"HIV In My Day" – Interview #61

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Interviewee: Jennifer Rose Schaldemose (JS) ; Interviewer: Ben Klassen (BK)
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BK: Alright, just sitting down with Jennifer this afternoon. Really grateful for you taking the time to share your story with us, so thank you so much for being here

JS: Thank you for inviting me.

BK: Just to get started, can you tell me a little bit about your connection to Vancouver, how you ended up here?

JS: Well, as I had told you before, I was originally born and raised in Winnipeg. I left home when I was 18. I went on vacation with my mother and my aunt and my nana to the Bahamas and met a sailor there, and decided to return to Winnipeg and quit my job and broke off my engagement and gave away the contents of my hope chest and threw all caution to the wind and went back to the Bahamas to run away with a sailor. Yeah, so [laughing] I was living in the Bahamas, I got my first apartment in the Bahamas when I was 18, and living with this man from Cape Maine, New Jersey who was a pit boss at the local casino on the crystal island there in Nasa, Bahamas. So I was there with him for a time until I realized that I wasn't the only woman that he was in negotiations with to try to have a child with in the Bahamas, so I ended up jumping ship on that one and took off to Florida. And lived in Florida for a few months and then came to Vancouver. And I have family here and had spent summers here as a child. My nana lived in Maple Ridge, which was called Haney back then, Maple Ridge, and my auntie lived in Port Coquitlam. So as a child I would come out for a month every summer and spend two weeks with my auntie in PoCo and two weeks in Port Moody, or, sorry, Maple Ridge, with my nana. And then my cousin would come back to Winnipeg with me and he'd spend two weeks with us and then two weeks with his dad. So my mom and my auntie had this awesome arrangement which I think now, like, oh man, if I had somebody to take my kids for a whole two weeks, how awesome would that be! So there's my kind of childhood connection with the area, and it was my dream basically to move out here once I got old enough to be on my own. But of course, it was a different reality back in 1990, things were a little bit different [laughing]. I think when you're younger you don't really think about how difficult things might be or what obstacles you might face, you just run headlong straight into it and just figure it out and don't worry about it. So yeah, I came here in … was about April of 1990. And I was living with my aunt and working so I had a reduced rent and family support and stuff, right, so that was good. Although I wasn't sure really what I wanted to do, I was still pretty young. I turned 19 in May, and then in August I was diagnosed by a doctor in a little doctor's office in Port Moody. And he'd never seen anybody like me before, and of course he didn't really know what to tell me. It wasn't like there was any options for treatment or, you know, basically at that point in 1990, HIV meant that you're going to die, like there was no … and the stigma and the associations that people had with it, right. [phone ringing] Sorry, I'll just… Oh, it's [inaudible]

BK: If you need to take it you can take it.

JS: Oh, I'll just turn it off. I'm sorry, I normally do that when I enter into places.

BK: No worries

JS: Yeah, no worries, shouldn't really be a problem. But anyways. So wow. 1990. Yeah, I was basically given the death sentence and sent home to die. I was on my own at that point, I had gotten a shared accommodation situation in Vancouver. I was living with a couple guys. And I was talking back and forth with the American man who I had thought at the time was the one that was responsible for infecting me, I didn't know for sure 100%. He did accept me and he did want me to come back to Florida to live with him. Course I didn't know what that was going to look like, and I was really naïve and didn't understand what this was going to mean for me, and that that one mistake would have consequences that I would carry for the rest of my life. Normally when you're 18 and you fuck up, you make mistakes, but you get a second chance, right? Yeah.

So as much as I've so defiantly fought to not have HIV define my life, it has. But more so how I have chosen to define myself in relation to it, and in defiance of it, and also in celebration of it. Having the perspective that I do now, facing my death again, with advanced metastatic breast cancer that I've been battling for the last three years, the differences between the two experiences are just, they're vast and incomprehensible. But most immediately, most profoundly is the difference in the stigmatization associated with them. As I said, never once have I had anybody ask me how I got breast cancer. 'What the heck did I do to get breast cancer?' Whereas especially early on, when you would disclose to somebody, the first thing they would ask you, whether they were a health care professional, a doctor, a nurse, a lab technician, your best friend, your parents was, 'Oh my god, what did you do? Who did you sleep with? Oh my god, you're not on drugs, are you?' Even my own parents. They just shook their heads in disbelief, 'that's impossible.' My father slammed his fist on the table and said, 'that's impossible. Not my daughter, not my daughter. But you're not gay! But you're not a drug user. But you're not a prostitute.' Right? Even the doctor scratched his head and said, 'How would you have even known? How would you have known to get tested?' And I said, 'Well I don't know. I just felt off like something was wrong.' Like when I was … really the only symptom that I had was that I would sleep like 17 hours at a time or something. Yeah, like I was so exhausted, and I think that your body when you go through seroconversion, there's something that your body almost reacts like it's got a fever and it takes a while. And then I think I was diagnosed so early after being infected. My cd4 counts were 1801. They'd never seen anything like it. I had no viral load, in fact I was undetectable until well into the 2000s, until they came up with the new test that was more sensitive to detect the viral load. So they were like, 'Wow, we're not really too sure what's going on here for you. We've never really seen anything like this.'

So when I returned to Winnipeg and to my family, it was my father who made my appointment at the Village Clinic which was a gay men's clinic on Corydon Avenue in what we call the village. Very much like Davie Street village, very very much like Davie Street village. It actually makes me feel a bit like home when I'm around here, which is funny because I don't really identify with being a big city girl at all. And of course, back in those days I didn't know anyone else who was positive. I didn't have gay friends. I didn't know any drug users or prostitutes. So the question on everyone's mind was 'How could you possibly have known, you don't fall into one of these high risk categories, how did you even know to get tested?' And yeah quite conceivably, with the general level of health and fitness that I've enjoyed most of my life, I could have gone years and years and years without knowing that I was positive. And I think as with any occasion where you're brought face to face with your mortality, you start to ask yourself some of those important questions, the big questions. And I was so young that my motto was 'I'm here for a good time not a long time. I'm just riding it for all it's worth.' I didn't think about the consequences of my actions. I didn't think about potentially getting myself into compromising situations. I had been sexually abused as a child, so I didn't have an ability to form appropriate and safe boundaries. I didn't know how to negotiate that. Alcohol use was an integral part of losing my virginity and coming of age, just part of the social fabric that I was part of. Both my father and my step-father were alcoholics so it was very much a part of that generation. You know, it wasn't something that people looked sideways at, it was a totally normal accepted part of society. When you're a teenager and get to be about grade 8, if you're part of the cool kids you're going to be experimenting and having fun and doing what we called fishing, standing outside the liquor store and asking someone to buy you a case of beer. That's what we called fishing on the prairies [laughing]. 'I'm going fishing.' And we'd be laughing, and the parents wouldn't know what you were talking about because you were going fishing! Anyways, I'm sure the code words nowadays in this generation are a lot different than that. But of course, my impending infection and diagnosis came right on the heels of that. It was very much a part of coming of age for me and I've never known any other life.

I've never … I've only had a couple of interactions with men where I didn't have to disclose and tell them something that could potentially get me beaten up or killed or God only knows what. It's hard to fathom, you know, especially now having breast cancer. Like the thought of someone trying to hurt me after I tell them I have breast cancer would blow my mind, but a person living with HIV faces that every single time they make a friend. Meet somebody that they like. I mean, even my husband when I told him, this summer it'll be 20 years that we've been together. And when I disclosed to him, we had had kind of a casual acquaintance that summer of 1999, and we had been getting to know each other more and more through the summer. And it wasn't until the fall at a year-end party or Halloween party that we connected, and he brushed against me in the hall, and my heart leapt. And I thought, 'oh my god he likes me too,' because up until that point I had no idea whether he liked me too. And then that fateful night when I told him, and I read him some poetry and I prepared for him walking away. So I was really surprised that he didn't walk away, he didn't run away. He bawled like a baby. And I held him in my arms for about 45 minutes and he cried so hard. And when he stopped crying he said something like, 'Look at me, I'm just a mess and I'm supposed to be the one being strong for you and I'm supposed to be the one holding you.' But he said, 'You, you must have had such a hard life.' And in that moment, he knew that I had to do that every time I let somebody close to me, I had to do that. And he knew that that meant I heard a lot of slanders and watched a lot of people walk away from me forever. And not because of anything I did or said. It was just like, my whole life I've struggled to be seen and to be heard through the shadows that people cast on me, their own darkness, their own fear, their own grief. And I think that's why you identify with that line in that song by Simon and Garfunkel, I have my music and my poetry to protect me. That's what I did, was I found a way to find my words and my voice, my poetry and my song and my dancing to protect myself. To transform myself. To fortify myself that no matter what the world would throw at me, like you know that scene in Cinderella where the evil stepmothers come, and they tear their dress off of her? It’s like that, you know, but its slower, its more painful. Because not only do you lose yourself, you lose everything you thought you ever knew, all the ideals that you had. Because you’re not ‘that kind of girl’, whatever ‘that kind of girl’ is supposed to be. But you’re never going to be that kind of girl, you’re never going to be normal, you always have this uncertainty hanging over you. And the way that people look at you. I know that people say, ‘Oh, well, we’ve come so far.’ People will say that to me and it’s just like, I just shake my head and say, ‘Really? Really? We’ve come so far have we? Really?’ I don’t know how many kilometers you need to drive north before you really haven’t gone far at all.

So I have both a historical perspective in terms of having been infected in 89/90, and then having my whole life turned upside down, having my own journey of self-empowerment and activism in the 90s and going back to school in the 2000s. And having this brief period of maybe what you call the closest thing to normalcy, where I live in a small northern community where nobody knows who I am or where I came from or that I’m the ‘poster girl’ or whatever. However, you want to conceive of that or perceive that. But yeah, it’s sort of … [name] and I, we’re friends, we were talking about that. This sort of weird state where you’re like kind of famous for something really unusual, well known by people that you don’t know who they are. And you have people approach you and they’re excited to get a chance to talk to you, because they’ve seen you do a presentation or they’ve seen you speak and they’re starstruck to get a chance to talk to you, and you’re like, ‘I’m sorry and what was your name?’ Because they already know you, right? So I think more than ever for me now, I think that finding my voice is really important for me. Moving forward in my life and with making a testament of my life for my four year old son, because I don’t know how much longer I have to live. Those big questions have come back right? But it’s interesting that I almost want to do a compare/contrast between … I had found myself. Everybody talks about this searching and finding yourself spiritual journey kind of thing, and I think yes you find yourself and then you need to lose yourself. You find yourself, you lose yourself. You find yourself, you lose yourself. And that it’s an ebb and a flow. The cycles of our lives, they’re not as clear cut and as delineated, you know childhood, adulthood, maidenhood, cronehood. In fact, my son has told me that I am becoming a little girl again and he believes that my baby will grow back, and my breast will grow back. Of course it won’t, but maybe he sees something that the rest of us can’t. That healing for me wouldn’t be the restoration of my breast or the elimination of the virus in my body. Healing would be a reckoning. A re-harmonizing, if you will, a kind of like all the pieces of the kaleidoscope slide into the places that they need to be in, even if they’re going to continue to shift and change and expand and contract. In spite of all of it, I must choose to have faith that the universe is so vast and so mysterious and so full of miracles and so vast that I could never possibly comprehend, and that’s okay. I think it’s a real travesty that we look at our deaths as a failure, that we ‘lose our battle to AIDS’ or we ‘lose our battle to cancer’. First of all, it’s not a battle, and secondly, while it could be construed as a loss, I want to be ready for graduation day. I want it to be a celebration. It’s been really hard trying to teach my four-year-old son to be happy for me that I get to go to heaven before him. I think I might just have a trick or two left in me [laughing]. I seem to have been able to manifest miracles here.

But yeah, I want the opportunity to be able to delineate some of that, be able to … that’s just it, I just wanted a chance to be a normal person, to not have people look at me like that. You tell them that you're positive and they get that look. People can't help themselves and they don't mean to do it, it's not intentional, it's just … I don't know … pity, fear, like 'ooh, don't get too close to me then' or 'Gee, what does that mean? Oh my god I just drank from the same glass as you, or maybe I just ate some of your cake off the fork.' And all the various things that have happened over the years, all the awkward conservations, all the times that you're told, 'Sorry, my bad, I was supposed to schedule your appointment at the end of the day because we have to do a special clean after you're here. Sorry, I guess the lady didn't know that.' It's like, really? And did you need to tell me that? And that kind of stuff still happens, even after all these years later. Health professionals that have had training in universal health precautions. There's been so many times over the past 30 years, nearly 30 years, where I've sort of shook my head and gone … I mean, well I think, I can take it, but then you think … you know, somebody who was newly diagnosed or had never encountered that kind of discrimination, they'd be really hurt by it. I can kind of go, 'yeah okay whatever,' but it's appalling. It's appalling, and it should never happen, and you should never be treated like you're some sort of special class of infectious … like 'lets move that to the end of the day, let's put that off in the corner,' you know. But it still happens. There was somebody who was writing a paper it on through the ViVA women's online listserv. She was asking for people's experiences just within the last five years. So I didn't contribute, just because my last five years have been about giving birth and having breast cancer, not about HIV.

But even in terms of the differences that I've seen in dealing with health care professionals and seeing how there's no confidentiality in the cancer world. So on the folder that has my file in it, there would be written in big bold letters, HIV Positive. Or it would have a bright pink post it note saying HIV, like in huge letters that you could see from … and then it goes into the folder, and every single person that comes into contact with me will see that written on the outside of the folder. Not the inside, the outside. And how many times I've said to somebody, when they ask me how I get HIV, so do you ask people how they got cancer? Why are you asking me how I got HIV? Like would you be satisfied if I told you, is it salacious enough if I told you I got it the gold old fashioned cock and balls method? Is that any of your business anyway? Or oh, I get it, because if I got it through IV drug use, then I would deserve it. Or what? Not sure, right? But yeah, there's … it really does blow my mind and there are often times when I just sit back and I go, wow. Wow. And even in terms of the doctors saying certain things to me about, 'well, you know, that other condition that you have' [whispering]. Because they don't know anything about it, they don't understand anything about it. I've said actually to my medical oncologist, man you guys could really take some notes from how HIV has been deal with not only in terms of how you treat the disease, in terms of an integrated approach, in terms of targeting different aspects of cellular life, like how cancer grows and divides and spreads, right. So they're starting to take more of an integrated approach and using combinations of pharmaceuticals that affect the replication cycle at different points, just like they do with HIV, but they're still really struggling with this. And this has been going on for how long now? Currently in Canada, one in seven women will get breast cancer. One in two men will have some form of cancer infection in their life and one in three women. So the one in seven is just for breast cancer specifically. And on top of that, you've got heart disease which is the number one killer. So I do recall, I don't know I think it was 20 some years positive and the doctor took me aside and said okay, she was all excited. I used to be a patient of Dr. Burgess, of course, I was at St. Paul's to start with. And I moved over to the Oak Tree Clinic with Dr. David Burge, and he had a doctor I mean he's long since retired, but there was a doctor that had come to help out at the clinic for a while. And her name was Dr. Kestler. I think she's in Calgary now. But she was so excited to meet me and kind of like, 'Do you realize how special you are?' and I just sort of laughed and was like, 'No.' And she was like, 'The numbers, so you're about one in forty people—and about 10,000 have been diagnosed in BC so far to date—that could be classified as a long term non-progressor. You've never been on medications, your viral load was undetectable, your CD – at that time my cd4's were still eight or nine hundred. And I've been through cancer and through giving birth and through living with HIV for 29 years and I'm still at 550 before I started the medications. So one of my girlfriends out east said, well typically if you were to leave it for a decade and not take medications, you could be in a situation where you're in the hundreds and millions for viral load, and less than 200 cd4 count. And so, conceivably I could have lived out the rest of my life without having taken medications, if it weren't for the breast cancer.

And the fact that I am not just responding very well. And there's the hormonal aspect and stress. So stress is a real wild card. And something that unfortunately, being in stress response really takes a lot out of your immune system. And it also kind of shuts down periphery function. So if you're in high high levels of stress all the time, you're what they call in fight or flight. So all of the other non-essential functions start to kind of fall away. And so your body can't allocate the resources that it needs to healing when you're running from the saber tooth tiger, right! So this has been a really big challenge for me to deal with the psychological and the emotional aspects of having breast cancer that mine all of that all stuff from my HIV diagnosis. It's sort of like, you know, picking up the rocks that have been hiding these things for years. Things I thought I had dealt with. Things that I didn't really think were an issue anymore. I had sort of moved on and moved upwards and didn't really … thought okay, yup, I've done that. Check, next. No worries. And then you go, oh … So in my experience the journey of life is not a straight line, a straight path, it's a spiral. And you come back to the same mile posts, if you will, at different junctions in your life and you realize, 'Oh, here I am. I thought I'd processed this but here I am looking at this in a slightly different way, from a slightly different perspective. And there's still opportunities there, to look at and peel back and unpackage what that is and what that looks like. I found some answers, I found answers in many ways throughout my life. And wanted to find meaningful ways to engage with people and I think that's why I became an activist.

BK: Can you tell me a little bit more about that?

JS: Well the first thing I went to was a focus group on hospice. And to put in my two bits on how I felt people needed to be supported in dying. And that really blew my mind. And then I took part in a nursing student's master's thesis on creating a mandala model of health for people living with HIV. And then I started looking around and looking a bit more critically at what was going on around me. The broader context, so not just myself but what is the lived experience and do I share some things in common? Like I said, I didn't have any gay friends when I was diagnosed, I didn't know any intravenous drug users, I wasn't in any of these high risk categories or demographics. How I even … I don't know. So at first at the Village clinic I didn't feel like I had a whole lot to contribute or participate in. It didn't feel like the kind of place I belonged, I mean it was a gay men's clinic and the only reason I was there was because that's where the HIV doctors were. And then I eventually, through meeting other people—there was a women's group through the walk in, or sorry, what we called the living room project which I actually ended up working through. And then I eventually became the secretary for the board of directors at The

Village Clinic and became the chair of the strategic planning committee, and we amalgamated 5 agencies into one over a several years process and created a new organization called The Nine Circles Community Health Centre. So that whole process took several years. I was also involved nationally as well as even internationally. So that was really eye opening. I didn't feel like I had much of a foundation though. I think part of me was just gobsmacked, part of me was just in awe that I had such a meteoric rise so quickly, but it scared me too, because the need was so great. Like the demands and what HIV would ask of me would never end. It would never stop, there would never be enough of me to meet the demand and what people needed. Whether it was women living with HIV in Winnipeg generally, women living on the street, sex trade workers, it didn't matter what demographic you either fell into by chance or by curse por whatever that might look like. And I just eventually after attending a conference in Toronto I was elected representative for the north American continent and sent to Geneva, Switzerland to represent the North American continent for the global network of people living with HIV and AIDS. Yeah. And I was sitting at the table with heads of state and health ministers holding the portfolio for their countries and looking around going, I'm just little me from the inner city of Winnipeg, and I'm uneducated and I don't know what I'm doing, like what am I doing here. And it scared me because it was so vast and so great and I didn't want to be a martyr. And back in those days, boy id tell you the whole AIDS industry was a real gravy train. There were these conferences going on all the time and doctors and representatives from NGOs and stuff. You could be going to different conference every week if you wanted to! We don't … there's big differences between the Canadian health care system, and we look at Big Pharma as this overlord, this evil overlord powering the world, and that it's all about money and greed and people are dying so pharmaceutical companies can continue making billions and billions off these medications, devoid or divorced from the impetus that got people health care in the first place, and that's to help people, to help people heal. There's this divergence, and we kind of lose our humanity when we get too diverted by all that stuff. So what mattered to me was being able to focus on the things that actually affected people's lives. Where the rubber meets the road, right? So I helped to fundraise for the emergency health fund for people living with HIV, because that directly went to people living with HIV. It wasn't like here's a big pool of money, you know. Because the organization that I helped create through this joint strategic planning process had a several million dollars a year budget and here I am, some illiterate uneducated women from the inner city helping to—there were people who felt that people like me shouldn't be on the board. That we didn't have the education, the capacity, but yet we were the people most affected. So there are lots of people saying no no we need to clear a space. No, her voice, because me as a positive women, I would have represented one voice in a sea of … being drowned out from all the other voices. So who better to represent the voices of people, all people, not just—because it's like you can't speak for the Aboriginal people unless you're Aboriginal, or you can't speak for the women unless you're a woman, or you can't, you know. And then we get all divided by you have to be gay over here, or you have to be straight, white—you have to fit in this little demographic pill box. It just separates us. So I think it was a little bit difficult in the beginning for women to feel safe and like they belonged in a place that was also for male sex trade workers. So our living room project was, we're trying to get this group going for women when it's also a drop in centre for male sex trade workers. And so I think in the early years, they just threw everybody into the same pot. 'That'll work out, no problem.' But I mean I think when it comes to women, we're just so diverse, that it's not as neat as saying you can have a gay man's clinic and you know who your audience is, you know who you're serving, you can delineate some of your terms of reference and what their needs are. But with women, you've got so many different defining factors. Do you live in a city? Do you live in a rural area? Are you married, are you single, do you have children? What's your family situation? I think it's a lot different, and having gone home this last year in May for my niece's wedding, and being back in my hometown again, and having the juxtaposition of living in this tiny northern BC town of 5,000 compared to going back to the big city, and remembering not just the places that were part of my life and part of what defined me as a prairie girl. And the places that either tore me down or made me stronger. It's an integral part of who I am. And I've always identified with being Prairie girl. And especially in this part of the world, in Western Canada, because people are so grand here. They're just so grand, it's so extreme. You know, you can't just be like, 'yeah, I ride a bicycle.' It's this extreme, you're either hardcore mountain biking enthusiast or road racer with the tight little outfit on and matching helmet. Like before I moved west, I had like two pairs of shoes. Here you got to have dock shoes and brogue shoes and hiking shoes. I don't know I'm not saying people put on my airs here, but I would describe people on the prairies as more salt of the earth folk. Unassuming, just friendly and open and not quite as self … I don't know if fulfilling would be the right word, but self-focused sort of. And maybe part of that is the time, too. The era and the generation. I feel like I'm straddling many worlds and straddling these very different worlds. And my experiences earlier in my life of living with HIV. You know when I would do outreach speaking occasions, I had a partner, and he did the HIV 101 with like the traffic light metaphor, like red—so we're talking about boundaries, so what would be a red-light situation? When do you put the brakes on kind of thing. Yellow light – when do you proceed with caution? When is it good? Just tools for teaching high school students how to negotiate safer boundaries, how to negotiate in compromising situations where there's maybe alcohol or drug use going on as well, or you're in a northern community and you don't have the support services or support even from you're family, and there's more pressure, more alcohol or drug use, and things like that that compound things, make it a little bit more difficult to be really clear about negotiating for safe and appropriate boundaries. And then I would stand up and just blow everybody's minds with like, I'm the girl next door. You'd never know it looking at me, would you? Right? So that's the idea, that it's up to us as individuals. Nobody else is here to save your life. Nobody else is going to say, 'm, yeah, by the way, I have an STD. that's going to be okay, right? Because you could beat me senseless or kill me right, but we're going to be okay with that, right? We're just going to double bag it,' or whatever the case might be. That's not going to happen. And I knew of several individuals who were continuing to have unprotected sex knowing that they wer HIV positive, and were just like, 'Pfff, I don't want to wear a condom. Oh well! Like I'm not a saviour, that's their problem, they get infected that's their problem.' You got to be kidding me, right? And that's way back, that's not even now when since '96 we've had anti-retroviral therapies that make you undetectable, so you don't even have to disclose anymore if you don't want to. And that to me, I think to me, speaking from a historical standpoint I think that's the most significant thing. To come from an era where, talk about body politics, right? My body is a legislated weapon. If I chose to be intimate with you and did not disclose with you, you could have me charged with attempted manslaughter whether I infected you or not. As if women don't already have enough to negotiate for their safety and well-being, then to add that to it. I can't possibly imagine … I actually have personally had very good experiences with my disclosure experiences. Right from telling my family, I mean obviously my parents were very surprised and very shocked and did not believe that it was possible. In fact my father would defiantly say, 'there's been a mistake. I cannot believe this, I cannot accept this.' And my mother, thinking I'm sleeping with gay men, like ‘oh my god! How can this be? This is impossible.’ And hearing that so many times after I’d been diagnosed. And now coming full circle having breast cancer, not a single person has asked me how I got breast cancer. Not a single person – this is the difference between the pity people for you. People feel sorry for me and I’ve had to forgive myself and accept the fact that it’s okay for people to feel sorry for me because it is tragic and it is sad. And I would feel sorry for somebody that has been through even a fraction of what I’ve been through. But especially to have faced all that I have faced, to persevere against just such tremendous adversity to be the caregiving executor for both of my parents while they died of cancer, have my own fertility struggles because I always put other people ahead of myself, and then to finally succeed in having a child only to be diagnosed with breast cancer a year after having my son. I just … I have accepted that it is a great tragedy and it is very sad. And I need, as I did with my HIV diagnosis as a teenager, I’m searching for the meaning in it. I’m struggling to have my creative fires transform me in a way that will allow me to face whatever is coming. I think when I first got down here for treatment in September, they probably would have just given me months to live. And now I think I’ve been finally responding to treatment and finally making some traction. But you know, whatever it is that allows us to heal, and I say allow not by accident, that it’s not a pill and it’s not a treatment. It’s not just a physical thing that you do, that healing is something that comes from within. And it’s a force that mediates between who and what we are and the earth. And that these … we don’t have to believe in it, we don’t have to understand it or comprehend it, but we have to be open and questioning. We have to be willing to be taken on the journey. And that in equal measure there is a letting go and a taking on or holding on. And I think that’s the balance that we’re trying to seek, finding in equal measure, that degree to which we must die in order to live. And as much as I don’t like to think about it, I am preparing for my death. And I don’t want to die. I don’t feel that I’ve done anything to deserve to die or to deserve to suffer so horribly, because it’s not the dying that I’m afraid of, it’s what will happen to me getting there. How often I joke about ‘Yeah yeah, they haven’t killed me yet!’ Honestly, I’m afraid of the Western allopathic medical paradigm and all the tools and tortures they have at their disposal. And I have been contemplating medically assisted induced death. A death on my own terms. That wasn’t an option for my parents. My mother used to say that we treat out pets more humanely than we treat each other, that at least you can help your pet end their suffering. With human beings, we prolong things to the point where it’s questionable whether you’ve entered into the realm of torture. So yeah, that sounds a little bit depressing and awful to think about the details of that. And most of us never do and don’t want to. But I think of all the ways I could have died, and all of the second chances that I’ve got. You know, when I was only given 2 to 5 years to live, it just seems like … 30 years next year, right? Touch wood. How is this even possible, I definitely didn’t think I would live this long and I remember there being a point at which it was like ‘oh, well, I guess I’m not dying am I? I’d better get on with it.’ My goal was to live as mindfully and as present in the moment as I possibly could and it took me several years to enter into that kind of mindfulness. I think it was pretty much two years of consistent yoga and meditation practice before I even experienced silence. I was just so explosively wound up and charged, I had so much that I had suppressed from my childhood abuse and everything that had gone on with my parents and my stepsiblings, that I was just so angry. I think there was just so much that how do you even clear a space to start to peel the layers back? So being diagnosed with HIV gave me the invitation to do that. And when I would go and do public speaking engagements, I would tell high school students that it was the best thing that ever happened to me. And people are like… don’t mistake that for me saying I wanted it to happen or would have chosen it if I was given a choice, I certainly would not have chosen this. But it made me stop and slow down and re-evaluate my life. And I know that I would not be the woman today if it were not for HIV. And full circle, HIV is saving me again, now that I have metastatic breast cancer, because it's the HIV programs and services that are helping me. And it's the people that are out there on the front lines supporting people like me, that are helping me to celebrate myself again and helping me to feel heard and seen and valued. The BC Cancer agency is just a kangaroo circus. It's just unbelievable what utter chaos and discombobulated … oh my god, yeah. And I mean, sure, you meet some very nice nurses and you meet some very personable doctors and everybody's hearts are in the right place, but it's so disintegrated and the throat doctor from here up doesn't speak to the internal doctor from here down, and the foot doctor doesn't talk to the hand doctor. Like it's just ridiculous, the whole thing seems like quite the comedy of errors. And you kind of have to shake your head and think I'm just not sure how any of us navigate through any of this and are able to come out with clear directives and a clear understanding of what you need to do. And it's true that I've chosen not a strictly conventional path, and I've been fortunate enough to have options for an integrated path and for choosing less toxic, naturopathic treatment. But now I'm on an oral chemo and I've done radiation. But yeah, I had to get to a pretty desperate state to submit to that. Because my concern was if I had full dose chemo when I was first diagnosed, the treatments would have killed me quicker than the cancer would, or worse yet, that the chemo would trigger full-blown AIDS. And of course, the doctors were like 'we don't know anything about that. We're not sure how to deal with you, honestly.' And you know, I mean since I have had since had adverse drug reactions, I can share a great concern with the fact that I believe that death from medical accidents and properly prescribed pharmaceuticals is I believe the 6th leading cause of death in the United States. I would imagine that's probably under-reported, especially in the cancer world. So my own adverse reactions to medications have left me with some really grave concerns about the fac that pharmaceuticals are not safe, they're touted as safe, we're told they're well tolerated, we're told that a small percentage of people have these side effects, and you know, the way they report all this stuff. And you think, how bad can it be? The goal being that a treatment isn't so toxic or harmful that it is irreparable. So that's the trick, is to find a treatment that keeps the situation enough in control that you're not in threat of imminent death, but it's a completely different … I don't know, did I go complacent? Did I think that because I was one of the lucky ones, having been able to manage living with HIV as a chronic manageable condition I can have for a lifetime, versus cancer which can basically chew you up and spit you out in no time at all. And how do you navigate that? I don't know, it doesn't seem to be something that there are clear answers to. And everybody's different, and that's something that they're having a real hard time accepting that 'well, yeah, we can try this and we can try that, but you're different. Everybody's different.' So when you enter into the more naturopathic realm or … I consider myself to be on an integrated path, although standard conventional Western allopathic oncologists might think that my path is quite alternative, I am on an integrative path, which means I'm perfectly happy with picking and choosing between a vast array of options. That I shouldn't be forced into taking some protocol that was established by some best practices at a teaching hospital in the united states and accept wholeheartedly, without any critical thought or consideration for what other unintended consequences the treatment might have. So luckily, my past experiences with HIV kind of helped give me some capacity and some tools for being able to talk to doctors, being able to ask intelligent questions, being able to weigh … do my own cost/benefit analysis, if you will. And the terminologies that they use, the terms of references that they're using, lot of times they are very surprised … I even had the radiation tech that did my radiation last week, I asked him a bunch of questions and he was like, 'nobody ever asks me how many gray their getting. Are you in the health field?' he said. I said, 'No I'm not in the health field.' And he said, 'Well, you're very knowledgeable.' And I said, 'Well, because I have to be. Well, thank you' kind of thing. But I thought yeah, basically, being diagnosed HIV positive , well, just after turning 19 and then getting advanced metastatic breast cancer at 44 has given me a kind of extraordinary, off the books education about how to navigate through all of this, and understanding that different disciplines have different words and different terminologies but that … My university education had a lot to do with studying ontology, which is worldview and epistemologies and methodologies. So understanding that it's a plurality of realities, that it's a multiverse not a universe, that there are many systems of science, many systems of knowledge, many methodologies, many ways of doing things. There's no one right way. And being able to embrace that, being able to celebrate that, being able to rejoice in that is one thing, but in practice, I'm not going to sit down and act the medical oncologist to speak to the efficacy of my naturopathic treatment, or speak to something that they know nothing about. 'So tell me doctor, which vitamins should I be taking?' they just look at you like, 'Uh, I received two hours of education on nutrition in my …' Yeah, so that's, no, you don't go to the mechanic when your washing machine breaks down. That's a big part of the negotiation process and I think that's something that's just really lacking in the cancer realm versus the HIV realm. And that, to me, to come from being diagnosed in a little gay men's clinic to then watching this organization grow, becoming part of the board, becoming the secretary of a very, very politically hot organization that had hundreds of members, like people were very involved and very invested, like the village clinic was their place. To then, joining the board with ongoing nepotism and gravy train gluttony going on like you would not believe. Being $80,000 in debt. Like all kinds of problems going on, friends hiring friends, board members getting their partner's jobs, and all kinds of crazy … To having this organization become more inclusive, growing, expanding, taking on new roles, beginning to reflect like a whole other world, a whole other part of the community, right. And that's another thing I've always sort of had a problem with, is referring to us as a community. An HIV community. It's like, a what? I sort of, you know that sound of the record scratching [imitates sound]? Like, wait a minute! Community, what community? So just because – circles back to this notion of women, how do you find a place for women to come together and relate to one another when women are so different? And how do you create a drop-in centre that's for male sex trade workers and HIV-positive women, just because there's nowhere else to fit the funding. But I don't know, I found it really fascinating just to see what can happen when people come together in a safe place, and where you can be yourself, and it doesn't matter, like you're not under threat of the imminent attack or destruction because of something you didn't even do anything, you know what I mean? Something you had no choice in, something you can't change, by hook or crook or prayer or theft, nothing is going to change or take that away. And to be cast, to have your whole life defined by something that you had no say in to begin with. I can only imagine how people that are born with HIV feel, and have to negotiate through all of that, like puberty … you know, I've been closeted in our town because, well you know, we have 5 street lights and everybody knows everybody, and I worried that businesses [inaudible] would walk away from my husband if they know that his wife was HIV positive, or parents might complain that they don't want their child eating lunch with my child because his mom is HIV positive. People think, 'Well that can't happen.' Oh yeah, it can. Yeah, it can. I mean if your child can be expelled from daycare for biting, imagine if you were HIV positive and you're biting. You know what I mean? But, I'm just amazed actually that as I was saying before, that the power of a pharmaceutical to remove the stigma of once you attain the holy grail state of non-detectable, you're free to go out and have non-disclosure sex with whomever you want, and your body is no longer a legislated weapon that you could be charged with attempted manslaughter. Has there ever been anything in the whole socio-political history of humanity that you can draw a parallel to? I don't know. Because I took the medications when I was pregnant, obviously to stop transmission to my son, which was successful, my son is HIV-negative, and he's just a miracle. But the fear, you know my husband calls it running the gauntlet. So I think that the greatest stigmatization of HIV is not what others judge of you or condemn you for, but it's how you condemn yourself. And all the things that I held myself back from in life because I was afraid of my infectiousness. If I let you love me, I could kill you. That's how I chose to feel. I've known people that chose to feel like 'fuck it, fuck this world. I'm going to go out there and I'm going to take as many fucking pricks as I can on the way.' I've actually known people, sex trade workers, who are like 'Pfff, I'm going to go out there and I don't give a shit who I infect. I'm going to do what I want. If you're stupid enough to not want to wear a condom, well that's your problem not mine.' Which I found shocking, I mean, I don't know how long it was before I even had sex. I don't even know, I think I regrew skin there it was so long! I was like a born-again virgin, never mind a born-again Christian. SO yeah, to go from that, where I didn't even know, couldn't even possibly, like I was so paralyzed by my fear that I couldn't let anybody even near me, not even touch me, not drink from the same cup as me, not get close to me, not – nothing. And then at some point I realized that I was spinning my wheels. I couldn't carry on in a life that was so isolated, that how was I to evolve as a spiritual being if I wasn't in relationships with other people? Because relationships are like the arena of our evolution. How do we evolve if we're not in relationships? It's like cutting my arms and legs off and then expecting to live this fabulous life as like a potato, without any means of locomotion. And so I think getting involved in HIV activism was a way for me to find my voice in a much bigger world and make meaning out of the tragedy that was my life and feel like if I could help somebody not go through the kind of suffering that I had gone through alone and isolated, that I would have done my job, that I would have served a purpose much greater than my own life, because at a certain point, it doesn't even really matter anymore, you know what I mean? It's like how I kind of feel like now that I'm stage 4, been kind of given the speech to get my advance directive in order and prepare for my death, that everything just falls away. Like window dressing. And you just don't cling to things like you used to when you were younger, and you were hungry and you want want want. Now I just feel like, you know, it's – I feel more in the absence of than in the presence of if you know what I mean. The days where I don't have any pain, I'm just so happy. I'm just so happy because I'm not in pain. And I would imagine that it gets to be like that the closer to death that you get. That everything just falls away and there's clarity and all the things that you chased, you know, you just have a different perspective on it and you kind of – like I look at my sexuality in my youth and I think oh dear, oh boy, gosh I wasted a lot of energy on, you know, late nights out dancing and caring about whether my nail polish matched my shoes and, you know, fashion. [laughing]. Fashion, that's a good one! Because that's what they say, you know, in our little town, we've got 5 street lights, 17 streets in one direction, 22 in the other direction, fashion, the point of fashion is to be seen. If there's nobody to see you, then what are you worried about? So I have a kind of functional chic I like to call it, sort of like a little bit sporty, little bit girly, but really functional.

BK: Very BC.

JS: Yeah! You know where you got the car hearts on the bottom and the lululemon on the top. You know, its like urban meets back country car heart. So yeah, you've got to be prepared for whatever comes your way. Life has kind of been like that for me, straddling these two very different worlds and trying to negotiate how to move forward and how to take the wisdom that I got from my early experiences with such a, you know, being so young when I was diagnosed, and kind of creating a fusion with my educational, my academic career and now being in a position where I'm in a large enough urban setting that I might be able to channel myself into something that I can find voice and vision and use my creativity to manifest my spirituality again. And that's, you know, I'm really in this place of creative fusion where I'm—it's like being in a messy kitchen, there's lots of smells and tastes and there's all this kinetic energy going on, and you're not sure exactly what's going to happen. You've got a basic idea of what you're doing, but even when you follow the recipe, you might end up with something that you weren't counting on or that wasn't really part of the plan. But nonetheless, I think it needs to happen. And I think if there was one takeaway, like I'm in the process of trying to create book for my son, but if there was one – if I could sit down and I had an opportunity to give takeaways to my son about my own life and about the experiences that I've had, as well as a takeaway for the world, if you will. It would have to be about, it's like Confucius said, wherever you go, take your heart with you. Give it everything you've got. I would want my son to go after life with all the gusto and all the passion and all of the pride and all of the glory that he could possibly ever muster for the whole world. But that for all of us, that we could step back and that we could see that death is something to be celebrated, that death is graduation day, that it's not a failure. We don't lose our battle to AIDS or cancer, we triumph. And I've heard some amazing stories of people who have undergone the most profound and transformative end of life experiences that don't result in healing and staying on this existence, but the peace and the, what would be the word, restitution, reconciliation, I don't know what the word would be. Kind of consolidating, if you will. That's what I would hope that people could see what an incredible opportunity the knowledge of your death will bring you, because if you had a clock that told you how many minutes and seconds and hours and days and whatever you had left, you would live your life differently. You wouldn't take things for granted. And you wouldn't say I'll get around to that, I'll do that not today, tomorrow, next week. I think HIV gave me that. But I grew complacent. I did, I thought that I'd beat it. And again, there's more of that language, but it's not about that. Because it's actually been more of a dance. It's not like I just left it in a dark alley and abandoned it somewhere, forgot all about it and moved on in my life and left it in some corner where it never gets pulled out or sees the light of day. But you know even for years I never eve wrote those words down in my journal. Like as if I just didn't write HIV positive on a piece of paper, if I didn't see it in writing, it wasn't real. And in many ways, it hasn't been real for me. It has, but it hasn't. Yeah. But it's been more of a gift than a curse. It's already saved me once and it's saving me again. And if that isn't a cruel irony, I don't know what is. So, I suppose I could have reacted to it a lot differently. Could have denied it, could have not embraced it, lived in defiance of it. But I think about all of what life has brought me, right on the heels. I wouldn't trade it. I wouldn't trade it for the most privileged of a life. I think that the struggle, it's the struggle that's real. And it's all that comes from that, all the unintended that comes from that that gives us our greatest treasures and our greatest gifts. And we don't see them like that, right? We struggle against it, we wish, 'why me'. But I don't think it's about why. So I'm actually kind of in the process of doing a little bit of writing and mind mapping and trying to figure out how I want to delineate, how I would want to tell segments of my story, what sorts of things I would like my son to know about me. What are the defining features? Because it's not just what, it's how. Won't be about why. And the world is just zipping along. Because this all happened before we had Hotmail and Facebook and Twitter and now I'm the old one. Now I'm like the senior citizen trying to figure out where the button is. Like when did I get to be the old one? I don't know. I look at myself and I don't feel that much different, I don't look that much different, but I'm a stick in the mud senior citizen that can't figure anything out. And my four-year-old is already treating me like, 'duh,' like he's a teenager and he's only four and a half! It's like oh my god, what am I in for.

BK: I think we've really covered most of the questions that I was going to ask you. I'm just very grateful that you shared this with us and with me--

JS: Thank you.

BK: --And just deeply thankful.

JS: Thank you, I appreciate that. I don't think there's enough real listening going on in the world.

BK: Was there anything you wanted to add before we wrap up?

JS: I look forward to learning more about your project and hearing some of the other voices. I'd really like that. Sometimes I feel like I'm a lone voice in a very vast forest and I'm not sure anyone can hear me. So thank you for hearing me, for listening to me.

BK: It really is my privilege

JS: Thank you.

BK: I'm just going to stop this if that's okay with you

JS: Sure.