

## What is the one thing you wish you had known when you were first diagnosed with HIV?

And, if you knew then what you know now, would you have done anything differently when it came to your treatment, care, attitude, outlook, or anything else? What advice would you have for someone newly diagnosed?

Interviews by **Maggie Atkinson**

We asked five people living with HIV/AIDS (PHAs) from across Canada to share their opinions. They discuss disclosure, support, becoming informed, finding a specialist and getting on with life. Some have many regrets, one has none. They all share a message of hope.

### **TERRY CHRETIEN**, 29

Licensed practical nurse  
Regina, Saskatchewan  
Diagnosed in 2003  
Viral load: 560  
CD4 count: 414

**I wish I had known that the AIDS service organization (ASO) was there** and that they were so approachable. Before I was diagnosed I hadn't really heard people talking about AIDS and I didn't know there was a support program for people with HIV, even though I'm a nurse. I found the number in the phone book about eight months after I was diagnosed. It took me a long time to get the courage to call.

When I found out my boyfriend was cheating on me, I got tested for every sexually transmitted infection under the sun. My general practitioner (GP) did no counselling prior to my HIV test. She said, "You have nothing to worry about, I shouldn't even test you." When I went in for a regular follow-up appointment she said, "Well, your HIV test results have come in and it's not good—it's positive." Then she handed me the forms from Public Health to fill out. She didn't give me any information. I cried in her office for an hour, and had to call my sister to come and get me. My GP had warned me not to tell

anyone. She said that my friends would reject me. She made me feel dirty and shameful.

I became very depressed over the next year and felt suicidal, but I realized that I did have some close friends who really cared for me, and that stopped me. If I had made contact with the ASO earlier I might not have spiralled into such a deep depression.

Although I am very open about my status now, I still feel shame around the HIV. My parents support me, but they are unsure about my being so open. Most of my friends have supported me. For the first year I didn't tell anyone outside of a few girlfriends and family. My co-workers have been surprisingly supportive. I am more assertive and stronger now because of the HIV. I feel that I have to stand up for myself because no one else will.

**ADVICE:** Don't be scared. Reach out for support.

### **JEAN**, 47

Volunteer, AIDS Community  
Care Montreal (ACCM)  
Montreal, Quebec  
Diagnosed in 1992  
Viral load: undetectable  
CD4 count: 300-400

**I wish that I had disclosed to my friends and family earlier.** I was afraid that they might reject me, so it took me a few years before I could tell my sister and a few more years before I told my parents. I found out I had a lot of support that I didn't know was there.

I could have used that support because I had tuberculosis (TB) and a CD4 count of about 60 when I was diagnosed. When I recovered from the TB a few months later, I considered

returning to work as an accountant, but I am glad that I went on disability because I went on to develop serious infections like MAC (*Mycobacterium avium* complex) and cryptosporidiosis. My CD4 count eventually dropped to zero. Although I was getting some counselling around the HIV, I wish I had tried to find out more information about healthier foods and supplements, because I think that might have helped me.

I wish I had joined a support group earlier. It was three or four years before I came out to meet other people in my situation.

There were years when I couldn't work, but I wish I had gotten involved in volunteering earlier to feel more useful—it can have a positive effect on your health and your outlook on life.

**ADVICE:** The important thing is not to panic. There are various treatments available and there is a lot of information you can obtain as to what the best options are for you. In the past there was one treatment and that was it. There are more choices now. Make sure you are starting on the best regimen for you. Lead a healthy lifestyle. Eat properly, exercise and avoid stress. Join a support group—it helps to talk to others like yourself.

### **CRISTIAN SARMIENTO-BARRAZA**, 53

Flight attendant  
Toronto, Ontario  
Diagnosed in 1987  
Viral load: undetectable  
CD4 count: 540

When I tested positive in the '80s, there wasn't much hope. There was no medication available. It was a death sentence. You had maybe a few

"Don't be scared. Reach out for support."



TERRY CHRETIEN



## “Keep on living.”

CRISTIAN SARMIENTO-BARRAZA

years. **I wish I had known then that researchers were working on medications that would mean that you could one day lead a somewhat normal and productive life.** That you could hold onto your dreams. I just moved on. I planned for the next couple of years, but I didn't think I had a future beyond that. When I was diagnosed, I had just completed my degree in architecture at UBC, but I thought, “What's the point?” I had put myself through my final years of university by working as a flight attendant. I had medical and disability coverage, so I decided to stay with the airline. I didn't pursue my dreams.

I would have planned a little better for the future, had I known then what I know now. I wasn't thinking of retirement. I stopped making contributions to my RRSP and pension plan. Instead, I spent time with friends and family and I travelled. I thought it made more sense to spend the money rather than save it for a future I didn't think I had.

**ADVICE:** Keep on living. It's not the end of your life, plans and dreams. Don't forget your responsibilities—to yourself and those you are having sex with. Educate yourself about HIV and the treatments. Look after yourself. Get a good doctor. I hear people saying it's OK to have unsafe sex because there are drugs now, but there is no cure for AIDS and not everyone reacts well to the medication or succeeds on it. That said, there is hope that things will be even better in the future—that the drugs won't have the same side effects and will be more effective.

### **JAMES EDWARDS, 40**

Support supervisor, call centre  
Saint John, New Brunswick  
Diagnosed in 1996

Viral load: undetectable  
CD4 count: 550

**I wish I had known that there were HIV specialists in Halifax.** I was



## “Get informed.”

JAMES EDWARDS

diagnosed in Montreal, where I was seen at Clinique l'Actuel. A year later I moved back to my home city of Halifax. I got a GP, who only had about 10 HIV-positive patients in his practice. He was pushing meds on me even though my counts were fine. Fortunately, I had been told at Clinique l'Actuel that I didn't need to go on drugs as long as my counts were OK. Also, my father has diabetes and has to take insulin every day, and he said, “Don't go on medication if you can possibly avoid it.” About a year later I heard about the HIV clinic and asked my doctor to refer me there. The doctors at the HIV clinic had more experience in treating PHAS, and they listened to what I said. I was able to go almost nine years without meds. I'm afraid that I might have become resistant if I had taken them earlier.

**ADVICE:** Two things: 1) Get informed. Local ASOs can provide information about clinics, doctors and meds—don't just try to sort it out on your own. Get informed about how to talk to your doctor. Get the number for CATIE [1.800.263.1638] and find out about meds and when to start them. The more info you have, the easier it is to communicate with your doctor. There are so few clinics in the Maritimes that people are afraid to speak out and disagree with their doctors. But because I had the information when it came time to start meds, I was able to explain to my specialist what my needs were as a person who had to work full-time. 2) Get referred to an HIV specialist immediately. In the Maritimes, especially if you're not in Halifax, many doctors don't have a large number of cases, so they don't have the experience.

### **MIKE FULTON, 39**

Volunteer peer treatment counsellor,  
British Columbia Persons With AIDS  
Vancouver, B.C.  
Diagnosed in 1990  
Viral load: undetectable  
CD4 count: 320

There isn't really anything that I wish I had known. **I wouldn't do anything**

**differently.** I didn't know much about HIV when I was diagnosed: I had only been out for two years and I was in a monogamous relationship. But I was well informed from day one by my doctors. My original GP referred me to the immunodeficiency clinic at St. Paul's Hospital. I did research on whom to see there and Julio Montaner was at the top of the list. I didn't have any misconceptions about the illness.

I told my mom within five minutes of finding out. I had already told my family that I was gay. My family was supportive.

I was 23, working in computers, and I kept working as long as I could. HIV threw my diabetes out of whack. I developed peripheral neuropathy and my blood sugar was on a rollercoaster. I had been diagnosed with diabetes at 18, and I think this may have helped me deal with HIV. I had already coped with a life-altering situation that required taking meds at a designated time. I went blind in December 1998 as a result of the diabetes. In February 1999, I got necrotizing fasciitis (flesh-eating bacteria) in my foot, and in June my kidneys failed. I was on dialysis for six years until I became the first HIV-positive person in British Columbia to have a kidney transplant about a year ago. Through it all, I have kept a positive attitude. I still have a lot to accomplish in this life.

**ADVICE:** It's not the end of the world, given all the innovations in HIV therapy coming out almost on a daily basis. A positive attitude is so important. Bernie Siegel's book, *Love, Medicine and Miracles*, helped me with everything: diabetes, blindness, kidney disease, dialysis. Hold on, keep going. +



“A positive attitude is so important.”

MIKE FULTON