



Positively Speaking

A Podcast from Casey House

Season 1, episode 2 - HIV and relationships

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[theme music]

Liz Creal [0:09]
[music continues to in 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.

When we first started work on this podcast, we polled our clients to find out what aspects of living with HIV they thought were most important to share. One that came through loud and clear was relationships and HIV. Clients said that we have to talk about how HIV impacts relationships. So, that's what we're going to do in this episode. You're going to hear four people describe how living with HIV has impacted their relationships. For some it's strengthened them. For others, it's forced them to examine their own needs and values and what's important to them.

Liz [0:58]
[atmospheric background music]

One consistent concern for people living with HIV is negotiating intimate sexual relationships. Disclosure is a huge issue. Also, we can't talk about HIV and relationships without touching on pre-exposure prophylaxis or PrEP, a drug to prevent transmission of HIV. Or, without talking about the evidence that if the viral load is undetectable, then the virus is untransmittable. Otherwise known as U=U. First up is Andre. He's my colleague and co-host of this podcast. He's going to start things off by talking about how the realities of PrEP and U=U have changed perceptions about HIV transmission.

[atmospheric music fades out]

Andre Ceranto
[1:33]

Now, I think we live in a very interesting era right now because not only the pre-exposure prophylaxis, but also treatment as prevention or undetectable viral load equals untransmittable. Where people that are living with HIV and are taking consistently their treatment and have their viral load undetectable, cannot transmit HIV to others as well. And, it has been proven that if it's not more safer than the condoms it's very similar. So I think it's a very interesting times for us. And I really hope that those, you know, prevention tools there, that are flourishing, will provide more opportunities for people to talk about HIV or even other sexual transmitted infections in their relationship.

Liz [2:32]

As Andre mentioned, these prevention tools have allowed people to have relationships and sexual interactions with people living with HIV without the fear of getting infected. They provide an

extra safety net and peace of mind for both HIV positive and HIV negative people. Greg is a long-term survivor. He reflects on the different realities of having a partner back when the HIV epidemic emerged as compared to today.

Greg [2:55]

My experience is a little more extensive because of the history that I carry and how soon I was infected in this epidemic. So, today is a little different than it was in the past and I think serosorting has become a little more, uh less talked about because of preventive treatments that are now on the market. So, there are a lot of people in the community that will use the pre - exposure prophylaxis, the drugs that will prevent them from getting HIV. And so, I think there's, you know, the shine on serosorting is kind of waffling a bit, I think right now. However, I do think there's a leftover problem that, maybe not a problem, but something that we need to take forward and understand better. And that is, 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. I think that's good to know when we're dealing in the community because you can often at times feel as if people now feel more liberated about getting rid of the condom because they can protect themselves against HIV with drugs. And, I'd like to understand a little better what their experience is? But, I'd also like them to understand that there are some of us who are still more comfortable using safe sex methods.

Liz [4:40]

There are many people living with HIV who are in healthy serodiscordant relationships because their partners were well informed and educated about HIV. Serodiscordant relationships, also called magnetic couples, are when the partners have different HIV status. One is HIV positive and one HIV negative. Serosorting is when a person looks for a sex partner who has the same HIV status. Like Greg, Jean is also a long-term survivor. She's a 55 year old trans woman living in Toronto. And she remembers that in the early days of the epidemic, the burden of educating people about HIV rested primarily on the person living with the disease.

Jean [5:17]

In 1991, you had to discuss it, more information. I had to learn the information. And, then when people ask me about HIV I gave them the information I had. So, it's difficult, we make a couple of friends. I had friends that were very happy, not happy, but glad that I told them. Happy and then maybe one or two persons who I know that wasn't educated, that needed to be educated. Like you can't get HIV from kissing, drinking from a glass, from a spoon, stuff like that.

- Liz [6:04]** As Greg and Jean have indicated, people with HIV carry a number of burdens. They need to disclose their disease and they need to educate people about it. On top of all that, they often need to support the people they just disclosed to. For Greg, that's one burden too many.
- Greg [6:20]** If you're at all interested in a positive outcome there, then people who don't have that information are going to hopefully benefit if you can share at least something that allows them to relax a little bit with you. But that expectation, I don't think, um, should always lie on the shoulders of people living with HIV. It's one in which we all take responsibility for educating ourselves about any of the diseases that exist in the world today, and how we can be more compassionate with and care for those who we care for and love. So, I would just caution that, you know, if someone does disclose to you that maybe you can take the time to go off and read a little more about HIV and AIDS and you know, current treatments and where we've been and where we've come from and what we know is true, so that misinformation is not further spread.
- [atmospheric background music]
- Liz [7:25]** Disclosure is something that is difficult for almost everyone living with HIV, because you never know how the other person will react or how you're going to be judged. Also, disclosure becomes an essential part of negotiating sex. Phil was diagnosed with HIV when he was only 22 years old. He describes his journey along this road.
- Phil [7:44]** Through self-advocacy and self-education it made me realise that it's more empowering if you use that that knowledge and those skills to help others and also help prevent others from having to walk the same hard road that I found myself walking. So, when I was using crystal, I was able to disclose very easily. But, when I wasn't using is when I met the man I would want to date. I didn't want to date someone who used crystal meth. I didn't want to use crystal meth. It was just medication.
- [atmospheric music fades out]
- Liz [8:21]** As we've heard from Phil, some people use substances in order to give them the courage to disclose their HIV status. When people are disclosing they often feel in control. However for Phil that control was taken out of his hands and the outcome was devastating.
- Phil [08:37]** The very first thing before it impacted my health or anything else for that matter, it devastated and completely altered all my relationships. The first thing that happened was like, I think my friends were affected primarily first. I had tons of friends and a massive circle of friends but only a small handful of friends stuck by me. It was almost like like, at the time it was I was somewhat ignorant of what was going on, but I was very aware at the same time. But like people I would meet, it was, it felt almost like I was
- [atmospheric music]

treated like I had the plague. People stuck like stuck away from approaching me or would very quickly like detach themselves for me when, when I when I met like new people at clubs or at the bars or on Church Street. And, this was largely due to the fact that almost everyone in Toronto knew from the get go that I had HIV. And, it was on a Sunday afternoon when you know the gossip queens were all out and anything you wanted to find out or anything you didn't want to find out, that was the day to find out. And, as I'm crossing the street there, my former best friend and then just a colleague, shouts out "Oh my god, you have AIDS" as I'm crossing the street. And, I stop dumbfounded. And, I looked up and down at everyone sitting down at Timothy's. And I was like, oh dear lord. Like yeah, thanks and now everyone in Toronto knows.

Liz [10:26] Unfortunately, Phil's story is not unique. Many people have been publicly outed in this way. And like Phil, that often leads to loneliness and isolation. Alberto's story goes even further. Alberto is originally from Mexico, and he found out about his HIV status there. And although he found support from his partner when he disclosed his HIV status, he still felt compelled to leave the country and come to Canada because of stigma and discrimination.

Alberto [10:52] I say to my partner, "I am HIV positive". He took the research, put it on the table and say "please don't say anybody, your family and your friend" for the stigma and discrimination. He gave me a very big hug, he told me "nothing change between us everything is going to be the same, I love you".

Liz [11:15] For Phil his experiences with stigma and discrimination weren't much different from Alberto's.

Phil [11:21] I went from being the person that everyone wanted to brush up against on the on the dance floor to I would literally be like, like, dancing on my on my own in the middle of the club, and everyone just stayed away from me.

[atmospheric music fades out]

Liz [11:38] Phil's story represents what we see every day, that HIV is still attached to a lot of stigma and shame. Many living with HIV end up isolated, because people distance themselves once they learn about their HIV status. Others preferred to isolate themselves as a form of self-preservation, because they don't want to disclose to someone they feel might reject them. It's easy for people to jump to conclusions and to judge how and why someone got HIV. But this can lead to stigma and discrimination. HIV is a virus that can be passed on in many different ways and that everyone is potentially vulnerable to contracting. It doesn't take into consideration skin colour, gender, or sexual orientation. And, it doesn't care about religion, level of education, where you came from, how much money you have, or how many lovers you've

had. We've heard about the stigma and discrimination associated with being HIV positive. Greg is a perfect example.

Greg [12:31]

[ambient background music]

I've had two serodiscordant relationships, one of which was 23 years and that person remained uninfected through the entire period. And we had a satisfying sexual relationship. And the relationship I have now which I never thought I would move into, because after the one period of, of living in a serodiscordant relationship, I thought, gee, it'll be so much easier just to live with someone that has HIV, it didn't work out that way. So, I didn't follow my own rule.

Liz [13:14]

[atmospheric music fades out]

Disclosing one's HIV status can be challenging and can have a negative impact on relationships. Phil talks about how the role of disclosing and educating became a healing one in his approach to relationships and sense of self.

Phil [13:26]

I learned how easy it was to disclose and how enlightening it was to me to educate about HIV to others while disclosing. Um, and it almost became a part of who I am. Both, both in my career slash my social and so when I wasn't drunk or high, I very much I became a pure kind of outreach kind of guy.

Liz [13:56]

We've also heard how the process of disclosure can be empowering and how HIV has had a positive impact on self. Jean talks about the choices she made about how to disclose and build a secure circle around her.

Jean [14:08]

[ambient background music]

I've had the best life I can have. People knowing and some people not knowing. But you juggle that, you juggle. And you know, who to tell and not to tell. And then you go and you get more wise and then you go and tell the other ones that don't know, now become your friends and part of the circle.

Liz [14:37]

For Greg, his early experiences of finding pride in his gay identity gave him strength. And it also gave him confidence going forward in relationships after discovering he was HIV positive.

Greg [14:47]

We were at university at the time and it was my first relationship. But, I was with a number of friends at the time, and we grew together. Certainly I was given an example of how to be proud of who I was as a gay man. And, it served me very well once I became HIV positive, because I had stripped away the stigma of understanding that I didn't have to feel bad about myself because someone else felt bad about me. So, there was that pre-AIDS period that actually kind of prepared me. It didn't, I don't know that it made the 80s any easier. But, by the time I'd gone through the 80s, and some of the fear had lifted, I think I've had much more positive impact on my own life and on other people's lives.

Liz [15:40]
[atmospheric music fades out] For some, disclosing their HIV status can be challenging. For others disclosure and educating about HIV can be empowering, while others have actually found love and support after disclosing.

Alberto [15:52] After 2 years I told my mom, my mom was very sick. And I told my sibling, my younger brother. And I say, "please help me with my mom because I can't help her". She was sick and I'm very depressed because I am HIV positive. He cried. He hold me. I say "I love you". He gave me big hug.

Liz [16:19] In Alberto's case he decided to distance himself from everyone he loved in order to hide his HIV status, afraid of how people would react and treat him if they found out he was HIV positive. When Alberto found himself in a situation where he desperately needed help, he found the courage to tell his family. Fortunately, they've taken the news really well and have supported him ever since.

[ambient background music] When Andre was interviewing our guests, he asked them if they had a message for our audience. This is what Jean had to say.

Jean [16:49] I live with HIV day to day. I take the medication and that's the end of it. I see my physicians But I love my body. I love me, HIV. I'm surviving, some complications. But like, I love my body and I love me. And, I have to have to love myself before I can love anybody else.

Liz [17:23] Many people with HIV feel a lot of guilt and shame, which impacts their self esteem. No one living with HIV should feel bad about themselves or let anyone put them down. As Jean said, "loving yourself can be the first step towards forgiving yourself and accepting yourself for who you are".

Greg [17:39] When you're faced with the fear of death, and you know you're going to leave this world, you begin to understand things a little differently. And that was a gift that I was given at a very young age, which I now see as a gift. I may not have at the time. Had you asked me back then I would have been quite upset to suggest that this was a gift. But, it has worked out for me because it's allowed me to understand love, to understand what it really does mean to, to be here and be present on this earth and love someone and care for someone and be part of a loving environment. So, that's the greatest gift I've got from HIV. And, it's one that I don't think is easily taught. I had to learn the hard way I guess, but I have got it and it is a very positive message.

Liz [18:32]
[atmospheric music fades out] Greg isn't alone in feeling this way. We hear from many people that living with HIV isn't easy. But for some HIV has had a positive impact on their lives. It's changed the way they understand and

relate to themselves, and consequently the way they relate to others. It's also made them appreciate and value their relationships much more.

[theme music plays]

In this episode, you've heard how HIV impacts relationships, some in positive ways, some negative. You've heard about the complexities around disclosure, stigma, rejection, isolation, relationships lost and fear of starting new ones. You've heard stories of resiliency, hope and courage. 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.

We'd like to thank our guests Alberto, Jean, Phil and Greg 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 and performed by Nick Nausbaum. Remember to subscribe to *Positively Speaking* on your favourite podcast platform.

Our next episode will be about HIV and mental health. Here is a short clip of what's to come.

Scott [20:14]

So 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, and that created a lot of huge mental health problems. They my mental health problems that were before I would, 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 over the edge.

Liz [21:01]

Thanks for listening