine what damage had already occurred. The results were not

promising. I had scarring of the liver and the only recommended treatment was “interferon”. I was told that this treatment could help or, in some cases, make things worse and that 1 in 4 patients did get good results. I figured that 1 in 4 was better than 1 in 0 and proceeded with the treatment. Unfortunately, I was unable to finish the treatments as my platelet count dropped to very low levels and I was forced to stop. Since that time, my platelet counts have not risen and my immune system is somewhat compromised.

I now find myself with less energy and my future on hold as I await the outcome of my battle with this virus. As time passes, I find symptoms becoming increasingly worse. Fatigue is the major problem, with napping, resting and generally taking it easy the order of the day. Getting out of bed some days is a major chore in itself. Most nights, sleep is restless and I find I will awaken at odd hours and not be able to return to sleep. The physical symptoms are redness of the palms and fingertips and “spidering” on the body. Most people would say, “Hey, you look pretty good.” But looking good and feeling good are two very different things. I can truly say that I can't remember what it feels like to “feel good”. I suffer from itchiness, body aches, headaches and feel tired most of the time. Depression is also very common, as is eye strain and lack of interest in particular activities for extended periods of time. I

have suffered spontaneous bleeds, which I never had before. Another bothersome symptom is lack of libido. My spleen is enlarged and I go for the usual battery of tests and ultrasound check-ups.

So, as time passes and I grow weaker and feel worse with the inevitability of a liver transplant somewhere in the future, I have lost hair, weight and teeth. Stress plays an important role in how things go as well. Just the other day I received notice that even when the day comes that I can return to work, my position will not be there for me. I fear that I will lose disability insurance, life insurance and medical and drug plans.

When people ask what I want, I tell them I would like to have my health back, be able to play with my kids, walk the dog and go to work. Maybe I'll even get lucky and get a new liver, survive the operation and not have my body reject the organ, and live a long and happy life. I've had a lot of things taken away from me but the one thing that remains is hope. I hope to beat this thing. I hope the medical community finds effective treatment and a cure. I hope that we have learned from the mistakes of the past. I hope that by putting some of my thoughts on paper I will help others understand how devastating hepatitis C and living with it can be.

Thank you for this opportunity to express my feelings.

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