

Steven: Surviving long-term

Created 22 Jul 2008 - 11:54am

'Over the last 22 years of having HIV I've made lots of changes as part of my journey with HIV. I've had everything: Kaposi's sarcoma, PCP, other things, radiotherapy, and chemotherapy, the cancer side of HIV. I've had eight different cancers.'

'It's been ongoing, re- evaluating things, different treatments, and their effects on me. To make those treatments as effective as possible I've had to look at exercise, meditation and other things.'

'I've been at the point of death numerous times. Every time I go see a doctor they say "Oh, oh you're still, oh, so you're well, you look fabulous." And I say, "Yes, well, I have to, I'm a poofter, I'm supposed to look gorgeous all the time."

'Twenty-two years ago we didn't have treatments. When I was diagnosed I said to the doctor "How long have I got?" He looked at his watch. I was just hanging there; my CD4s were going down. I had 160 Kaposi's sites on my body from my tear ducts to my legs and hands. I couldn't drive or walk. I had issues about how I looked.'

'I was on the first AZT and other drugs and got sicker. I had early dementia for about four months, I couldn't remember where I lived or my partner's name. It was overwhelming. I still cringe when I think about those days. I could have been depressed about it. But I kicked myself in the arse and got on with it. I saw I needed to own having HIV, to move with it and adjust as quickly as possible to what-ever was going to come at me.'

'A therapist taught me relaxation and meditation – that meditation isn't about stopping thinking, but about slowing down, reflecting back, and focusing on something. You can let your thoughts wander and come back. People think "I can't just sit there doing nothing for an hour." It's not about that, it's about reflection, spending time breathing and listening to yourself and your body, getting in touch with it. It was a big learning curve for me.'

Now Steven finds that meditation and relaxation give him the strength he needs 'I rise at six, take my dog for an hour's walk then meditate. Before the world goes off I just sit and reflect and breathe. And the dog lies next to me and has a little break. It's the best part of the day. I enjoy watching the sun come up. I've made it to another day. It reinforces all of the things that I do. It's been wonderful. It's given me the impetus to go out and share that with other people, and be an activist and play a role in the HIV sector.'

Having a dog helps Steven stay active and motivated. 'After our morning walk we play three or four times during the day. He's an inspiration to me. When I've spent half the evening in the bathroom from diarrhoea and colitis and don't feel like getting involved he jumps up in the morning with the ball ready to go. I'm duty bound to participate. Once I get up and get dressed, it doesn't matter if it's only 3 degrees. When you get out there and start walking you forget about all of that. It's helped me to manage my symptoms a lot better and to have a more positive outlook that I can overcome things. I'm greater than my mind and my body.'

Maintaining a good diet has been an important part of Steven's health management 'Improving nutrition has played a huge part. Convenience was my catch- cry. If I could get it pre- packed ready to go, I was on it. Now I make everything from scratch.'

Like anyone living on a pension, Steven is forced to budget, but he has found ways to turn this into a positive. 'I need to find the best quality for the best price and quantity.'

I go to the markets every weekend. I pick up other people and we make a day of it. We have a coffee or go to a few galleries afterwards. Now I never think "Oh I've got to go fucking shopping." And at the markets \$10 worth of food would cost \$30-\$40 at Woolies.'

Part of Steven's process of taking control of his health was to stop smoking and to drink less. 'It was a budget issue, but about the side effects too. Smoking caused mouth ulcers and hairy leukoplakia, and between diarrhoea and the vomiting my quality of life was just awful. That discomfort was purely from my diet and excessive use of drugs and alcohol. Now my mouth doesn't have any of that nonsense and stopping drinking reduced the colitis

attacks and bowel disorders. I had 6 CD4s, now they're increasing all the time. My [viral load](#) [1]A measurement of the quantity of HIV RNA in the blood. Viral load blood test results are expressed as the number of copies (of HIV) per milliliter of blood plasma. is undetectable.'

For Steven, the hardest thing about all his changes is isolation. 'When you're not working and not drinking and smoking you are somewhat isolated and capped by your financial status. You can't spend a third of your pension getting wasted and dancing on tables. I used to do that a lot. People are quite surprised at my huge turnaround, like the QE2 turning around.'

Steven's advice to others is about self-awareness. 'My advice about having HIV is to learn to look and listen to your body and appreciate who you are. Anything is possible. I often say that keeping healthy is 40% because of the medications and the other 60% is the hard work you put in. This is not something that's encouraged. I've nearly died about 11 or 12 times then suddenly I come back. The doctors assume it's because of their treatment. I think it's a lot to do with taking more care about what I put into my body now.'

Steven's advice to others: 'Don't get overwhelmed by major changes. I found that it's the little changes that I can live with. I could live without drinking every second or third day. Then it worked out to being once every couple of weeks. Now I can go for months without a beverage and if I do, two or three is more than enough. I know what my limit is now. So gradually there's a huge change in that whole concept of who you are and how you treat your- self. And you really get to think about 'what is a good time?'

Managing HIV. It's about [balance](#) [2].

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Links:

[1] <http://www.napwa.org.au/glossary/term/416>

[2] <http://www.napwa.org.au/hivbalance>