



Positively Speaking

A Podcast by Casey House

Season 1, episode 6 - Living positively with HIV

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[theme music]

Liz Creal [0:05]
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background]

Welcome to *Positively Speaking*, the podcast that explores experiences of people living with HIV, the virus that causes AIDS. I'm your host, Liz Creal, I'm a social worker at Casey House, an HIV specialty hospital in Toronto, Canada. If you've listened to our previous episodes, you'll know that we've discussed a wide range of topics. Some of the stories were hard to hear.

Despite all the medical advances, living with HIV is not as simple as some may think. Many people go through extreme hardships. We see that every day at Casey House. The people we work with do not represent everyone living with HIV, but their story should still resonate with many.

[theme music
fades out]

For our last episode of the season, we wanted to end on an encouraging note. So, we're going to talk about living positively with HIV. You're going to hear from for people living with HIV, three of whom are long-term survivors. Despite multiple adversities all were able to turn their lives around and overcome the many challenges they faced. Let's start with Robert. He's a long-term survivor who was diagnosed with HIV at the beginning of the epidemic. At that time, he was told by his doctor that he didn't have long to live. Robert reflects on his journey with HIV on his life after the diagnosis, and how it impacts him today.

Robert [1:29]

We all as human beings can get sad and get depressed. And if you're HIV positive, a lot of things are taken away from you and the opportunities that are lost that you never get back, life just slips by people slip out of your life, those opportunities slip out of your hand, and your life takes a whole different direction. And, sometimes when you're alone, and you feel I am going to talk about myself, sometimes when I am alone, even till today, I always feel like what if, you know what if this hadn't happened? Where would I be? What would I be doing? Would I be happy? And then I always think about where I'm at. And you know, just the fact that I'm alive. And I have to be thankful for that, and I just go into reflection, and then I'm fine. I'm strong. Again.

Liz [2:20]

Robert has realized that regret is a negative emotion that can weigh you down. But thankfulness can lift you up. It can even inspire you to do more than you would ever have thought possible. That's certainly true for Kenneth. He's a 60-year-old gay man, originally from Hong Kong. He moved to Canada in the mid 70s, and has been living with HIV for 33 years. 13 years ago, Kenneth was diagnosed with AIDS and came to Casey House for end-of-life care. Remarkably, he survived and

left Casey House after two years. Despite losing his sight due to an AIDS related infection, he now lives independently with the assistance of a guide dog. He's also a dynamic and active member of the community.

Kenneth [3:02] I look good physically, I look well. But I still have a lot of health issues, you know, such as my osteoporosis you know, and also my visual impairment that I have to deal with. So something that is not easy not to think about it, right. It's always comes to your mind, how you deal with it. But at the same time, I have to accept it. I want to keep myself going. Every day when I get up in the morning, I want to do something. I have a goal. What I want to do, I want to accomplish something maybe giving back to community and maybe do something good for my own self.

[atmospheric background music]

Liz [3:46] Elliot is a 38-year-old gay man. He's a former professional principal ballet dancer, and was the spouse of a Canadian diplomat for 12 years. He was diagnosed with HIV five years ago. Elliott shares how he came to the realization that getting the support he needed had to start from within.

[atmospheric music fades out]

Eliot [4:05] It wasn't until I was in a group, sort of like training session in a rehab facility that people talked about support, and what support networks were available and thinking, Okay, well, I don't know what that looks like. I don't know what support is. And then I realized, well, it starts with me.

Liz [4:25] Group support helped Elliot changed his entire perspective on his illness and his life. It did the same for Francois. He's a 63-year-old gay man, originally from Quebec. Francoise has been living with HIV for 30 years. He became involved with a number of HIV/AIDS service organizations in Toronto when his first lover died of Casey House. He finds support through his meditation group and healing circle.

Francois [4:52] On Sunday, we used to have a healing circle, which were probably close to 50 people meditating and try to refocus our lives. And that was a very lifesaver for me. And that's where I learned meditation is extremely important in my life. So, my support system, which is very vital for me, not only to live, but sometimes when I think like when I'm will be on my deathbed, I won't be alone.

Liz [5:22] Being able to share experiences and knowledge with someone who's also HIV positive and understands your situation can be very powerful. It can also have a positive impact on others. Kenneth found a community, a sense of belonging, and a place he felt safe to share and learn from others.

Kenneth [5:39] I think HIV brought to my life is the community, it's the community that I never expect that they are so welcoming, they create a safe space for me to participate, and to learn from each other. And always give me a great resource and information about how to seek help. I think this is a gift to the community, and to me as well.

- Liz** [6:10]
[atmospheric background music] Disclosing HIV status isn't easy to do, and as we've heard in previous episodes it can even be risky. When people feel empowered and safe to disclose, it can result in a positive experience, Kenneth talks further about how disclosing his status was empowering and enabled him to find acceptance.
- Kenneth** [6:30]
[atmospheric music fades out] Slowly disclosed my status to people that I trust. For example, when I remember I disclosed my status to not to my family first, to my very close friends, and to my partner, on the same day that I disclosed my status. And I was expecting a little bit more pushback when I disclosed my status, but I was very grateful and very fortunate that they were really understanding. They also open their arms and excepting me that I'm HIV positive, nothing will be changed between our relationship.
- Liz** [7:17]
[upbeat background music] Having a supportive family can make the world of difference. In the episode on HIV and isolation. We heard from people who ended up isolated and lonely when they were estranged from their families. But that's not always the case. Robert describes how his kids are a source of great strength and joy for him.
- Robert** [7:35] Well, now it's my children. I have two little people who rely on me, who love me very much and who I love very much. So, I'll give you a small example. I was woken up on my birthday, which was in June. And they came to me and they sang me happy birthday and kisses, hugs. And I mean, it's so simple, but something people will say, Oh, yeah, so what? But for me, that was like huge. It was like, very powerful. I wouldn't trade that in for anything.
- Liz** [8:06]
[upbeat music fades out] Robert also illustrates the importance of organizations like Casey House that provides support for people living with HIV. He talks about not only receiving support, but the opportunity to contribute.
- Robert** [8:17] It's always good to have external support that you can fall back on. Because sometimes life just gets overbearing for anyone for you know, so to have that Safety Network is extremely important. So, for now, Casey House has been extremely powerful for me, with my caseworker with the with the day program, with connecting with this program talking about myself candidly in my journey. It's all extremely powerful. And it's a network for me, it's there. I know, Casey House is there for me. And I'm there for Casey House too.
- Liz** [8:52] In Toronto, we're fortunate to have many support services for people living with and affected by HIV. Kenneth talks about how significant these have been for him.
- Kenneth** [9:01] I have to say, I get a lot of support from the mainstream AIDS service organization (ASO). When I first get diagnosed, I tend to reach out to the mainstream ASO. There is about three AIDS service organization in Toronto, that really supporting for people living with HIV. So when I reach out to them, they've been very helpful, very supportive.
- Liz** [9:40]
[atmospheric] As we've been hearing, believing in yourself and using one's own experience to help others can be very powerful and very liberating. This was the case for Francois and for Robert.

background
music]

Francois [9:50] I have no time for self pity. This is not helpful at all. It's actually guilt. Also, it's not guilt a one that I feel guilty about. I stand for myself, which basically, it's based on all the experiences I had. And I believe in myself. I believed in what I learn, or learned. And I use that learning experience to help others also.

Robert [10:21] Actually, what really helped me was I went through a six week training program with CATIE, and I became a treatment counselor. So I would voluntarily answer the phone for people who would call in and give them, you know, access to research that I had at my fingertips. So, if someone had a question, and someone was depressed, just to be able to give them resources really quickly, and to guide them in the right field. And if I didn't know the answer, then I'd get someone very quickly, who knew the answer so folks didn't have to wait, they didn't have to think so if they're really depressed or sad about something, we connect them very quickly with the right person with the right service provider.

Liz [11:02] For Kenneth, his pathway to happiness and fulfillment came through sharing his own hard earned wisdom,

Kenneth [11:08] I think my value is basically helping people, right? In a compassionate way. But at the same time, I when I support someone, within my own capacity, you know, some of the peers or some of the, my friends who come to talk to me about certain issues or certain problem, I will listen to it, maybe give some advice or give some resources for them. At the same time, I think it's up to the individual, whether they want to seek help, or they want to take action for themselves. But, many times when I support my peers, some of the peers come to me say, hey, thank you very much Kenneth, which gives me a lot of joy and happiness, that I do something great for that person.

Liz [12:01] Like Kenneth, Robert had been a Casey House client for many years. Also, like Kenneth and many others, Robert transitioned into a service provider role and was able to use his lived experience to support others.

Robert [12:14] I got a true understanding of myself, because first I was a client. And I had a lot of needs. And then I became a service provider, and everything was turned around because clients had needs. So I was kind of able to see both sides. And I could understand how clients' needs couldn't always be met, but also putting myself in their shoes. And, you know, explaining to them properly, it actually helped a lot, because I had that perception to be able to do that.

Liz [12:50] Kenneth speaks about how having a mentor had a positive impact on him, and taught him the importance of balancing the different roles that he carries.

Kenneth [12:58] One of my mentor will be from a mainstream organization, he used to do health promotion. And then he's been working in this field for so

many years. And he teach me the role: how to do a little bit more self care how to be a very holistic well being. And because of him, I think I sort of pace myself that I'm working part time as a health promotion coordinator in an ethno-racial community, AIDS services organization.

Liz [13:37]

Being open to mentors and reaching out to peers allowed Kenneth to accept his HIV status. He's now in a position where he mentors others utilizing his own lived experience.

Kenneth [13:48]

I really think that you have to accept yourself that you're HIV positive first. If you can get over your own status, you sort of, you know, barricade yourself in that little circle and you cannot move forward. So if you can accept yourself that you're HIV positive, and reaching out is also one of the main thing that I do, mostly, when I first found out that in HIV positive. Reaching out to other community to ASO reaching out to your peers. I asked him for advice and learn from them. Don't isolate yourself, don't get cooped up in your own little four walls, you know and feel sad about it. There's many people who went through the same experience like myself, and other can share that experience for you in a positive way.

Liz [14:48]

[atmospheric background music]

Getting an HIV diagnosis is a life transforming event. For many people. It takes time to come to terms with their HIV status, but Elliot was able to confront his new reality and turn it into a positive.

Elliot [15:03]

[atmospheric music fades out]

I think one of the positives of becoming HIV positive is I got informed. Rather than living in this fear of our heritage, I got informed about the facts of HIV. I lived in naivety and I lived in a hole. And many people because of the stigma of our history, live in that place. They are uninformed, and they remain there. And I think that one of the positives that came out of this, I suddenly realized how lucky I am. How incredibly, how incredible our outcomes are now.

Liz [15:43]

It's hard to imagine that anyone living with HIV would consider themselves lucky. But for Elliot, this realization changed his perspective and his life. We hear this a lot at Casey House, how a simple change of perspective can change everything. Take Francois, for example. In the years following his diagnosis with AIDS, Francois dealt with some serious health issues, including a heart attack and pneumonia. But he managed to change these life-threatening health events into something positive.

Francois [16:13]

[atmospheric background music]

I'm so grateful, then I am what I am, the time of my life. I'm 63 years old, my sexual life is gone. And you know what? there is life after sex, let me tell you. There is life because there's not enough for 24 hours in a day, for me. I really have to unplug every night and go to bed is there's it's wonderful what I'm going through. Because if I would have not been HIV, my experience would have been different. I believe, then each condition, physical condition or disease, then a person going through receive a lot of power to deal with it. Some of us are capable of seeing the signs, others cannot. And I don't know what's the reason behind it. And I'm not saying then because I'm very grateful to be, to be HIV, that's not what I'm saying, what I'm saying is the experience of

going through it is positive. All the change in occur in my life, the only decision I made was because I was HIV.

Liz [17:32]
[atmospheric
music fades out]

Taking the positive from a negative experience is a powerful tool for people living with HIV. But it's easier said than done. Everyone finds their own way to do it. For Robert, it meant educating himself on his illness. Knowing and understanding how HIV was affecting his body helped him feel more in control of his own health.

Robert [17:53]

Well, for me, what really worked well was understanding HIV, and taking away the fear of being HIV positive by actually stripping it down to its bare bones and understanding it very scientifically. And my mind does work very scientifically. So I could actually go down, do CD4 CD8 ratios. So even when I got my own blood work, I would able I would drive my doctor crazy. I'd asked him 20 questions. And he'd go like, 'Whoa, are you going to become a doctor? Or what's going on here?' And I'd say, 'No, no, I just need to empower myself about my own health.'

Liz [18:29]
[atmospheric
background
music]

Because HIV has no cure, and is considered an episodic disability, people living with HIV experience intermittent challenges. Robert reflects on how yoga, meditation and reflection helped him overcome some of the inevitable challenges of living with HIV.

Robert [18:46]

Anger, denial, guilt, and all that kind of stuff. While those feelings come and go, they're still there. But I'm quite able to deal with them now, I know how to deal with them and what to do. I do a lot of meditation, I do a lot of yoga, I do a lot of reflection. So, I'm able to curb them and handle I'm quite well known.

Liz [19:07]

Learning to cope with all the emotions associated with HIV is important to living positively, especially the emotions of others. Just ask Elliott, he managed to maintain a positive attitude despite being judged by others. And he's grateful for his ability to overcome the challenges he's faced.

Eliot [19:25]
[atmospheric
music fades out]

I'm ultimately very grateful. And I think that gratitude is now the lens through which I participate in life. I can fixate on how I've fallen from grace and people's opinions on who I was and who I am now. And I am not oppressed by those judgments or those calls or those fears of other people. I am living for me. I am grateful for everything that's gone before. I'm grateful for everyone that has offered me hope, everyone that has given me difficulty. Everyone that's given me shit, because overcoming that has taught me who I am, how capable I am, how much I have to do to outrun those obstacles, and to ultimately build myself to be able to, to succeed.

Liz [20:17]

For Kenneth disclosing his HIV status publicly has given him strength.

Kenneth [20:22]

On a personal level, I would say when I disclose my status publicly, it actually helped my own self, it really feed my soul. Because sometime I find way to grieve, or maybe I have some anger within myself about my HIV status. By speaking about it, actually I feel that it's a comfort within me.

- Liz** [20:48] For Elliot, it was important for him to ask for help and creating a vision of where he wants to be. All while being prepared to move there slowly, step by step.
- Eliot** [20:56] I had the skills necessary to ask for help. I mean, it's a process, you can't jump into any step. You can't go from A to Z, you have to have your B, part one, B, part two. It's incremental, it's slow, and you don't know where you're going. You're just at sea, but I knew that I had light ahead, I knew that I had a destination in mind. And that was happiness, like true happiness again.
- Liz** [21:23]
[upbeat background music]
- Robert** [21:35] I've been through the highs and lows and life for anyone is highs and lows. It's never a high or just a low. Otherwise you never even appreciate it, right? But when someone is living with HIV, and if I'm sending a message out to someone, is to respect yourself. Love yourself deeply. To treat your body, like with respect. Be careful what you put in it. Because what you give your body is what you're going to get from your body. Try not to self destruct, try not to escape, try and be with the moment and try and come to terms with who you are, and where you're going. And be real about it to yourself and to others.
- Kenneth** [22:23] Have a little bit more compassion and understanding towards people living with HIV. And to the people who are living with HIV. I think it's up to you to support other people who are living with HIV. Providing a little bit more compassion, a little bit more empathy towards each other, and create a very safe and welcoming space for the community. In terms of the community, I think the community have to come together, voicing out exactly what we need in the present moment. Maybe finding treatment, finding cure, or maybe having a voice about 'we are just a normal human being, but the only differences are we are HIV positive'. But we could still living in very long live healthily, up to the 70s and 80s.
- Francois** [23:23] We can't give up. It's not over, the AIDS crisis is still here. And it just has changed face. We no longer dying from HIV and AIDS, from what some people say. But we do die from the cause of the medication, and living long-term with HIV/AIDS. So we have to be careful of thinking it's all over because it's not over until it is over. So if there's something then that would say to people would be look at yourself, and try to find who you really are and what you can bring to this planet. And God knows we need some healers with what's going on on the planet, it's just very difficult to look at sometimes, and just enjoy the ride.
- Eliot** [24:20]
[upbeat music fades out]
- I still hope, but I can only help them understand by leading my best life and living amongst the people that do accept. And then take every opportunity to forgive, to teach and to lead. There's very few people that expect you to succeed. And as I said, being a social pariah is a gift. Because we no expectations comes absolutely no pressure. So even though small minds can take you out of the game, you have big ideas

and small minds can take you out. Dream big anyway because everyone's watching, but no one expects you to succeed. So succeed anyway.

Liz [25:06]
[theme music]

In this episode, we've heard about the importance of support for people living with HIV. Equally, we've heard about the importance of being able to give back to others and about the power of knowledge. And we've also heard individual stories of overcoming challenges and stories of self acceptance. We'd like to thank our guests, Robert Kenneth, Francois and Elliot for sharing their stories. And a special thank you to all our guests throughout the season who participated in this podcast. We'd also like to thank our podcast advisory group, and all the people who work tirelessly behind the scenes. Garnett and Tony, we couldn't have done this without you. And of course, a big shout out to you, our listeners. We're overwhelmed with the support and feedback we've received. And thank you to Casey House for providing us with this opportunity.

This episode was produced by the RTA School of Media at Ryerson University. It was written and produced by Andre Ceranto, Amanda Crawford and me Liz Creal, the music was composed and performed by Nick Nussbaum. Remember to subscribe to *Positively Speaking* on 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. You can also visit our website at caseyhouse.com for a transcript of this episode, a glossary of terms and occasional bonus material.

We're excited to announce that we're hard at work on season two. Our format for this season will be slightly different based on feedback we've received. One episode will focus entirely on the experiences of Eric, his remarkable life and his decision and journey to a medically assisted death. Here's a short clip from that episode.

Eric [26:48]

As I understood that I was losing my ability to move around and my legs got weaker and weaker, that sort of became my line, you know, my sort of, once I need to be hoisted everywhere. Once I have to have a team of people to eke out a daily existence that would no longer be what I wanted. And I'm headed very quickly in that direction, things are in fact accelerating. So I've decided or I know when I made the definitive decision I spoken to the great people here Casey House to just to think things through and I've decided that I've totally lost my independence now. And for me, it's time to move on.

Liz [27:40]

Thanks for listening, and see you next season.