



Positively Speaking

A Podcast by Casey House

Season 2, episode 4 – HIV and substance use: Fred's story

Air date: March 29, 2023

[theme music]

Liz Creal [0:05]
[theme music
continues in the
background]

Welcome to Positively Speaking, a podcast that explores the experiences of people living with HIV. I'm your host Liz Creal. I'm a social worker at Casey House, a subacute Specialty hospital in Toronto, providing inpatient and outpatient care for people living with or at risk of HIV.

This episode is about HIV and substance use. And a warning. This episode contains content that might be upsetting to some listeners. Please take care.

At Casey House, well over 80% of clients report using substances. Sharing needles or works is the second most common mode of HIV transmission after sexual contact. If you're interested in learning more about HIV transmission, please see the Episode notes.

The reason people use substances is varied. At Casey House many clients tell us they use to self medicate, often to forget about the trauma they've experienced and to numb the pain. As well, some people talk about the connection and community they feel with other people who use substances.

In this episode, we're going to hear from Fred, who at the time of recording was 62. Fred identifies as bisexual. He's a proud father, grandfather, and recently became a great grandfather. He's also a cancer survivor, and has worked for many years as a peer in HIV and harm reduction.

[theme fades
out]

Fred [1:46]

Well, I've been HIV positive per 32 years. I've lived a very colorful life. I'm ex trans. I prostituted myself. Did drugs in order to forget what I was doing. That's how I started my substance use. As I've said, I lived a very colorful life. I'm bisexual. I've done the party and play. You name it, I've done it. I'm a great grandfather now. Yep, my 15 year old grandson had a son. I wasn't pleased that he was only 15. If my stepfather had a lived we would have been five generations. We lost him to COVID Three months ago. So it's only four generations now.

Liz [2:44]

Fred recalls running away from home when he was only 11 due to sexual and physical abuse. He started engaging in sex work to earn money and started using substances to dull the traumatic impact of

the abuse he'd experienced. And to escape from the pain of what he was doing in order to survive.

Fred [3:02] Everybody has their own story. My reasons for using our mine. I don't know what their problems are. Like when I first started you using I was an 11 year old runaway. And that became a way of life. Because that's what I had to do to forget what I was doing. I was sexually abused by a family member. Most sexual abuse's are by family members. Now that family member sexually abused all of us. I come from a family of 15. Every one of us were abused, sexually abused. Except for my youngest sister. That family member was dead by then, when she was born. I'm a triplet. There is me and my two brothers, and 12 sisters. I've had six sisters commit suicide. They all took their lives later in life. Because they started to deal with what had happened to them as a child. See, with me, I escaped that reality. I use substances. It helped me get through that till I was ready to deal with it.

Liz [4:24] Receiving the news that he was HIV positive was another traumatic experience. Today in most cases, when someone tests positive for HIV, they're offered counseling services and referrals to doctors and community organizations for support. But this was not Fred's experience.

Fred [4:41] I was in the emergency room. I'd been admitted to hospital and the doctor from the emergency room had come up to my room. And he said to me, "You have AIDS". He literally walked in, said "I've got something tell ya. You have AIDS." Turned around and walked out. I went on a major party. My substance use then increased, like you wouldn't believe. I basically was doing the drugs trying to kill myself and the drinking.

Liz [5:15] As Fred said, people use substances for many different reasons. For him using drugs has served various purposes throughout his life. Nowadays, Fred uses for pain control.

Fred [5:29] Well there was cocaine. Nowadays, they call it crack, but back then they called it dreebase. I did acid. I don't consider marijuana a drug. I never have. So I'm not even going to put that in there. But I've done heroin, speed, uppers, downers. I do a bit of fentanyl for pain. I prefer smoking it. But I have had to inject because they don't have a smoking services at the what do you call them? That's why I prefer smoking. And that all stems back from my use of using heroin years ago. I use drugs now to help with some pain. But no drug is going to get rid of your pain. I've overdosed twice with fentanyl. Little did I know back then that it was carfentanil. Luckily a friend of mine had just popped by the first time I overdosed. I was expecting him and the door was open. So when he, when I didn't answer the door he came in and I was on the floor. And I spent 10 days in the hospital. They weren't sure if I was going to make it through the first time. The second time I made sure somebody was there. I always make sure somebody's there when I when I use fentanyl. At all times. See, now I'm a functioning addict. Years ago I was a non functioning addict. Because I don't use fentanyl for the high. I use fentanyl for pain. If I'm having a really really bad day, pain-wise, I go and get a bit of fentanyl and it brings my pain

downwards manageable. A lot of my pain now is due to the cancer I have. I am six months past the time they gave me. I battled it five times and won. This time I'm not winning.

- Liz** [7:52] After overdosing, Fred realized how important it is to have allies who can watch out for one another.
- Fred** [7:59] I do harm reduction services. I'm called a satellite site where people pop by my apartment and pick up supplies. I would prefer people being safe and clean when they're using substances and having access to the supplies at all times 24/7. It's like all somebody has to do is knock on my door 24/7 I will open the door. Get them their supplies.
- Liz** [8:36] Fred reflects on how sometimes regulated medications such as the early HIV treatment can cause as much damage to someone's body as some of the unregulated drugs that can be found on the streets today.
- Fred** [8:49] The medication they had then, the side effects of those medications killed most people. Like AZT. One of the worst medications they had. I took AZT. That's also a lot of my pain is caused from those earlier drugs. I also have diabetic neuropathy because I'm diabetic as well. So like have the time I can't feel my feet.
- Liz** [9:21] Fred's story is incredibly painful and difficult to imagine. But it also is a reminder that sometimes behind a person's behavior is a history of pain, abuse and trauma.
- Fred** [9:33] You don't know what that person's personal pain is. Whether it be psychological pain caused by something that's happened or physical pain. Nobody should judge why a person uses substances. Fentanyl is very very dangerous. And I only use the fentanyl as a last resort when I've gone through all the other drugs, and they haven't helped. And my substance use went through the roof during COVID. Because I was paranoid because I had no access to a lot of the programs that I used on a daily basis. Number one, Casey House, the Day Health Program. So, all the things the physiotherapist here taught me, I did at home. I did make shift things. I have a broken ten speed at home and I rigged it up so I was pedaling the bike there. Like my mental health really suffered. Thank God for certain friends that I called.
- Liz** [10:59] When Fred was using heavily he stopped taking his HIV medication
- Fred** [11:03] I went off all meds for close to three years. So yeah, substances did affect my HIV.
- Liz** [11:15] At that point, Fred's doctor gave him a reality check.
- Fred** [11:47] He said, "You've lived longer than what they already said. Do you want to continue living? Or do you want to die?" And it was the way he said it and looked at me that I snapped out of reality. Snapped back into reality I mean. The way he said it and looked at me at the same time. I was like, "Yeah, I want to live."

- Liz** [11:47] That was in 1998 when Fred restarted his HIV medications. He continues to have an undetectable viral load, which means that HIV is not detected in his blood, and he can't pass on HIV to someone else.
- Fred** [12:03] When I went to prison, due to my colourful life and substance use, I went to prison for importing cocaine. But it was while I was in prison that I, I turned my life around. I did schooling. I took every course you could possibly take while I was in. Plus having to do my daily work. Cuz in prison you have to work for \$4.90 a week.
- Liz** [12:31] Fred's experience working while in prison provided him with skills and education that would serve him well after he got out. But being in prison did not mean his substance ended. Fred used crack despite being subjected to regular urine screens. Here he describes what happened if they found crack or other substances in his urine.
- Fred** [12:52] You would lose your um, security level. See I was in a minimum, which they call camp. I would have had to, they would have had to put my security level up to medium which is basically I could walk, walk around a free. I could have walked right out of jail. Walked away. The medium is your behind walls and bars.
- Liz** [13:22] Fred now lives in an apartment building and provides harm reduction supplies to other tenants. He also takes it upon himself to ensure there are no used needles in and around the building, especially in the playground.
- Fred** [13:35] I'm out there at 6am scouring a playground. Cuz you still get these stupid idiots throwing their needles all over the place. And I pick them up.
- Liz** [13:48] But not everyone who lives in Fred's building is on side with his harm reduction work at the building.
- Fred** [13:54] Here's an example. I got two tenants that live on my floor. if anything goes wrong in the building, I'm to blame. Because I supply harm reduction supplies. I've had one tenant calling the police on me on a daily basis.
- Liz** [14:15] Despite having the police called on him, Fred continues with his harm reduction work and continues to support people who use substances. Fred was asked if there was anything he hadn't shared that he thought would be important for listeners to hear.
- Fred** [14:35] Don't judge. Don't judge somebody else's reasons for using. Be sympathetic with them. Try and understand what their pain is. The person has enough stigma on them. They don't need anymore. You never know the addict you're judging could be you someday.
- Liz** [14:15] In this episode, we've learned about the horrific impact of child sexual abuse on Fred and his siblings. How it played out through his escape to sex work and substance use and drove him to self destructive behaviors, including abandoning his HIV medication. His main message is one of understanding and not to judge. Of the necessity to see the

person behind the substance use and to support people where they're at.

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.ca for a transcript of this episode, a glossary of terms and links to other resources.

Thanks for listening.