



Positively Speaking

A Podcast by Casey House

Season 2, episode 1 – Eric’s journey to a medically assisted death (MAiD)

Air date: March 8, 2023

[theme music]

Liz Creal [0:07]
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Welcome to Season Two of 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. We had to delay production of season two due to the pandemic. But we are happy to be back with new themes, some format changes and material that we hope you’ll find informative and compelling.

So let’s get started. Episode One focuses on the story of Eric, his life and his journey to a medically assisted death. I met Eric two years prior to this interview, Eric was living with HIV and ALS, often described as Lou Gehrig’s disease. Eric was clear from the day I met him that he wanted a medically assisted death or MAiD when he could no longer look after himself, which he defined as a time when he no longer had use of his arms and legs and needed 24 hour care. Before we get into the interview, a bit of context about medical assistance in dying or MAiD. MAiD is a topic that deserves a whole series in itself. So this is just a brief overview. We’ll have links to some key information and resources in the Episode Notes. In June of 2016, new federal legislation enabled eligible adults in Canada to request a medically assisted death. There were a number of criteria that had to be met; the person had to be 18 years of age or older and suffering from a grievous or irremediable medical condition where their death was reasonably foreseeable. They also had to be informed of the various approaches to address their suffering, including palliative care and other supports. They had to give informed consent and be given the option right up until the time of the procedure to change their mind. In March of 2021, the legislation was amended to include eligibility for people who met all the criteria, but for whom their natural death was not foreseeable. Mental illness as a sole criterion was deferred to allow for review and recommendations by a federally appointed expert panel that will become legal in March of 2023. At the time of recording this episode, details have not yet been released. As eligibility is extended, there’s ongoing debate about MAiD, including concerns that people who are eligible will choose MAiD because of poverty, lack of access to basic rights such as safe, affordable housing, appropriate health care, and other supports. Casey House as an organization has supported MAiD since 2017. And to date those individuals who chose the procedure, including Eric, all met the original criteria. You’re about to hear extracts from a conversation I had with Eric on September 30 2019, two days before his medically assisted death. Eric wanted to do this interview as part of his legacy, and by offering his own experience and perspective

to those who may have limited knowledge of or who may not agree with MAiD. Here's my conversation with Eric.

[theme fades out]

Liz [3:22] Eric, thanks so much for being here today.

Eric [3:25] It's a pleasure

Liz [3:27] So Eric, I wonder if you can tell our audience a little bit, just a little bit about yourself.

Eric [3:31] Sure. I am 52 years old. I'm a gay man. (laughing) I was born in Montreal, and you know, my parents moved to Toronto in 69, so I was still a baby. They moved to Newmarket. My dad was a baker and they started a bakery, their family business. And I worked in the business for many years until well, I don't want to go too far back. But I worked for a little while. to, I did my undergrad in business administration at Laurier in Waterloo. And then I worked for a little while and then I did an MBA at York, where I met my first, well just before I started my MBA I met, met my first partner. And we ultimately ended up getting married. And in 99, he was transferred with the TD Bank to New York. And I was working as an associate equity analyst at CIBC World Markets. So I thought what better place to be than New York with that kind of background so we moved together in 99. Anyway, we lived there for 12 years before my partner in 2008 was diagnosed with a form of cancer, at the base of his tongue called squamous cell carcinoma. And although the initial prognosis was actually very good, he, he didn't catch a break. He, well, it just spread and spread. And ultimately they went in to remove his tongue and his right mandible. And that lasted a little while, but it came back again and they had removed so much it couldn't remove anymore without harming him, his spine. So anyway, he passed away in Brooklyn where we lived in February of 2011.

Liz [5:28] I'm so sorry.

Eric [5:30] Yeah. So it was, we were together, almost 20 years. It was a huge loss for me. Very rudderless, during that period and went to a very dark place, did some things I regret. And that's sort of when, in that era, I became poz. And I moved back to Toronto then because my family was such as it is, I'm an only child so my mother and father were living in Collingwood at the time. And they were all I had, me my family my Steven was dead. So I moved back to Collingwood, to Toronto with a friend. Part time in Toronto in early 2012. I didn't really work. I was just sort of rudderless half-heartedly looking for work and just trying to sort out next steps, right. I was, was in a dark place and nothing really. I had no direction and I just felt so empty and alone.

Liz [6:31] Did you have friends in Toronto?

Eric [6:33] Oh I did but I was more referring to the loss of Steve, right. The huge void that left inside me. So ultimately, I ended up getting a job with an

insurance company in based in Vancouver. So in October 2013 I hopped in my car and drove up to Vancouver and had a wonderful three and a half years there were just a great job great people really enjoyed the city and the travel. But in April, well now I know the date April 26, shall live in infamy - April 26 2016 I had a preliminary diagnosis. What was happening is I was skiing at Whistler in January of 2016 with, it's called Whistler Pride or Whistler Altitude or Altitude I don't know what they call it now. But the gay ski week in Whistler. I was skiing with a bunch of guys and we went into the lodge at the top of the mountain to have lunch. And I ordered this thing called the Thai Bowl which required the use of chopsticks to eat and, I'm pretty good with chopsticks and I went to pick them up and they sort of just fell out of my hand. I thought maybe it's just a cold. It was fine. Anyway and note to self, I'll have that looked into. So three months later, January, February, March, April. Yeah, four months laterish I got a diagnosis, after going to see one specialist to another, of ALS. So I really didn't know really know what it was other than that was pretty, pretty, pretty grim diagnosis. Anyway. Yeah. She said we think you have ALS we're not sure but we're fairly. They did the AKG's you know, where they sort of zap your nerves and see what your responses are. And some of my nerves had been totally fried. So um, I'll never forget, though that oddly enough, my very first emotion, after I was told that sitting in the chair in the hospital was a sense of relief. Subconsciously. I'm not really a spiritual person, spiritual person. But the first emotion was relief that I would finally be able to, I would no longer have to find, find the happiness that I once had with my partner. That I was still very much mourning his loss very much alone, feeling alone, emotionally. And that was my first thing that I'll finally be able to join him. It was almost a relief. Although I don't really know what's next. I don't have any firm belief on what's next. But oddly enough, that's where my subconscious took me.

Liz [9:13] You wanted that connection with your, with your Steven. So it wasn't a it wasn't a relief that Oh, now I know what it is. It was more that wanting to be with him.

Eric [9:24] Yeah. Knowing that I was going to die prematurely brought on this - my first reaction, subconsciously was one of relief. Not of fear, not of sadness, but a relief. Of course, many emotions followed that. But that was my first one. And it always struck me as being odd.

Liz [9:45] And I guess at that time, or I guess they don't at any time, they don't really know what ALS is going to look like. Is that true? It's different for everybody?

Eric [9:53] It's true. It presents in so many different ways. I mean, the outcome is usually the same. You get a gradual loss of your muscles. Your voluntary muscles shut down as they are no longer activated by the nerves. The nerves die. The nerve endings die. They don't know what causes it. So you eventually become a total, in the end, you're, you're in a vegetative state. Right? And the last muscles to go is usually the breathing. I didn't realize this, but breathing is a voluntary, muscular action. And that's usually the last one to go. But they can get around that now with ventilators in various machines, but you're still just

sitting there breathing. A lump of flesh with a fully functioning brain. Which is kind of like the worst version of hell anyone could possibly imagine just being trapped in your own body. But, um, so I got had my my definitive diagnosis in Vancouver in September of 2016. Oddly enough, I was still working that following month in Ontario. I was in Toronto on business. I'm met this wonderful man. His name, you know, him, his name was Kabarri. (crying) And ah, you know, eyes wide open, he loved me.

Yeah, knowing all my flaws and all this timeline, you know?

Liz [11:20] Mm-hm. And I guess you didn't know the timeline, you didn't know, like you said, you didn't know how it was going to... Is that right?

Eric [11:23] Three to five, that's an average. What goes when is, you know, no one knows. But most people live post diagnosis three to five years. Some longer, some much more aggressive. That's just how, how different the disease presents itself, right. Some people it starts in what they call their bulbar functions and starts. Their first symptom is a loss of speech, or breathing or swallowing problems. And there's the limb, I'm one of the limb variants. It started in my left fingers, my left hand.

Liz [11:56] So that's when you noticed?

Eric [11:58] Yeah, so but so some people, the first thing, they get up in the morning, and they can't speak. So it's just such a crazy disease that way. It presents so differently. But the outcome is always the same. So I am now you know, I was diagnosed, initially in April of 2016. So I'm right in that sort of, I hate to call a sweet spot, but the average is three to five. I'm three and a half now. Um, you know, I I don't know how long I would live still, if I let the natural, natural, natural sort of progression do its thing. I could, probably, and I'm guessing probably, I have a few years in me, maybe three years, maybe. Who knows. With a ventilator hooked up to something and wheeled around, I could probably you know, live long. But that, for me is not the quality of life. It's you know, it's not for me. Some people do it and I'm in awe of them in their determination. Um, but it's not for me. So as I've felt this disease spreading through my body and as I've lost one capability after the next you know, first it was of course my arms and being able to eat and then it was you know, I mourn the loss of being able to skate. (crying) Then it was biking, and then one thing after the next melted away. All the things I love to do.

Liz [13:39] That you loved, yeah. And when you first came to Casey House, Eric, you were pretty clear about your decision to go with MAiD when the time.

Eric [13:54] When the time came.

Liz [13:55] And you kind of had a clearer sense of what that would look like.

Eric [13:58] I'm not sure I had a perfectly clear sense. I knew as time went on, and you know, I thought oh, it'd be this it would be that. And I figured it out, you know. But then sort of, as I understood that I was losing my

ability to move around and my legs got weaker and weaker. That sort of became my, my line. You know, my sort of once I 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 don't know when I'm in the definitive decision. I spoken with yourself and with 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. I just don't you know, I've had a great, I've touched on my life and going on. But I, what I can say is I've been very fortunate. I've had a great 52 years. I don't feel the need - is the expression I've used in the past - I don't feel the need to squeeze blood out of a stone. You know, I've, I've no regrets. I have had a wonderful life. I never had to fight or never wanted for anything. And I just don't need to, I don't feel I need to just stick around for the sake of sticking around with that constant dread of what's going to go next? What will I need next? If I were in the state and things stabilized, I would figure it out. I would reinvent myself. I'd get the wheelchair. I'd get the tools. I'd figure it out, like I've done so many times over the past three years. But at some point, you just get tired of having to figure it out. Every time you lose another motor skill or another function. And the quality of life. My world has the walls have closed in on me. My world has become smaller and smaller and smaller.

Liz [16:23] And is there a sense. I mean, I sense from you, with MAiD you can have control at least of that one thing.

Eric [16:32] I can have control of that one thing. And get in front of this disease and make it my decision. Not only that, I mean, knowing that MAiD was there for me emotionally, at some point down the road, helped me through many periods of real depression and anxiety when I may have done something prematurely or rash that I didn't want to do to my loved ones, right? So knowing that MAiD was available to me improved my quality of life, up to up to the end. I'm I have to say that. You know, it's made me less anxious, less fearful, less full of dread than I would have been had, I thought, Oh, my God, I've got to take this to the end, to the limit. And I think people need to understand that, you know? People look at MAiD as sort of a premature ending of life don't understand that having it for those that potentially might use it gives them peace of mind that may actually help them prolong their life. And may help them avoid taking rash or premature actions that that wouldn't be right for them longer term, or their loved ones, right.

Liz [17:50] And I guess it's given you the opportunity to say your goodbyes to people.

Eric [17:55] Absolutely. And that's a good segue to what happened yesterday.

Liz [17:58] Yesterday. Do you want to tell us about what happened?

Eric [18:00] Yeah, I'll probably cry again. (crying)

Liz [18:01] That's okay.

Eric [18:03] Tears of joy. (crying) So we had a celebration life yesterday. And ah, all my friends that I invited, over the course of my life, showed up. Friends and family. My mum was there. My father-in-law, my mother-in-law from my previous husband. My partner, current partner, and of course, so many others. There were 60 or 70 people there. And it wasn't easy and I was anxious going into it. I didn't I didn't want it to be a sad event, but I knew there'd be tears. But it was so cathartic to just get together with everyone and cry. And be sad. But also laugh and celebrate. And we looked at pictures and reminisced. And talked about the memories which were so great ALS will never take those memories away. Right. But to have that closure. (crying) And as I saw people and they were saying their goodbyes, I could sense some of them were holding back their tears. And I said, no, let's cry. Because it's so tragic. Let's fucking cry. And we did and it felt so good. It felt good to have that completion. To have everything come full circle. At the party, at the party there was such a feeling of that it was the right thing. And I felt at peace and a calm that I haven't felt in a long time. I'm not saying it was easy. And I'm not saying that it was a nonstop party. But it was just so right. And I hope, I think I did it for the other people too. You know they had their, I don't know if closure is the right word, but their, their opportunity to process their emotions.

Liz [20:08] Exactly.

Eric [20:09] Whether it was crying or laughing or just standing in the corner and, and thinking about things for themselves with me present.

Liz [20:16] And being able to say things to each other. Right. for you...

Eric [20:19] Exactly. And new connections. That common thread and I hope that they will become, and new friendships will come of it. So my, my passing will bring good things as well. Right? Things that are durable that will last well beyond me. So it was really tiring. And my good friend who has been looking after me since forever. We went out afterwards. We went out to McDonald's and had some french fries, (laughing). My last french fries and a hamburger and just enjoyed that. And then we went back - he had a hotel room that he's staying in. He lives outside of the city, and I slept there just to get a bit of a staycation from Casey House.

Liz [21:03] From all of us at Casey House. (laughing)

Eric [21:04] (laughing) And he's special. He reads my mind and I, I can be I can be the worst person, the best person around him and he doesn't, nothing fazes him. And he gives Kabarri a break, my partner. So that was nice. Then I just got back here and we're still on for two days from now.

Liz [21:24] Two days from now.

Eric [21:25] And that's not going to be easy either. There's people who are close to me. I said, if you want to be there, you're welcome. But if you don't, I totally understand. And I don't want you to come just out of out of obligation. Do what's right for you. Because that's gonna be what's right for me. So my mum will be there and she met with the doctor.

She happened to be visiting me with her caregiver. She just lives, you know, a 10 minute walk from here, which is great. In a long term care home. And she happened to be there when Dr. Wales came in, and we had just a really frank conversation about, you know, what will happen. And she asked him random questions like, like, you know, just, you know (laughing), can she hold my hand? Of course, I said, you can hold my hand, you know. And, and she started to sing as she's want to do. But it helped her I think just to see him so things won't be so new and um, foreign on the day of the, on the day of the, what do you call it? The moving.

Liz [22:40] The moving on.

Eric [22:41] The release. And so on. So I hope she'll make it.

Liz [22:46] I think she I would, I think it would humanize him for her.

Eric [22:50] It does, It did. She just chatted with him about random stuff, irrelevant stuff. And I think it just helped her become familiar with him. They were just by chance, you know. And that really, really worked, worked out well. So she'll be there and she'll certainly hold my hand. And maybe Kabarri will hold my other hand. Other close family and friends will be there. And uh, I mean, I'm not gonna lie, it's gonna be tough for everyone. But, I have the, I can change my mind whenever I want.

Liz [23:21] Absolutely. Absolutely.

Eric [23:22] But in my heart of hearts deep down, I, I feel it's the right thing. And there's an anticipation of the release. I'm tired. I'm tired. And just moving on will be, for me, for the conscious me that exists now, a moment of calm. Not having to deal with the stress of just living anymore. Yeah, living anymore.

Liz [23:53] Living, yeah, You've talked a lot about that. How hard it is. How much harder it's been just living.

Eric [24:00] When I first decided, it's funny, you know, when I first decided to do the, to do the moving on. I was still able to walk. I was in much better shape than I am now. Much maybe not much but better shape. You see me progress.

Liz [24:18] Yup.

Eric [24:18] So all the affirm, all the all the, it's all been positive reinforcement, right? That's the problem with this disease. It just never stops. So I could postpone it. But my life isn't going to get any better for me or anyone around me. So it's something that I, I may I may eat these words I'm saying now. I have every right to do so.

Liz [24:47] And that's okay.

Eric [24:48] But for me right now it feels like it will be a relief. A relief. Like I said earlier, I yes, I have regrets. We all have regrets. I should have taken that course instead of this course but you.

Liz [24:59] Of course, sure.

Eric [25:00] The small regrets we all have. But bigger picture regrets

Liz [25:05] You don't have any.

Eric [25:06] I don't have any. I understand that, I have said this before too, how fortunate I am to have been born in Montreal in 1967. Right? What a gift that was in terms of having a safe, full life. We're so privileged here and that privilege I'll take to me to my grave. You have been how, how? How lucky I've been and no lie. I'm not gonna. I'm not gonna lie. Losing my partner was horrible. And getting this disease is all horrible. But I, it's random crap that happens, right? And it's, I'm not gonna play the victim. You know, I've had a good life, my glass will always be half full. Because, A, playing the victim doesn't change anything.

Liz [25:55] No, it doesn't.

Eric [25:56] And B, the truth is, I've had a good life. And I've been very fortunate. And I've had parents that loved me. They sacrificed so much for me, and I'm so thankful for that.

Liz [26:07] And you've given a lot, you've given the team here at Casey House, so many gifts.

Eric [26:12] It's very kind of you to say.

Liz [26:17] It's true. So I know we need to wrap things up because you have to massage.

Eric [26:20] Ha ha. Priorities. (laughing)

Liz [26:21] I'm just wondering, you've given so many beautiful messages, Eric, um. I guess maybe I'm wondering if, everybody processes things differently, and I wonder for you coming to the decision, was it something that you had to process verbally with friends and people close to you? Or was it something that it was more you had to figure that out on your own?

Eric [26:42] No, I it's a combination of both right. You know, a lot of talking with people and then just a lot of thinking in my own head. But a few pivotal moments. I had a conversation with someone who who'd lost her husband to ALS, and he was seven years post diagnosis. And I can't imagine what that would have been like for him at the end. Very early on, he had a trach, you know, put in. Because he could no longer eat so he is more bulbar, a combination of bulbar and limb. But he lasted seven years. I'm only, only going to imagine the last few years were pretty much just laying there. With the person I spoke with, his wife, had had a lot of confidence in that was the right decision. And that just really opened my eyes. How can anyone be so certain? How can any of us, I'm not so certain that I'm making the right choice. For me, it seems like the right choice. But how, who am I to say there's not a cure? A cure found the day after I move on. Right? You can never be

certain of anything being the right choice when it comes to this personal.

Liz [28:08]

No, it's true.

Eric [28:09]

Such a decision. And her certainty just scared, scared me

Liz [28:12]

And you knew you didn't want to get to that point. That was something you are certain about.

Eric [28:17]

Right. So there was that. There was a movie I saw, actually just not that long ago. The German film called *Hin und Weg*. The English title is *Tour de Force*. It was about a young guy in his mid 30s, who gets diagnosed with ALS. And has all these friends, they go into cycling tour. They do, up until that point, every year they went on a cycling tours, friends. And it was his year to choose the destination. He chose Belgium. Because he had his diagnosis and he wanted to go there and die. He didn't tell them until they started cycling. Wow. And it's a very, as you can imagine, it's a very emotional, very emotional movie. And a lot of people are questioning him. Why are you still in such good shape? This and that. And the way he articulated why. It's not about you. I know you want me to live. So, it's just really profound and so articulated what I felt. And of course, the millions of other discussions that I've had over the past few years. But just know it was there for me gave me such peace of mind. And it's been so good up until now. And part of the reason it has been so good up until now is because I've known, in the back of my mind, that I will have control in the end. Not someone else. Not this terrible disease. But I will and that's given me many more laughs and joyful moments of happiness than I would not have otherwise had.

Liz [29:56]

That's, your words are beautiful, Eric. I want to thank you so much for sharing so much with us today.

Eric [30:04]

It's been a pleasure.

Liz [30:04]

Thank you

Eric [30:04]

Knowing you.

Liz [30:07]

Thank you, you too.

[theme music]

Eric died two days after this interview, on Wednesday, October 2 2019. I had the privilege of being in Eric's room along with several of my colleagues. Eric was surrounded by family members and friends, and his partner was by his side. Eric had a beer, at his request, just prior to the procedure. His favorite music was playing and a bouquet of flowers lay beside him on his pillow. As he looked around the room at his family members, friends and partner, shortly before he died, Eric said, I feel like I'm already in heaven. Eric died peacefully as he wished, bathed in love and tenderness.

[31:00]

If you have any comments or questions about this episode, we'd love to hear from you. You can email us at [podcast at Caseyhouse.ca](mailto: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. This episode was written and produced by Andre Ceranto, Amanda Crawford and me Liz Creal. The music was composed and performed by Nick Nussbaum, our sound engineer was David Matta, also special thanks to Tony Boston and Adam McGee for their creative input and support. Remember to subscribe to Positively Speaking on your favourite podcast platform.

Thanks for listening.