

**Living well** — what the pros call “quality of life” — is the best revenge on HIV. But it can be hard work for PHAs, who tend to have a lot on their plate: diarrhea, neuropathy, lipo...and all the other medical minutiae that come with taking handfuls of pills every day. Even if you're not on meds, the many issues to deal with — from addiction to rejection to chronic infection — can make quality of life seem impossible. Aren't you overjoyed that AIDS is now a “chronic, manageable disease”? Hey, kitten, it's better than the alternative.

**Chatty CATIE asked 5 PHAs from across Canada to define quality of life and reveal what they do to get it.**

**Kim Johnson, 31**

Provincial peer network coordinator, Voices of Positive Women  
Diagnosed with HIV: 1996  
Viral load: 19,000  
CD4 count: 220  
Toronto, Ontario



From struggling with addiction to losing everything I owned to being diagnosed with HIV to giving birth to my son, I've become far less limited in my definition of quality of life. I used to say that all I wanted was to be free (I was in jail at the time). Then I discovered that prison had very little to do with bars and more to do with my ideas. To define quality of life would be to make finite what I've come to realize is infinite: *Freedom from the inside.*

Here's what I know: *Whatever you put into your life is what you will get back.* Quality of life is not about time and space so much as it is about the moment. *My life is a series of moments* — some good, some not so good, but they're mine and I'm free to do whatever I choose with them. If you catch me in a certain moment, I may have a lot to complain about, but the truth is, all is well and *I am truly grateful to be alive.*

If I struggle with things beyond my control, I tire quickly and my energy seems wasted. If I point a finger at other things as the source of my pain, anger or frustration, I do so at a great cost. I will miss the moment. I may miss my son's first day of school — not because I'm not there but because I'm *not there.* Living with HIV can be unnerving. I've thrown my hands up and yelled, “OK, how much time do I have? I have a lot to do, dammit!” It was a long road that I trudged to be here and to be, of all things, a mother. What a waste to miss any of it.

I eat well most of the time. *I take supplements.* I do my own vitamin B<sub>12</sub> injections. I sing all the time. I laugh and play a lot. I smile at life as often as possible. *I meditate.* I have the privilege of working with the greatest women in the world. I constantly remind myself where I've been and where I'm headed so as not to be stuck in either place and miss out on right now.

**John Arenburg, 44**

Support coordinator, AIDS Coalition of Nova Scotia  
Diagnosed with HIV: 1985  
Viral load: below 50  
CD4 count: 1,085  
Halifax, Nova Scotia



Quality of life is living my life as I want to live it, being happy and healthy. To do that, I have to have a *positive attitude* and not be judgmental. Being judgmental is a negative response to life.

I work hard. I try to not create stress in my life. *I keep up with my meds.* Actually, I just went off them, but taking them didn't interfere with my quality of life because I didn't have any side effects.

*The AIDS Coalition of Nova Scotia has been a big contributor* to my quality of life by being supportive to me over the past 13 years. I was 23 when I finally came to terms with being gay, and then, whammo!, at 25 I was HIV positive. It took me awhile to come to terms with that, and I did so with support from this ASO. Just knowing that there was somebody who could relate to me was very important. To this day, I still get the support I need here, through the other staff and our members. Some of our members who come to see me don't realize that they actually help me too. Working here also gives me the opportunity to give back to my community what that community has given to me.

Even though I have HIV and I work with other PHAs, it's not the first and foremost thing in my life. If a person is consumed with being HIV, it's not healthy at all. *I don't define myself by my HIV* or by the fact that I'm gay. I'm John Arenburg, and I'm proud of who I am as an individual.

You can eat healthy and take your meds and all that, and that does help your quality of life, but I think more important is *how you feel inside.* If you're dedicated to yourself and you love yourself, you're better able to love others and share that. *Knowing that you are loved is so important.*

**Maggie McGinn, 45**

Executive director, Living Positive  
Diagnosed with HIV: 1992  
Viral load: 180,000  
CD4 count: 580  
Edmonton, Alberta



How do I define quality of life? *If I feel good.*

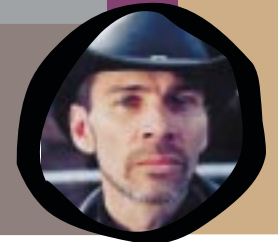
What makes me feel good? *I attend my 12-step meetings.* I yell and scream if I feel like it, and I listen to other people yell and scream. I made a choice of *not using or drinking at all,* and I haven't for 10 years. I'm taking better care of my health and my emotions, rather than burying them under drugs and alcohol.

A really important piece to me around quality of life is that *I'm nonjudgmental* and I surround myself with people who won't judge me and who will take me at face value. *One of my favourite sayings is:* “Your opinion of me is none of my business.” Sometimes, though, I still sort of sweat under the armpits when I do things that I'm worried people will judge me about. But I do them anyway because, at the end of the day, it's me living with my conscience and peace of mind.

I probably wouldn't still be here if I hadn't had my kids, *Stephanie and Jessica.* They gave me the sense of responsibility I needed to take care of myself. *They're my will to live and stay well.* Stephie crawled up my knee when she found out I was positive and said, “Mommy, I don't want you to die.” And I said, “Stephie, I don't want your mommy to die.” It's not about I don't want *me* to die; I don't want *Stephie's mommy* to die. I've still got my mommy. She's 77, and she's still my mommy, whether she likes it or not.

**Michael Linhart, 44**

Former prison coordinator, BCPWA  
Diagnosed with HIV: 1991  
Viral load: 176,000  
CD4 count: 80  
Vancouver, British Columbia



It's quite simple. To me, quality of life is the ability to go about a relatively normal life without too many inconveniences as a result of meds or medical conditions; to be able to *live on my own without assistance,* to take meds that will allow me to do the things a 44-year-old would do.

Anything that got in the way of me being able to take care of and *play with my dog, Shasta,* would interfere with the quality of my life. She's a purebred American pit-bull — a 55-pound lap dog — an inspiration and a motivation.

My friends and personal interests keep me up and moving around rather than focused on the fact that I'm taking massive cocktails and I have diarrhea and don't really have the energy. *Mental headspace* is a really big thing in my quality of life.

Because *I'm co-infected with hepatitis C,* I went on ribavirin and interferon treatments last year. About three months into it, I got pneumonia and nearly died. At the time, I was on a five-drug HIV cocktail and the hep C combination, and I had virtually no quality of life.

*In prison, I fought tooth and nail* for virtually anything and

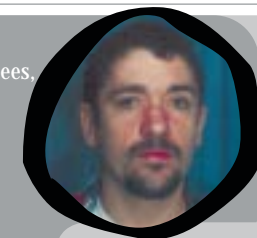
everything that was available outside. Achieving quality of life in prison is a lot more challenging. You don't have the same access to general standard of care. It was very difficult to get a proper diet or things that help with side effects. Most often, you can't even get additional food so you can take your meds properly, the way they're prescribed. Plus, there's no access to adequate vitamins or supplements. I basically used the negative aspects of being positive and taking meds in an *advocacy capacity* to enhance my quality of life and, hopefully, to make a difference in other people's. That became much of the premise of my job at BCPWA.

*To PHAs in prison,* I'd like to say: Quality of life is based on how you perceive it, and then in your determination to pursue it in a positive, pro-social manner. It's what you're willing to fight for. There are grievance systems you can use and community agencies out there that will help with advocacy issues.

The value that we're able to put into and take out of each and every day is far more important than the number of days we have. So, to use a Latin cliché, *Carpe diem.* Seize the day. Get the most from it that you can.

**José Sousa, 40**

Waiter; works on many committees, including Canadian HIV Trials Network and COCQ-Sida  
Diagnosed with HIV: 1985  
Viral load: 14,000  
CD4 count: 310  
Montreal, Quebec



Quality of life is where *the good things in my life outweigh the negative;* that the benefit of my antiretroviral therapy outweighs the negative side effects. Although I'm currently not on antiretrovirals

because I'm in a structured treatment interruption study, I still take approximately 60 pills a day — *various vitamins and minerals* — which I do for my quality of life.

*I try not to overwork.* If I do, it's usually in my HIV-related work, which contributes to my knowledge. That, in turn, contributes to my health, which in the end leads to a better quality of life. I watch comedy programs on TV almost every day because *laughter contributes a lot to my life.* So does my dog, Porto (named after the Portuguese sweet fortified wine), because the unconditional love I get from him makes me go to bed with a smile on my face.