



# Positively Speaking

## A podcast from Casey House

### Season 1, episode 3 - HIV and mental health

**Air Date: January 21, 2020**

[theme music]

**Liz Creal** [0:05]  
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in background]

Welcome to *Positively Speaking*, a 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 standalone hospital for people with HIV/AIDS.

The focus of this episode is HIV and how it impacts mental health. The topic of mental health is often in the news these days, and for good reason. According to the Centre for Addiction and Mental Health, in any given year, one in five people in Canada will experience a mental health problem or illness. And, by age 40, about 50% of the population will have or have had a mental illness.

[theme music  
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As we all know, mental and physical health are very much linked. People with long-term medical conditions such as HIV are much more likely to experience mental health issues. At Casey House, we see the real-life impact of that statistic every day, more than 80% of our clients have a mental health and substance use issue.

In this episode, you'll hear a guest tell you about their own experiences with HIV and mental health, from the shock of diagnosis, to the isolating effects of stigma and discrimination. As well, you'll hear how they've been able to create a positive path forward.

First up is Scott. He's a middle-aged gay man living in downtown Toronto; he was diagnosed with HIV 18 years ago. Since then, he struggled with the impact that HIV has had on his mental health and on a sense of self and on his place in the world.

**Scott** [1:35]

After the diagnosis, that's when I started to experience the loss and the extreme trauma and the realization that my future would be very different than what I had planned. And, that created a lot of huge mental health problems, they, my mental health problems that were before I was able to maintain them and maintain the illusion of being fine, I couldn't do it anymore. I just broke down. And, I needed help. So that HIV was what sort of pushed my mental health to over the edge.

- Liz [2:20]** While HIV is now considered to be a chronic treatable illness, the impact of the diagnosis still dramatically changes many aspects of one's life. Scott explains what getting the HIV diagnosis was like for him.
- Scott [2:32]** When I was diagnosed 18 or 19 years ago, you know, the doc, my doctor at the time said, "You know, it's not a death sentence anymore". But in my mind, it basically was, it was a death sentence of my life. Getting back to that, of just your life just changes and implodes.
- Liz [2:58]** Scott's story is a perfect example of impact that HIV has on someone's psyche. HIV may no longer be a death sentence physically, but emotionally, it can take its toll. That certainly was the case for our next guest Rod, as an Indigenous man and another long-term HIV survivor. He talks about the impact of depression and changes to his memory.
- Rod [3:19]** How it affected my life, I guess, I'd have to say I really had to look at my spiritual aspect of my life, because with mental health you know, if your illness is not going the way you want it to go, and you're always having complications, you know, people, myself included, you know, deal with depression. So, depression is a big issue around mental health and how you how do you deal with it? And for me, I'm seeing a traditional helper once a week just to talk about my week and my challenges that I face, like, like every day. I deal with neuropathy, and I, you know, I don't complain about it, but it's there, you know, and right now, it's the HIV or the meds are affecting my, my memory. So, you know, there's a lot of things that people, including myself, I deal with every day.
- Liz [4:33]** Many women have been diagnosed with HIV and their stories are just as relevant as others. And, just as heartbreaking. Take Debbie for example. Debbie is a long-term survivor, a mother and a grandmother who struggled with mental health and substance use issues along with her HIV for many years. She describes how the impact of the diagnosis and the resulting stigma and discrimination not only affected her but also her young daughter.
- Debbie [4:57]**  
[atmospheric background music] I tested positive originally in 1985. I was living in a small town at that point, and really had no support. There was not, there wasn't information, there was nothing really, my daughter was five years old, I just come back from New York with reconciliation with my husband, all that stuff. And so my ex husband used my positive diagnosis to try to get custody of our daughter, which in turn led to the school that she was going to school at, so they had her suspended from school, she was forced to be tested for HIV, and still no supports nowhere to

turn, you just don't know what to do. I'm thinking we're gonna get stoned, or something, you know, it was scary days, back then. It affected me in a lot of really negative ways. I started to drink, I did drugs, I abandoned my daughter at some point. And, it just wasn't a good situation. I just buried myself in just trying not to think about it.

**Liz** [6:01]

When Debbie refers to burying herself, she's speaking metaphorically, many HIV survivors talk about burying their feelings or trying to avoid the reality of their situation, often through the use of alcohol or drugs. But for others, like our next guest, Steve, it's no metaphor. He was diagnosed with HIV when he was very young. And, living in a small rural community on the east coast of Canada. Steve describes the devastating impact of his HIV diagnosis, and how it led him to try to take his own life.

**Steve** [6:32]

I tried to commit suicide and sat myself, got on top of a bridge and I was ready to jump off. Had a police officer save my life that night. Having HIV, you don't feel like going out and you're just finding out and you don't want people talking. And you feel that stigma and discrimination right away because some people may have heard or, you know, you might hear or get a message online or something saying, "Oh, are you alright?" And then you're like, Oh, my God, I gotta get rid of my social media, because I don't want people talking about it. So, I kind of closed myself down for the first year.

**Liz** [7:10]  
[atmospheric  
music fades out]

For many people, an HIV diagnosis can be a tipping point, forcing them to deal with the underlying mental health issues that have been suppressed and unresolved. That was the case for Scott.

**Scott** [7:21]

Well, I've always had issues with mental health from the time I was quite young, with depression and anxiety and things, and but I learned to sort of deal with it. And, I came from an era where you didn't really talk about those things, and you put your traumas in your back pocket and just kept on moving forward. So, it wasn't a huge issue for me, until I got sick. And, then the mental health issues really exacerbated.

**Liz** [8:01]  
[atmospheric  
background  
music]

Loss, as our clients of Casey House tell us every day is a huge issue for anyone living with HIV. And, it takes many forms. Sometimes that loss is a physical one, when someone we cared for deeply passes away. At other times, it can be an emotional loss, like when a relationship ends. Both can be devastating and hard for even the strongest of us to deal with. But, it's even harder when you're facing challenges with your mental health. Rob and Scott have both suffered traumatic losses in their lives, they've lost friends, lost social networks, and lost the sense of their life trajectory.

**Rod [8:36]** Back, back in the day when I tested HIV positive. I made the mistake, I don't know if it's a mistake, because I had mentioned it to one of my cousins, and she went and told somebody else and somebody else told somebody else. So, it went like wildfire through the community. And when I did go home, you know, people were nice to me upfront, but I found out later that threw their dishes away, and their silverware and stuff like that. And you know, that really hurt, but at the same time, you know, it was a learning experience and you know, know who I could trust, you know, and but, you know. And so I kind of threw myself into that after where were I made a point to educate my people, you know, I didn't care if I got blacklisted or what, but I did.

**Scott [9:45]**  
[atmospheric music fades out] Well, the HIV, what happens and usually people experience this after the diagnosis, for me it came later once I got sick, but it's a loss and it's trauma. I mean loss in a sense of losing your life. Basically, you lose your friends, your social life, your career, and in a big extent your future, because we all have plans for where we want to be in the future. And, those are annihilated. So, your whole life blows up. And, you have to regroup, and start, start all over with whatever time you have left.

**Liz [10:33]**  
[atmospheric background music] The stigma associated with being HIV positive is still very much reality for many people. They often experience prejudice and isolation. They feel marginalized and devalued. All of which can adversely affect one's mental health and substance use issues. For Debbie and Scott, the damaging result of internalizing the stigmas had a profound impact on their lives.

**Debbie [10:53]** The stigma is of, is, makes you feel so dehumanized and so belittled, and you just put it into all these categories. And I don't feel like if it wasn't for HIV, I never would have done the drugs that I did, I never want to drink like I did, I never would have done those things. So it all sort of came with it, there was a lot more, I developed Hep C. Lots of crazy things as a result.

**Scott [11:24]**  
[atmospheric music fades out] I think that the stigma part of it is kind of like living with a secret. Because you don't know who to tell. You don't know who to trust, because there is a stigma attached to it. So, you kind of live in your own little secret world, you know, maybe you have some one or two close friends you can confide in, but you live in the shadows a bit. And that, to me was the biggest stigma of all. So, there's a lot of ignorance out there still, which creates that stigma. And then there's a lot of mean people who will just turn it, use it against you.

**Liz [12:13]** As we've heard, experiencing stigma is still very much a reality for many people living with HIV. And, the stigma can adversely affect someone's mental health. To make matters worse, there's a shortage of accessible and affordable mental health services

that specialize in people with HIV. Scott remembers his struggles to find the mental health support he needed.

**Scott** [12:35]

Well, I had been asking my GP for many years about getting psychiatric help, and there just wasn't any really available. There's just so large shortage of mental health practitioners, and therapy, there is a lot of psychologists and therapists out there, but they charge \$200 an hour. So, that's not an option, really. So, it took about six years to find some good mental health help. I think the biggest barrier is the fact that there are not enough psychiatric clinics offering help to people. In fact, I just was, saw my therapist and he actually was telling me that there's like hardly any clinics like the one that I go to where people can access the health that they need the health help they need.

**Liz** [13:38]  
[atmospheric background music]

So what happens when you're living with HIV, have mental health issues as a result and can't find or can't afford the services you need to cope with all this? At Casey House, we see a lot of people who turn to substances as a coping mechanism. Destructive as substances can be, people sometimes find a community in that world. Scott, Debbie and Steve talk about why they self medicate.

**Scott** [14:01]  
[atmospheric music fades out]

My coping strategies were number one, to just ignore trauma and traumatic events, because that's the way I was raised that we don't acknowledge trauma, we just move forward and suck it up. And so, when I look back, I was I wasn't being real with myself. I was adopting characters. I was drinking a lot. I was, I was in denial basically. I was just partying my way through it. So, I mean, that's, that's one way to cope. But, eventually it all falls apart and you need to just start at the beginning.

**Debbie** [14:55]  
[atmospheric background music]

I just have to say back then, like I said, I drank I did drugs. I did a lot of really stupid things. But, you know, you still I still had to look at my daughter, I have to be her mother, and pull it together. So, if I didn't have her, I would have lost it.

**Steve** [15:13]

I guess my biggest one would be substance use, you know, I turned to drugs. Because I had had that feeling inside like, like coming from a small-town Salisbury, like I felt, no one's gonna understand me, people and like, I've known only I've ever known one gay person growing up in high school. So it was just like, you know, I can't really go back home. I can't talk about my lived experience or what I'm going through or my challenges. And, who am I going to talk to about that? Because no one is going to understand what I'm going through. Because I haven't heard of anyone in Salisbury that's ever had HIV or anything like that before. So yeah, I did kind of turn to drugs.

**Liz** [16:01]

Using substances can sometimes be the easiest and most accessible way to deal with the pain and frustration of living with

[atmospheric music fades out] HIV, but there are other ways. For Rod that meant going back to his roots.

**Rod [16:14]** That's when I started seeking spiritual healing and spiritual wellness. I saw a healer from Six Nations, Diane Longboat, and she put into the spiritual and Aboriginal contents towards the medicine wheel. And that stuff made a lot of sense, you know, but it did take time for me to, to get past that depression, you know. Like during... even after I got outta Casey House, you know, when when somebody does something for you every day, and they're looking after your every need...

**Liz [17:03]** For Rod, spiritual support was the answer to his mental health issues. For others, the most effective support comes from the connection they get with a peer. That was certainly the case for Debbie. She describes how peer support was helpful for her when she met another mother with HIV.

**Debbie [17:20]** And, I feel a lot better when I talk to a peer it doesn't necessarily have to be a psychiatrist, a psychologist. It helps to maybe do that, you know too, but to have another woman to talk to you that has been through, walked in my shoes, I want to hear from them.

**Liz [17:35]** Of course, for Debbie and Sabini, a 30 year old from Africa who identifies as gender non-binary, support is not solely about formal mental health services. Friends, social networks, and as already mentioned, peers are all essential parts of their support system.

**Debbie [17:50]** I find, though, that there are a lot of gaps in services. For women. Yes, a woman can go anywhere, but it doesn't always feel welcoming. It's not always a woman friendly, if you know what I mean? And so, I think there has to be more places like that.

**Sabini [18:05]** The first ones would just be nice things closer to home, like, it's nice to be able to phone a friend, just to talk about the day. It's, nice to be able to have a respite, you know, at Casey House, for example, or wherever else they offer respite or something like that, you know. Or psychiatrists, you know. There's so many types of supports, you know, for me have come in, in and so many different ways, sometimes in unexpected ways, you know, from strangers. But, when I say supports, you know, I mean, like, having a family doctor, you know, is a big deal. And, a good one, you know, it's just a really big deal there. And, that already takes a lot for me, a lot of the edge off mental health. Just having a family doctor, and having good friends. Having yeah, those types of supports, you know, and also community events, you know, that are getting better and more people are showing up to you know, that makes me feel good. That I feel more ready to go

engage when there's a community that I can actually go out into and enjoy with people. So yeah, that's also a support for me.

**Liz** [19:37]  
[atmospheric  
background  
music]

As we've seen, HIV can take a significant toll on one's mental health. And, the challenges of accessing mental health services specifically for people living with HIV are numerous. But, for some people, overcoming all these challenges can lead to a sense of self empowerment, and can help them redefine their lives.

**Scott** [19:56]

I think it, it's off because my mental health, I have been working on it, and I've had the support that I need, I'm much more able to deal with all those things: the loss and the trauma, and the abandonment and all those things that come with HIV. I've learned how to deal with them and cope with them, without reverting to bad habits or using medications. And, and that's sort of making my mental health better...

**Debbie** [20:34]

I hope that I'm trying to build a community of women again, you know, that are Indigenous and so that there are some cultural things in there, some spiritual stuff, and just hoping to bond and connect with other women. I've started back to work finally, just baby steps. And, we'll see where that takes me. But I feel like I have so much to offer. And, to go the distance I have that energy.

**Sabini** [20:59]

Generally, strategies for depression, really, ultimately, it just boils down to just finding activities to do that make me feel, you know, happy. That's where it ends up. So yeah. That's where it ends up now. Starting somewhere, you know, to be talking to someone.

**Rod** [21:24]  
[atmospheric  
music fades out]

I went back to Marathon, Marathon high school. I did a presentation on HIV/AIDS for our youth in Pic river and Pic Moberg to learn about HIV, because I didn't want anybody else to get it, you know, and go through what I went through.

**Liz** [21:50]  
[theme music  
plays in the  
background]

In this episode, you've heard how HIV diagnosis can impact someone's mental health. You've heard about the loss of place in the world, loss of friends, and the damaging impact of stigma. You've also heard about the risks of self medication, the lack of access to relevant services, and the importance of supports both formal and informal. But, we hope that you've also heard the messages of hope, courage, and resiliency.

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). You can also visit our website at [Caseyhouse.com](http://Caseyhouse.com). For a transcript of this episode, a glossary of terms and occasional bonus material. 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 Nausbaum. Remember to subscribe to *Positively Speaking* on your favorite podcast platform. Our next episode will be about HIV and housing. Here's a short clip to give you a taste of what's to come.

**Xica** [22:58] Looking back and thinking about what would have happened if I wouldn't have found proper housing for me at that particular time. I think I'd be dead. I'd definitely be dead.

**Liz** [23:13] Thanks for listening.