



Positively Speaking

A Podcast from Casey House

Season 1, episode 5 - HIV and Isolation

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[theme music]

Liz Creal [00:05]
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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. In this episode we'll be talking about HIV and isolation.

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There are few medical conditions as stigmatizing as HIV. Tell family and friends that you have diabetes or even cancer and they rally around you. Tell them you're HIV positive, and the response is often quite different. And often, quite negative. We hear this regularly from our clients at Casey House. They tell us how their families, friends and sometimes even lovers abandon them because of their HIV status.

One of these people is Alan, a 51 year old gay man who was diagnosed with HIV in his early 20s.

Allan [00:56]

I come from an era of being gay that, you know, it wasn't, I wasn't accepted when it came out and I came from a Catholic family, so there were a lot of bad messages about it. So, I had a lot of internalized homophobia and you know, that caused a lot of depression. Then the HIV caused its level of depression. Sean passing, loss, you know, the loss of my career as an artist. Loss of my virility from HIV, like my ability to stand out there and feel like I can take care of myself.

Liz [01:32]

Allan is considered a long-term survivor, someone who's been living with HIV/AIDS for more than 25 years. According to author David Fawcett, a social worker, clinical hypnotherapist and someone who is HIV positive, isolation is a significant issue among older people living with HIV. The stigma, shame, physical pain and fear discrimination or violence can push someone living with the virus to withdraw from their social circles, often with devastating health effects.

But age isn't the only reason why people living with HIV feel isolated. For Michael, circumstances conspired to drive him into isolation. He's a young man originally from China who came to Canada as a refugee after his relationship fell apart. Michael recalls the joy of being with his partner.

Michael [02:19] The happiest time of my life is like, like something like you, before you met him, you feel like you have never lived your life and you have never laughed. Until you lived with him and then here you love him. I cannot tell how much I love this man and I believe [at] that time he loved me also. And in January 10th we decided to get married. We don't want waiting for too long to end up the suffering.

Liz [02:54] Michael's life changed completely when they decided to get tested for HIV before the wedding.

Michael [03:00] And at the same day, I suggest we went for an HIV test. And the result come out. He was negative and I was positive. HIV is a new thing to me, before, before myself get affected by HIV I really, like, refused to know anything about this. And after I get affected by HIV and my ex-boyfriend, he abandoned me. And we were supposed to get married. So that time struck me hard, and I didn't know what to do. And also I completely cutting out from all social activity from people. That is the most depressing time of my life.

Liz [03:48]
[atmospheric background music]

Michael's experience of abandonment by partners at the time of diagnosis is not unfamiliar, but it's not always one sided.

The diagnosis can often lead to self-imposed isolation. That was certainly the case for Michael. He acknowledges that he pushed his soon-to-be husband away because he was afraid of passing on the virus.

Michael [04:14] I know at the beginning he was trying very hard to accept me. He even trying to encourage me and he said that he will never leave me, love me forever, no matter what. I know he was trying. And I also was trying hard to, how do you say, at the beginning I tried to push him way. Because I think about I'm HIV positive, I don't want to affect his life.

Liz [04:39]
[atmospheric music fades out]

Michael saw his relationship ruined when he was diagnosed with HIV. This was before he knew about U=U and PREP. U=U means undetectable equals untransmittable. In other words, you can't pass the virus to others if you're taking HIV medications consistently and your viral load is undetectable in blood tests. PREP is pre-exposure prophylaxis, a once a day HIV medication regime which prevents someone from getting infected with a virus. Knowing this might have changed Michael's perspective, and possibly could have saved his relationship.

Michael [05:13] That time we didn't know much about HIV, if you know, U=U could possibly another story. But that time we didn't know. I think about, I mean, if you get affected by HIV, that's something that didn't give you a choice. The worst thing you can think about is like you could possibly pass this virus to the one you love. And I refused that to happen.

- Liz** [05:37] Pushing significant others away is very common for people living with HIV when they're first diagnosed. For some, coming to grips with the diagnosis can have a disastrous impact on their lives. Take Scott for example. He's a middle aged gay man living in downtown Toronto. Scott was diagnosed with HIV 18 years ago. Since then he's struggled with the impact that HIV's had on his mental health. He describes how he wasn't ready to deal with his HIV status, and how this led him on a path to isolation.
- Scott** [06:07] For the last 10 years, I've been completely isolating myself. Just because of that whole, not knowing how I fit in and where I fit in and who I could trust and plus, as they say, your friends, most of them abandon you. And it's just sort of, you're left in a void and trying to figure out how to, you know, find your place in the world is tricky.
- Liz** [06:43] As Scott mentioned, fear of disclosure and fear of people's reaction often lead to self-imposed isolation. It's perceived as a form of self-protection. But it can lead down a much darker path.
- Scott** [06:55] It is self-protection, but at the end of the day, it's self-destruction. Because it tends to morph into agoraphobia, and it perpetuates people. The isolation perpetuates itself, because you cut yourself off from people. And then like I say, you end up in this vacuum, with nothing.
- Liz** [07:19] Finding emotional currency, the energy needed to communicate with others and get things done is something Alan battles every day.
- Allan** [07:27] I manage it every day, like every day I get up and I kind of figure how much what they call emotional currency, I have to get things done that day. And you know, I have to put some things on the back burner to get other things done. Like coming out to Casey House for lunch. It's trying for me to leave my apartment and come up here. So sometimes I have to make a contract with myself that I don't have to do this or that to go and make my way up here. You know, because I don't have enough emotional currency for all the things I want to do in a day, or need to do in a day.
- Liz** [08:00] Alan considers himself broken because he's battled both depression and agoraphobia most of his life. Agoraphobia is an anxiety disorder that leads people to avoid situations that induce intense fear and panic. Alan describes how hard it is for him to leave his apartment, and how important it is to have support from others.
- Allan** [08:21]
[atmospheric background music] The agoraphobia it's, it really wants me to stay in my apartment. Like I plan, it's hard not to like, like I try to plan so that I can do my shopping and have like a few days where I don't have to leave. But I have a friend who tries to help me get out and tries to find things we can do together. He comes up here to Casey House for lunch and he, right now he's currently walking me up because he knows that I'm having trouble getting out and coming up here again. So agoraphobia, like

going into the shop, the food, Loblaws. That's difficult. I sweat profusely and just want to get through and out. So I kind of, I guess the tactic is I make sure I know exactly what I want. And I go and pick those objects up and... But the downfall with that is I kind of pick the same objects all the time like. So my diet is always the same.

Liz [09:23] When we're isolated, sometimes we ruminate on what we feel we're missing.

Allan [09:28]
[atmospheric music fades out] One of my best friends, has got a beautiful family like what I call a Walton's family. You know, for the young people, that's a TV show from a long time ago, about a happy family. But yeah, she has this great family that communicates and you know, even when they have problems, they like, they'll go, they go to family therapy and they work them out.

Liz [09:49] Alan goes on to describe another dimension of his feelings of missing out.

Allan [09:54] Sometimes too, it's hard, especially in the summer to go outside and like see what I'm missing. And then it feels like it kind of hurts, because I realized that there's good weather out there and that there's another life I could be having. Instead of, you know, isolated playing video games and watching movies and what not.

Liz [10:17]
[atmospheric background music] As you've heard, self isolation by people living with HIV takes many forms. For Tim, a 63 year old gay man, originally from Hong Kong, it's meant distancing himself from the friends and family he left behind. Tim was diagnosed with HIV in his 50s. Since then, he's been afraid of both disclosing and not disclosing his HIV status. He fears the possible negative consequences of not disclosing and then people finding out.

Tim [10:46]
[atmospheric music fades out] I have an issue. I have a few friend who live in a country, like in Hong Kong. And they always ask me to go back and visit them. I always say oh, I don't have time. It actually, I want to visit them, the problem that I feel I don't want to go back because I will stay at their place. And for me if I stay at their place and not telling them that HIV, how about during the time when I stay with them. They find out I'm HIV, and then they have children around. I do not know how to react. And this is what [I] constant worry about.

Liz [11:32] For some people living with HIV, the fear of people's reaction fades away with time.

Scott [11:37] Friends and family. It can be difficult. And so that's why, I mean, for me, that's why I say stigma was all about living in the shadows and living a secret because I wanted, I didn't want people to know. Because I knew that people weren't gonna react well, some of them. So I just kept it in, kept it to myself. And then 13 years ago, when I got very sick,

I had to come clean. And I've since then, have sort of, you know. I'm not ashamed. I'm pretty open about it.

Liz [12:23] Scott was able to overcome the anxiety that often comes with being HIV positive. But not everyone feels this way. Tim describes how fear has permeated his life and still haunts him after many years of living with the virus.

Tim [12:38] Since I got diagnosed about six years ago, and this issue about HIV never came off from my mind. Always put that into the back of my mind. Whenever I face some kind of new person, or people, I always conscience that I'm not saying, I'm HIV person. And I sometimes struggle to ask myself, should I disclose myself? Or should I just keep it that way? Seems like I'm still the same as the person that they found me long ago. This kind of negative mindset still remain in me that I have to deal with it once a while. When I face a situation it just automatically brought it up to my mind again, then I have to be, deal with it accordingly.

[atmospheric background music]

Liz [13:48] Some people from other countries have ended up alone in Canada, while their friends and family stayed back home. Others came from places or cultures where the stigma around HIV is highly pervasive. They felt they had to distance themselves from loved ones rather than tell them about their status, driving them further into isolation. Michael describes the challenges of coming to Canada as a refugee without any supports.

Michael [14:13] [atmospheric music fades out] This HIV thing, just didn't give me any choice make me have nowhere to go and it's like kind of gambling, I come here. I don't know what will happen to me. And I don't know what I should do. I don't know any people, I don't know any organization. I don't have too much friends and also at that time I don't have community. And now because HIV thing really you have to, you have to change yourself. And also being HIV and isolation. I mean before, like isolation for me is a problem and it is not that big problem, I can handle it. But when if HIV and isolate, related together, I know that were not doing good for me, and that do, you know like a very, very bad effect on me.

Liz [15:06] In addition to physical and emotional isolation, a lot of people living with HIV initially isolate themselves sexually as well. Seeking partners and disclosing their status when HIV positive is not an easy task. Some long-term survivors report totally avoiding any sexual contact from the time of their diagnoses. It's difficult to anticipate the reaction. This is something that worries Tim. He talks about how his status interferes with him seeking sexual partners.

Tim [15:35] Like, you're not as open as before. If you want to go out to have sex, you worry people ask you, "Are you positive?" Even though the medication say that, you'd have to tell them, but sometimes you feel like if I said no, does that mean I'm lying? If I say yes, but I'm how you call those, "Yes, I'm HIV, but I'm undetectable", does that mean

anything to that person, right? If they're not really educated in that way. I really, in a way, stop me from moving forward to have sex or looking for something, some kind of adventure. Always back of my mind, because I don't want to get into this kind of problem.

Liz [16:31]
[atmospheric
background
music]

Long before Allan was diagnosed with HIV, his childhood and family life were fractured. He spent much of his childhood in care. Stability came to him in his adult life when he found his partner of 17 years. But tragically, this stability was cut short when his partner died prematurely five years ago.

Allan [16:50]

You know, I had a very difficult life. I was in group homes most of my life. My father had nothing to do with my life and had a lot of trials and tribulations and I thought, you know, when I met Sean that maybe the universe was giving me something beautiful. And it did for 17 years, but then it kicked me in the nethers.

Liz [17:15]
[atmospheric
music fades out]

Some people living with HIV feel they don't have someone they can talk to. Someone who will understand and have compassion, because HIV is usually packed with judgement. Just ask Allan, his relationship with his family remains challenging, and he can't look there for support

Allan [17:34]

I guess I get a little bit of like stigma from my family, some members of my family, my mother doesn't really get the depression and the weight of it. She just, her idea is that I should just buck up and do what I'm supposed to do. You know, my family's a bit broken, their communication isn't the best and, you know, so they're not, they're not something to rely on.

Liz [17:59]

When relationships end, friendships and loyalties can become a big issue. Allan describes the impact on him when a previous relationship ended and his circle of friends diminished.

Allan [18:11]

I feel isolated most of the time. Even with this group of friends it's now like most of my friends are straight. I don't have a lot of gay friends, maybe a couple. I lost them all to one of my divorces early on, one of my early relationships. He got all the friends. Well, I made a bunch of new ones, but they are all straight. And as we got older, they started having families and, you know, obligations started coming up. So the time that we can spend together is more limited now. So, but I definitely, I guess I block it out when I'm at home, I just lose myself in fiction or lose myself in a video game and try not to focus on the fact that I'm completely alone.

Liz [18:59]
[atmospheric
background
music]

In an earlier episode we explored mental health and HIV. Our guests spoke of some of the strategies they use to cope with issues such as depression. One strategy we didn't explore was the importance of pets. Pets are the only company some people have. For many, pets are their family. Allan describes how his cat is the reason he's still alive.

Allan [19:20] You know, every couple of years, I end up with a really, you know, end up maybe in the hospital like with, you know, suicidal feelings or you know. Especially since my husband passed, I've been, you know. When he passed, I kind of made a pact with myself. We had four cats together. And I knew I had a responsibility to take care of those cats and I made a pact with myself that I would stay alive as long as they were around. But when my last cat passes, which he hasn't yet, that I would stop my HIV cocktail and let things take its toll. So, I deal with that with my therapist all the time, but it's always a sort of safety plan in the back of my mind, you know? So.

[atmospheric music fades out]

Liz [20:07] Pets aren't the only answer to isolation. Tim found a solution to his fear of disclosure by finding a community of peers.

Tim [20:15] When come to friend, since I get diagnosed, my new group of friends, mostly they're HIV, and this barrier for me when I deal with them, hang out with them. I don't have to be constantly thinking about it. Because we are kind of equal.

Liz [20:39] And despite all the adversity in Allan's life, he's managed to find a group of friends with common interests.

Allan [20:46] I have a group of friends, I play Dungeons and Dragons with regularly. I play board games with them regularly we go to movies and do barbecues and what not. They're really good spiritual people, I'm very lucky and happy to know them.

Liz [21:06] Finding the right support allowed Michael to find a way forward.

Michael [21:10] Right now it's much better, it's much better for me, and right now it's like I will never think about suicide again. Especially now my viral load is undetectable. Before you know you get HIV affected and you think about you don't have too much time. You think, still think about that kind of stigma. You're ruined and you know, like everywhere, on your body we are decay and you are die in kind of shame. So, and also you think about, you don't know how to face it with your family and also think especially, thinking about my ex-boyfriend, I mean, how he left me at that time. Like that, that was a difficult time but after that, since I come to Canada, I, since I found some help. I found the light it I mean that thought is no longer with me anymore. And I know in future I can be better and better. I think I come here in complete darkness. And at the same time I trying to help myself trying to light a candle for myself. And then I found slowly and slowly I found more and more people or organization, the lighting the candle all my way until I can see the light and the I can see my way and keeping moving forward.

Liz [22:43] Our guests today have all suffered isolation and loneliness as a result of their HIV status. Some of it was self-imposed, some was imposed on them by others. But they've all come through that isolation and found some peace within themselves. So we asked each of them what

[atmospheric background music]

message they'd like to give to anyone who's currently feeling alone due to being HIV positive. Here's what they had to say.

Tim [23:07] Find a person that know you deep enough that you can discuss with them.

Scott [23:15] Because my mental health, I've 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.

Allan [23:34] So stay connected, if you are connected, and try to keep those connections because they, they get harder and harder to rebuild the older you get. If you're still young enough and you haven't quit your job or you're thinking about leaving your work because of, to go on disability, don't do it. Going on disability was probably one of the worst things I did. Or quitting my job. I should have, I could have been on disability and at least kept working. But being outside the work market now I feel very disconnected from the world. And now I'm so far removed from it I don't know how to approach it anymore.

Michael [24:14] In future, if I could have the chance to meet my right person. If he only, if I can, surely I won't push him away. If one day I start to, looking for my relationship. I don't want to lie. I mean, even when the law says like you are undetectable, you don't need disclose yourself. But for me, I just want to keep you frankly, I am HIV positive. If you want to stay away from me, just stay away from me at the beginning.

[atmospheric music fades out]

Liz [24:53] Loneliness and isolation are increasingly being recognized nationally as major health issues. In this episode, we've extended how they manifest themselves in the HIV community. In doing so, we hope this podcast will help people reflect on how they can help people living with HIV feel less alone and more connected. If you're someone living with or affected by HIV, there are many wonderful organizations and groups in the community who can provide supports and services. Please visit HIV411.ca.

[theme music]

We'd like to thank our guests Michael, Allan, Scott and Tim for sharing their stories. 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. 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 performed by Nick Nausbaum. Remember to subscribe to *Positively Speaking* on your favourite podcast platform.

Our final episode of this season will be about Living Positively with HIV. Here's a clip from that episode to give you a taste of what's to come.

Robert [26:15]

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 to 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 [27:06]

Thanks for listening.