



# Positively Speaking

## A podcast from Casey House

### Season 1, episode 1 – HIV and long-term survivors

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[theme music]

**Liz Creal:** [0:08]  
[music continues  
in background]

Welcome to *Positively Speaking*, a new podcast that explores the experiences of people living with HIV, the virus that causes AIDS. I'm your host Liz Creal.

*Positively Speaking* is being produced by Casey House, Canada's first and only stand-alone hospital for people with HIV and AIDS. In each episode, you'll hear from a diverse group of people, each will be sharing their own unique journey with HIV and AIDS. Some of these stories are tragic, some are heroic, but I think you'll find that all are compelling.

Our hope is to resonate with people who are living with HIV and AIDS. And equally, we think that the content of these podcasts will be helpful for others who are connected directly or indirectly with HIV and AIDS. This includes family members, friends, lovers and caregivers, and in fact, everyone! So let's get started.

[theme music  
fades out]

The topic for our premiere episode is long-term survivors. That means people have been living with HIV AIDS for more than 25 years. People like Allan. Allan was officially diagnosed with HIV in 1988. At that time, the notion of long-term survival was a foreign concept. Allan remembers those dark days.

**Allan:** [1:18]

Finding out my status did very little other than it labelled me. I went to be tested because I was beginning a third relationship. My previous two partners had died. Four months, another one in five. And no one knew what was going on. No one knew who to believe. And you had all these, even in our own community, groups that decided how they wanted to deal with it. So, in my case, in the early days, my partner didn't want to talk about it.

So, for six years, I didn't talk about it. But when it became me and my body, I wanted to know everything I could, find out everything I could. But you had no one to ask. You had, you did not know where to go. And you were just basically told three things. They believe that stress was the main thing that could make your condition worse. I don't know how they knew that at the time. They knew it was terminal. They felt, they thought it was a death sentence. And I was told to quit my job. Write a will and plan what you want to do for the next year.

**Liz:** [2:58]  
[atmospheric  
background  
music]

Allan's experience is typical of what gay men faced back in the 1980s. Being diagnosed with HIV back then was basically a death sentence. It was the same for Murray. He was diagnosed in 1991. He remembers what it was like to get the news.

**Murray:** [3:14]

Well, I know it was a pretty severe diagnosis to receive, like, there was very little hope. There was very little sort of hope of long term. You know, by the time I was diagnosed, I'd had three friends die, get sick and die within the space of a year and a half, two years. So that was sort of your outlook was like about a two year span and that was the way I looked at it, you had about a two year period between diagnosis and death. And that was like my realistic experience. So that's what I felt that we all had about two years to wrap things up.

**Liz:** [3:52]  
[atmospheric  
music fades out]

Muluba's story is very different from Murray's and Alan's. Muluba is 26 years old and was born with HIV.

**Muluba:** [3:58]

And, even doctors kind of say yes it's something you want to keep private, especially at this young age. Like, at 11 years old, the best friend that you have now, are they really going to be your best friend later on? But it was tough because, you know, I think at 12 or 13, I had my first like, almost sex ed class in a Catholic high school, in a Catholic school, so, but the teachers weren't even that much educated. So, you know, they said, HIV people, women, can't have kids. And, I know my doctor had been telling me since six years old, oh, you're going to have babies. But I'm thinking if I raise my hand and say that's wrong, she'll be like. Oh, how do you know? You must have HIV. So it's all these things and things that I personally don't think that a kid should have to worry about.

But, people won't listen to you and it's just, it's difficult because it's, it's a factor of having to grow up early because you having to keep the secret. You're having to deal with people's arrogance and hold your tongue. Having to not release your feelings all the time. And even though I had my mom and my sister which are great, supports. It was difficult at times when I was having problems taking meds because for them it was easy to take pills. And this is something I have to take for the rest of my life and I want to talk to somebody else. And then when you go to health care providers, and I appreciate everybody that has provided for me, but as a child growing up, you go to the clinic, and I honestly felt like my pediatrician and my mom, were just discussing my health and I was just in the audience. Just watching them and felt like and even when the doctor would say, is that okay Muluba? Okay, my own my mom would be looking at me and I was like, I have to agree. So it didn't really feel like I was conversating with them and really deciding so I had to learn to find my voice and my adulthood with that.

**Liz:** [5:42] As bad as the diagnosis was back then the treatment was not much better. Early HIV drugs were experimental at best. Doctors didn't know exactly what they were dealing with. They basically would try different drug protocols and doses to treat the symptoms. But the side effects of these treatments presented their own challenges. They were brutal.

**Allan:** [6:02]  
[atmospheric background music]  
In my case, I took more side effect pills than the 50 or 60 or 70 pills that I took for HIV. You spent more time healing the side effects from thrush, to chronic diarrhea, to projectile vomiting. There was all pills to take to alleviate that. I got shingles on my tongue. So your life was just consumed every day solving the next problem because in my case, I can only speak for myself, when they said the "D" drugs, I mean D4T and DDI cause minor neuropathy. I have chronic neuropathy now from elbow down in both arms and from knee down in both legs. And that's as we speak my feet are freezing.

**Liz:** [7:08]  
[atmospheric music fades out]  
Jon is a long-term survivor as well who was diagnosed in 1984. He remembers all too well what those early treatments were like.

**Jon:** [7:16]  
The medications were hell back then. They didn't quite know what people were supposed to be taking and they would add medications to counteract the medications so you're not so sick. But, they made a lot of people more sick. Now, thank goodness today we have it a lot easier. Medications-wise, they work with your body and with your physical being. Anyway, so yeah there are so many horror stories of different people with different types and who are still here and who are not.

**Liz:** [7:59]  
People associate long term survivors with older people. In Toronto, Canada, where Casey House is located, that's usually the case. But as you've heard, Muluba shatters that stereotype. She's only 26. But she's considered a long-term survivor because she was born with HIV. So her perspective is much different. She's dealt with many of the same issues our other guests have dealt with. But she did so at a much younger age.

**Muluba:** [8:23]  
As a child, I was put on some meds that didn't even work and I was almost a test dummy. And, I came as an immigrant in Canada, so it's even hard to get on the drugs. And then it was really hard to adhere to them because I'm an eight year old girl, I don't want to go to sleep over and have to go into the bathroom and take pills and I I honestly felt like these pills were trying to choke my throat. I still feel like they are trying to choke my throat. And then it's like, wait, I have to do this for the rest of my life? There's not even an end date? And that's been a challenge and honestly is still a challenge and it's finding that relationship with meds because I really and still sometimes will look at the medication as, this is something I have to do, as opposed to, this is something that's going to save my life and it's a breeze. And, I honestly, I think that's stuck in my brain because that's something that I've been doing since childhood. And that's definitely been a challenge.

- Liz:** [9:13] Another key issue for long-term survivors, one they've had to deal with for decades is a dramatic sense of loss. In the 1980s and early 90s, HIV AIDS devastated the gay community in Toronto and around the world. Most long-term survivors have lost many, many people over the years. They've lost family members, they've lost colleagues, friends and lovers.
- Jon:** [9:36]  
[atmospheric background music] Most of my friends from that period of time are gone. And then it was just down, down slide from there, at that point on over the years. And I lost count many years ago. And not to be rude to people but I cannot go to a funeral.
- Muluba:** [9:54] There's going to be similarities that we have, there's similarities I have with young people that have just been diagnosed cuz it's just going through the motions. And there's similarities I have with some people that are long term survivors. Because it's, we've been dealing with this for a long time. We've lost people in our lives. You know, sometimes men will say to me, yeah, I watched all my friends pass away. And don't think I understand that. But I watched my parents pass away from it.
- Rod:** [10:20]  
[atmospheric background music] I have to admit there are periods in my life I'm very, very lonely. Traumatized! You have people dying around you all the time. People you know, there's always the big issue. Am I going to be next? Am I going to get ill? What happens if I get it ill? How am I going to take care of myself? At that point my family didn't know. Friends were not able to assist me because they were all ill. That was really a very, very tough period.
- Liz:** [10:55]  
[atmospheric music fades out] Rod was diagnosed with HIV in 1984, but thinks he contracted HIV a number of years earlier.
- Rod:** [11:02] The difficult part of the losses we were never told, we never experienced these, these losses in our lives. It was certainly not part of our upbringing. Certainly not part of day to day conversation. We expected to live to 70, 80 years of age. Not to lose people in their early 20s into their 30s was a tremendous part of what was happening that was occurring within the community. And parents of course, you're losing your children before their, their demise. But that was a very, very difficult part of the whole process. And yes, there's a lot of guilt that developed. Why are we still alive? You know, why? Why not us? You know, that was one of the big questions. You know, why me?
- Murray:** [11:53] One of the aspects of surviving was the pressure. Like what am I supposed to do with the rest of my life now? Like, you've lost these friends. You know they would have loved to have a chance at it now, where do you go with that? Do you, you know, run a marathon? Do you write a book? Like what significant thing can you do to justify

your existence? So there's that pressure on like, what do I do now? How can I you know, what can I do with this time that I've been given?

**Allan:** [12:27]

[atmospheric background music]

You know, a lot of things in my life, I don't fit into that hole. I don't feel any survivor guilt whatsoever. And I empathize with all the people that have. I'm not religious, but I think that certain things in your life happen for a reason. And I can know now that once I started taking care of myself, eating better, being healthier, maybe it was a heads up to you know, you're not taking care of yourself. And I always knew, I thought I had faith that there would be a cure a solution. But I always felt that inside I had the strength to fight whatever came my way. And when I stopped feeling sorry for myself, after 10 years, I got out of bed and started to do something about it.

**Liz:** [13:41]  
[theme music plays in background]

It's important to know that the people we've been speaking to; John, Allen, Rod, Murray and Muluba, are all alive today because of what happened in 1996. That was the year that HAART, the highly active anti-retroviral therapy was introduced. This multi-drug therapy was the first treatment that actually slowed down the HIV virus and extended lifespans.

**Andre Ceranto:**  
[14:03]

Doctors they usually measure the T cells, which also called CD4, which are the cells in the immune system that they, they checking the blood work to measure how strong the immune system of somebody is. So the higher the number, the stronger the immune system is.

**Liz:** [14:24]  
[theme music fades out]

Andre Ceranto is my colleague at Casey House and the co-host of this podcast series. He's been doing all the excellent behind the scenes interviewing you've been listening to. I asked him to explain what doctors are looking for in the treatment of HIV and AIDS.

**Andre:** [14:37]

And then there's the viral load, which is the count of virus in somebodies blood, that ideally when you're taking medication, they want to know if medication is working well. Then your levels of virus can go all the way to undetectable.

**Liz:** [14:55]

We've heard from our guests what it was like in the early days of the epidemic and how the early treatments were almost as bad or worse than the virus itself. The treatments available today are much more effective with fewer side effects than in the past and much easier to take, sometimes requiring only one pill a day. Although these new treatments can make HIV undetectable, they're not a cure. And being infected with HIV still presents multiple challenges, issues and life changes.

**Andre:** [15:23]

When we talk about medication has progressed a lot and it's much better today. But it's interesting that in the past few years, we've seen an increase of young people getting infected with HIV. Maybe because they lost touch and don't know the history about how serious HIV can be? And also, you know, one thing that I think has not changed much since the beginning of the epidemic is the stigma around HIV. So even

though it might be easier to treat HIV today, with one pill a day for most people, there is still a lot of stigma attached to that and an isolation and people losing jobs, losing friends, losing family, everything.

**Liz:** [16:09]  
[atmospheric  
background  
music]

As Andre mentioned, stigma is still a huge issue today. And I've witnessed firsthand the profoundly negative impact stigma plays on people's lives. At Casey House, I've seen family members reject their loved ones. And I've seen people at end of life have no one there with them. Muluba describes some of her experiences facing stigma.

**Muluba:** [16:29]

Nobody knew that I was HIV positive. So they would just talk about HIV freely and just be arrogant about it. I mean, first of all, just looking at the Internet is a terrible and lovely thing at the same time. So you hear, it's a gay disease, it's an African disease and all this people making fun of people and offending. Not recognizing that people can be born with it. And then, you know, being in classroom, sex ed classrooms and people joke about HIV and getting it from a doorknob. And then, of course, just people having rumours and talking about it and, and then also just hearing that this is something you have to keep a secret that you do feel like eventually, there's something that you did wrong. There's something wrong with you. And then when I did become public with my status at 21, when people find out I'm born with it, "oh, it's okay because you were born with it." "Oh, I feel bad for you." And I'm like, do you recognize that you're disrespecting my parents to me? Because you're telling me I was born with it so I'm innocent. But you're saying my mom and my dad weren't innocent? And, they've passed away now. And so that doesn't, that doesn't make me feel better that you're telling me and I don't want to separate us all that are living with HIV. These are my brothers and sisters. I'm not going to say I'm better than them. Yeah, and that's, that's even really hurtful. And, I don't think people realize that.

**Liz:** [17:48]

As a young person living with HIV, Muluba not only faces stigma externally, but also within her own community.

**Muluba:** [17:55]

Sometimes when I try to go to groups for long term survivors or explain to people. It's like, what are you doing here? Explain yourself? And, that's difficult because you don't want oppression within your own community.

**Liz:** [18:12]  
[atmospheric  
music fades out]

We've heard about the early days of the HIV epidemic, the early treatments and their side effects. The loss long-term survivors have had to bear and the stigma as well. Our panel of long-term survivors had to endure all this and more. Based on all those experiences, we asked them what their advice was for people today.

**Muluba:** [18:31]

Finding your resilience, and finding the choice that you do have. My mom and dad raised me that this has to be a secret. But, at 21 years old, I was a journalist asking other people to open up to me about their life and figured I want to open up about mine. And, I'm giving myself

my best chance and that's the one thing I tell people living with HIV. Give yourself the best chance. If you want to keep it to yourself, keep it to yourself. That's not the whole world's business. If you want to tell selective groups, talk about it in private situations, do that. Do what's best for you. If you want to blast it everywhere. Do that. I'm very extra. I'm very open. I'm very out there. So, I just told the whole world!

**Jon:** [19:12] Have fun, but be careful, is all I can really say. And at this day in time, you know how to be careful. I think just in general, that being HIV over the years has changed. So it used to be the hidden secret. Whereas now, people could say, Hey, this is me.

**Allan:** [19:35] After 30 years, I'm still shocked at the number of people that don't have information. We are lucky, we live in a city that has everything, but you go a one hour out of the city and that person you're talking to will never have heard of the word "undetectable".

**Murray:** [20:01] I just think that people should be very careful. We mentioned earlier that it's, it's not a picnic, whether it's a lot of pills or one pill is still an illness, chronic illness that nobody would invite, and, you know, bring on themselves. So have enough respect for yourself to take care of yourself, and to avoid getting ill.

**Rod:** [20:20] I always say that the main, main message would be play safe. Don't get HIV positive, don't put yourself into a position or a spot where you could seroconvert to HIV positive. Pill, one pill a day, and you're fine is certainly incorrect, it's not the truth. There's a lot of issues with a comorbidity that's other diseases that develop as a result of the HIV virus in your system. You don't want to have neurological disorders, you don't want to have cardiovascular disorders. You don't want to have neuropathy, loss of nerves in your feet. You don't want to have diabetes, is another case another situation that develops, another condition that develops. You know, it's not just one pill, believe me.

**Liz:** [21:18] Important as it is to avoid getting infected Muluba brings up a crucial point about how to view and respect people living with HIV.

**Muluba:** [21:25] For people not living with HIV is continue to protect yourself because it is something that is out there. And, so I think prevention is key. But, also maybe know a little bit about HIV. And, I think that it's such a double edged sword talking about prevention because I don't want to scare people and that you need to protect yourself. That when they meet somebody living with HIV, it's scary and they want to give them an exorcism. Is really respecting them and showing them love because they're not a risk to you.

**Liz:** [21:58] In this episode, we heard from long-term survivors. People who've been living with HIV and AIDS for over 25 years. We've heard about the early days of the epidemic when the gay community in Toronto and other communities were being decimated by HIV and AIDS. We heard about the challenges of the early medications and the loss. And

we also heard about resiliency, hope and courage. I urge you as you think of HIV and people living with this disease, not to bracket them as victims or sufferers, but as the people they are, all of us. If you're someone living with HIV or someone affected by HIV, there are many wonderful organizations and groups in the community who can provide supports and services. Please visit [HIV411.ca](http://HIV411.ca)

**Liz:** [22:44] We'd like to thank our guests today John, Allen, Murray, Rod and Muluba for sharing their stories with us. This episode was produced by the RTA School of Media at Ryerson University. And the music was composed and performed by Nick Nausbaum.

**Liz:** [22:59] Our next episode will be about HIV and relationships. Here's a short clip to give you a taste of what's to come.

**Greg:** [23:05] We've come through a period where safe sex was the only sex I was allowed to have. So, for me, using a condom and other pieces of latex to protect my partner and protect myself became a ritual part of my sexual expression. For me to move beyond that now is very uncomfortable.

**Liz:** [23:27] Remember to subscribe to *Positively Speaking* on iTunes or Spotify or your favorite podcast platform. If you have any comments or questions about this episode, we'd love to hear from you. You can email us at [podcast@caseyhouse.ca](mailto:podcast@caseyhouse.ca).

**Liz:** Thanks for listening.

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