

HIV in My Day – Interview 17

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Interviewee: Jake Thomas (JT); Interviewer: Jackie Haywood (JH)

Jackie Haywood: Good morning, Jake. Thanks for helping us out here and sharing your story. When did you first become involved in the gay community? When did you first become involved in gay outreach?

Jake Thomas: I came out very, very young. I came out in my hometown. I had a friend who was part of Wallaceburg Little Theatre that was married to a kindergarten teacher but wore dresses. They had a very open relationship and he sort of mentored me as a young gay man. There was never any sexual contact with each other, but he knew I was gay and eventually brought me to see the gay community, and it was quite wonderful actually.

JH: What did that gay community look like then?

JT: It was very secretive. It was three stools in this bar, or this path in this park, or that sort of thing. It was all very hush-hush, and nobody knew about it. At the same time, it was kind of wonderful, 'cause everybody had to sparkle and be bigger than just stay bland commodity of being accepted. We had to make our own way, our own lath, and I think that gave us a more power because of it.

JH: Did that move onto a larger community, a larger city, or branch out more?

JT: Well it's – yes, I had trouble fitting in with wherever I went. I didn't feel comfortable in the gay community, I'm not exactly sure why. I never felt I was a hippie – I loved being a hippie, but because I was a homosexual, I didn't quite fit in with them either. So, I had a lot of trouble finding exactly where I should be. Theater was the one place that I felt at home and it was odd because it was older people, wasn't a lot of people my own age, but I felt very comfortable and very... I could do anything there and I was accepted, and I really enjoyed that. The gay community, you had to be pretty, you had to be butch, you had to be this, you had to be that. Not all the time, but sometimes, it could be very difficult to fit into what they wanted you to be.

JH: What was that age, that date – what years are we talking about here?

JT: Nineteen. Well, from when I was fifteen till I went to theatre school at twenty-two, I guess.

JH: What did the community look like from your vantage point before AIDS, looking out at the whole community?

JT: It was a wide-open wonderful experience. It was the age of love, the summer of love continued on, and the gay community was very much a part of that. We were freewheeling. I met my lover in 1973, I went to Fredericton, New Brunswick, to have an affair with the prop master. The prop master was having a meeting about organizing a gay community for Fredericton and my lover showed up at this meeting and wasn't leaving till he got laid, and I came home that

night and Tony was there. And I was there and I never had the affair with the prop master, 'cause I couldn't get out of bed with Tony. So, it was pretty wild and I got to go to San Francisco and see what was happening down there at the time and we had travelled a lot in the early days, bouncing back from Vancouver and Toronto, San Francisco and Seattle. So, I got to see a lot of gay communities. The drag queens were wonderful, the clubs were wonderful. It was a very special time.

JH: When did you first hear about AIDS?

JT: I guess I heard about it when friends of mine started having strange diets. They stopped eating bread, they stopped eating certain... they, you know, said it was because of this or because of that. And later on, I realized that there was an epidemic going on and it wasn't just a diet that they were going on, they were trying to fight a disease.

JH: Let's move you to Vancouver. When did you move into Vancouver from the travels?

JT: I came and worked at Kaleidoscope Theatre in Victoria – I guess that was about 1976, and I lived in Victoria till '79 or '80. Till about '79, yes. And then I came over to Vancouver. I started a gay theatre company called Stage Drawer Johnnies. We did a little production called *Touchdown* at the Arts Club on one Sunday night and we did a radio program for Co-op radio, a gay version of the King Arthur Legends, where Merlin disappeared in pink smoke and Arthur broke his four-inch alligator sling back pumps romping through a forest one night and had to get a cobbler named Lance to fix his shoes, and so the story goes. It was very Monty Python, sort of fun, and very interesting.

JH: Did AIDS surface in your theatre experience in Vancouver? Did you see it in the community?

JT: The AIDS?

JH: Here in the city, yes.

JT: Um, well... [long pause] Shortly after I was diagnosed, I went out and found out what was going on, although at the time I was very afraid of the stigma of AIDS and HIV. My lover was positive at the same time and he wasn't [afraid of stigma]. He joined PWA Society, he went on this fabulous retreat on Vancouver Island, came back with a dress he had stolen from their costume box, and talked about how much fun he had had and how great these organizations were. But it took me a long time before I could walk in the door of an AIDS organization, because I didn't know if I wanted to belong to that community. As I said, I have trouble fitting in and I didn't know if I would fit in to this community. But eventually, after Tony died, I finally walked in the doors of Persons With AIDS Society and met Jackie Haywood, who immediately asked me if I would be interested in doing a theatre program around HIV/AIDS, and we did it, and it was great. And I also eventually ended up volunteering at their little clothing store, Polly and Esther's, which I still work at to this day.

JH: What were the sources of information available, with you, when you were first diagnosed?

JT: Word of mouth, mostly. I can't really remember a brochure and there was so much misinformation going around, you know, that – to begin with family, my family would immediately wash all the towels when I left the house. They didn't know how it was – nobody knew how it was transmitted. There were a lot of people that were very uptight. The original IDC clinic at St. Paul's, the door was right on the main road and anybody going through that door could be seen by the general public. And that was a big stigma of walking through those doors and being identified as needing these services. So, it was misinformation and what information was out there, it wasn't very good – it wasn't very good at all. The best thing that happened to me was that I didn't do early AZT when they were giving giant amounts that eventually ended up killing people. So, I think by the time I started the drugs, I was also on the D drugs, which weren't very good in the end anyway, but they at least were better than the massive doses of the AZT.

JH: What was the impact of the news about AIDS with your friends on you and your peer group? How did relationships change, how did people interact?

JT: Well, it made it very difficult to be a gay man. Of course, immediately, it changed our sex lives because we had to be very protective about what we were doing and a lot of us were doing very risky sex, sexual things before that. So, that sort of stopped immediately. And then people would look at you in terms of trying to judge whether – judge you, you know, whether you were a healthy person or not a healthy person. The community went in two directions and there was a lot of confusion and fear, but at the same time there was some extremely powerful people that went to bat and got money organized, everything, to this day. We started these walks, and now everybody does walks. We started the ribbon, and everybody now does the ribbon. We had some very, very powerful people at the beginning that did the organizing of this and as a result the disease I think had a very good grassroots backing. And a lot of money too because gay men tended to be a little better off, better educated, and that was the beginning of the clientele. The Downtown Eastside didn't get involved until a little later and then there was poverty involved in the HIV component, and that made a big difference. And then there was a huge split in the resources of the community and a lot of problems about how do you service the community, and still service that community? How do you service men, how do you service women, how do you service Indigenous people? All of those problems came up almost all at once.

JH: How did the gay community react to the infusion of other groups?

JT: Some not so good. There was a lot of resentment. It was supposed to be a private party and they weren't quite sure. That's just some people. Some other people saw that everybody deserves everything, and it was difficult – it was a bit out of your safety zone a lot of times. And people of different classes, of different backgrounds, of people addicted to drugs, and people that were straight, you know, and had got it from blood transfusions, would walk into a room. And it was very, you know – if it was a gay men's health club or was it going to be an open thing where women could feel comfortable? It was a confusing time of where it all fit in.

JH: How do you think it is today? Just going to roll this forward because you have brought up a very interesting phenomenon.

JT: I think it has gotten better in terms of each little organization has found their niche. The women, I don't think they mind working with us, but they need their own space and their own resources. Same with First Nations people, same with Downtown Eastside, same with professional gay men, and they can all come together, but they all need separate services.

JH: How did the government react to this particular – how did they react in the beginning?

JT: In the beginning, Vander Zalm wanted us all to be put on some island and isolated, and that was it. There was like not much sympathy from the government. People had to really fight to get the drugs, to – they had to fight to stay alive. We were very lucky to have St. Paul's – other hospitals weren't taking people with HIV or AIDS. And they made a decision there that nobody got turned away and that was a wonderful, wonderful thing. And I think Vancouver became a leader in HIV responses because of St. Paul's original commitment to it.

JH: Maybe we could take a break and fill that glass up.

[break]

JH: So, in the days when the government wasn't cooperating, and sounds like they were hostile, what was the impact? Were you impacted in any way? What was your involvement then? What was it like for you in those times?

JT: It was economically challenging because I had stopped working. My doctor told me I had two years to live, so I went on a very small pension from the place I worked at the government – fought us tooth and nail. In terms of any money that we needed, any – housing was a problem, everything was a problem. Groceries was a problem, finding caregivers for all the people that you knew that were ill, hospices – all of those things cost money, and it was very, very difficult.

JH: Were you involved in any organizations at that time that were advocacy based or were you part of any of that?

JT: No.

JH: Okay. So, what was the medical response like in the early days?

JT: I was first diagnosed in Toronto by a doctor who said I had all the symptoms of being HIV positive but he didn't test me for insurance reasons. So, that ended up saving my life because at that time they were giving the strong doses of AZT, so it wasn't until two or three years after that that I actually got a test and knew for sure that I was HIV positive. And that was an experience that was quite remarkable in itself. This doctor at IDC told me that I had PCP, I believe it was called – it was one of the lung diseases that was going around – and put me in a little room and told me I had two years to live. And later on, they discovered that I didn't have PCP, I had scar tissue on my lungs from having pneumonia as a baby. So, he had to come back and apologize that he had given me this bad advice, but later on the blood work came back and I was HIV positive. But I thought, how wonderful. I have always been afraid of doctors and this doctor has

already had to apologize to me. So, I went, “I want you for my doctor,” and this man, Dr. Madsen was fabulous. He guided me through so many things. I was smoking, I eventually got COPD – my doctor was never on my case. He said, “When you are ready to quit, Jake, you will quit.” I also had an addiction to crack cocaine and talked to my doctor about it. He would ask me every week how I was doing with it – not belligerently, not... But he said, “When you are ready, you will quit.” And he had so much faith and confidence in me. And when I stated to do theatre, he came and saw the plays, which was unbelievable for me. So, I have had a great relationship with my doctor and everything – something comes up and he doesn’t know what is going on, he sends me to a professional. He says, “I don’t know. We’ll send you to somebody and find out what this is.” And I really really appreciated that.

JH: Do you still see him?

JT: He is retiring this year [feigns weeping] and I got this wonderful card with all these little chit chit chits until the day of retirement. “I wish I had the dates of the first day I saw you, the day that I quit smoking, the day that all of the bumps and grinds that we have gone through.” But I am certainly going to miss him. He works at IDC as well as has a private practice, and he has mentored a lot of people and he is a great doctor.

JH: Could you tell us about your theater experience in regards to the HIV/AIDS movement?

JT: I walked into Positive Living, or PWA as it was called back then, and Jackie Haywood approached me and said she had a little money in her budget to do a theatre project. Would I be interested? And I thought, yes, this is a wonderful thing. And I thought of all the actors that were HIV positive that I knew of – lots of them had died at that point. We had lost Larry Lillo and lots of people from the theatre community, and so I went out and asked Ian Wallace if he would join me in organizing this. And Ian was busy doing clown work at the time, so Ian couldn’t do it, so I asked Lee van Passen to come and join us, Mickey Brazeau – these are local actresses and directors. Nick Tattersall came in, so we started with this wonderful group of very talented, very professional people, and rounded up some people from AIDS community, and what we did is we tried to do a program that was by, for, or about people with AIDS. So we, because of the stigma of AIDS, some people didn’t want to be identified, so having professional actors on stage with them, you never knew whether this person was a professional or if this person was a person with AIDS, so that kept the blindfold on what we were doing. And we developed – at first I would give them – sorry, I’m stumbling here.

JH: Did the company have a name or title?

JT: It was called Theater Positive and we had started it around 1994. And what we were doing in the beginning – there was an International AIDS Conference in 1996 and we managed to get some grant money from them. So, the first performances of Theatre Positive, I actually got to pay everybody, but it meant a lot to these people to have a little extra money in their pocket. So, that was really wonderful and we got to work in some beautiful beautiful theaters because of it. We originally did some scripted pieces: *André’s Mother* by Terrence McNally, *Poster of the Cosmos* by Langford Wilson, *The Way We Live Now* by Susan Sontag, *Soul Brothers* by Jackie Haywood, and we did a lot of our own work. We did this thing I call the line, where people

would turn and do a sound bite about their experiences of living with HIV/AIDS, and the soundbite might be, “Every time I hear the word AIDS, all I want to do is yawn.” Or it might be, “Bite back and tear every muscle, bone, and fibre from the bone of society.” I had drag queens, I had political activists, I had little grandmothers. I had this wonderful woman, I wish I had made her knit socks on stage, but she would stand on stage and say, “Who is going to make love to a woman who has a deadly virus in her body?” with such sincerity and such heart. And this woman, backstage, would be throwing up – she would be a mess. We had, I think, three or four people prepping her every night to get her out there on stage, and once she got out there, she blew the audience away. And she went on to do a lot of public speaking and being on a lot of boards and did a lot of very, very good work. But she was scared – boy, she was very scared.

JH: I understand there was some community bringing Theatre Positive out into the community with the Fringe Festivals.

JT: Yes, after we did the International AIDS Conference, we looked around for a venue and we thought we would fit in with the Fringe. They did all their advertising, they supplied all the technical people, they gave you a venue to perform in. I think we did six or seven years of Fringe shows. We did one called *Dancing With My Dead Lover and Other Stories*, we did *Westside Story*, we did *Synergistic Energy Exchange*. We had various titles, we wrote some of it, and some of it was scripted. It was very interesting, but it was also very difficult because all the time, rehearsals, you were dealing with people who were ill, and it was hard to schedule rehearsals – people wouldn’t show up. Eventually Theatre Positive died out because I was using the same people over and over. I personally was getting burned out and tired. It needed an infusion of life at that point that just wasn’t coming. And it is a very difficult thing working with people who have an illness and can’t stick to a schedule the way that other people can. It would be a little easier now that the drugs are better, and now that people have a better handle on what this disease is about. They could possibly, because it was also an emotional investment that was very, very large to go on stage and possibly be known as somebody with HIV – that took a lot of courage, I’m sure.

JH: What was the impact of the theater work on you as an HIV positive person?

JT: It overwhelmed me sometimes – the dignity, the depth with which people... I would give them a little seed, a clue, you know. “Tell me how your parents took this news. Tell me what your hopes and dreams are.” And they would come back with the most fabulous stories. I was amazed with their openness, their honesty, their wonderful creativity in how they wanted everyone to know what was going on with them and their lives.

JH: How did the public react to the epidemic through your eyes?

JT: I think the public was very afraid of HIV at the beginning. Nobody knew where it was coming from, so it brought about more isolation than it should have, stigma and poverty because of it. Society didn’t handle it very well at all, and then things started turning around once information started getting out there. The more information there was, the better people could understand – healthcare workers, general public, families. Families were probably the hardest hit

when they got news that their son or daughter was HIV positive – they had no support. Who do they go to to find out, “What will I do for my child now?”

JH: How did your family react?

JT: I told my oldest sister that I was HIV positive. By this point, my mother had died and my father was quite old. And she asked me not to tell my dad. I think he knew anyway, ‘cause he was a smart man and he just knew me. But it was never discussed – I discussed it quite openly with my brothers and sisters, but yeah.

JH: How did – gay men that survived the epidemic, how did they survive?

JT: It was difficult. There was a lot of, “Why did they die and not me?” in the community. When my lover died in 1993, he died of aspergillosis, which is a fungus that is not a very common way for people to die, but it was horrible on him. And we went and looked at hospices to put him in and they all looked very sad, and he said, “Please don’t leave me here,” and so I kept him at home until the day he died. And so, the way aspergillosis works, his doctor said that it will eventually eat away at his lungs and one day they will pop like a balloon and he will drown in his own blood. And one morning he was ill and we called the ambulance, and the ambulance men started yelling at me that, “He has shit his pants! Did I know that?” And my lover is crying and I said... And I said, “Please take him and I will...” I didn’t want to get in the ambulance with these men. And I said, “I will join you at the hospital in a few minutes.” And an hour later, his doctor called me and told me he had died in emergency. That was very, very difficult because of that, and then that very evening, the police showed up at the door. I think they wanted to do a B and E. “Do you know the man who lived here died today? Who are you?” Luckily, I had some powerful women there with me. I was running around trying to find the will to show them that I lived here with this man and it was very very strange. It was like I didn’t understand what they were doing there and it was at one in the morning that they showed up. So, that whole day was very bizarre. I never knew exactly if my lover’s lungs burst the way his doctor told him they would burst, and that he died, hopefully, immediately and without pain, but it wasn’t a very nice day.

JH: Is it a different day now with HIV positive people? What lessons, if at all, have we learned from that time?

JT: I think the care is much better now. I’m not so sure about hospices – I think that they are still very sad places to take someone, but that is sort of the name of the game. If you are dying you are dying, and if you are put in a room with other people who are dying, it’s not going to be very pleasant. So, it’s hard to work around that. Dr. Peter Centre has done a lot in terms of taking the edge off of that. They have wonderful facilities, a music room, lots of programs, good nutritional program – people that belong to it really, really get a lot out of it. So, it is less harsh than some of the other places. Luckily not as many people are dying nowadays either – we have stemmed that. I don’t know what the statistics are anymore. When I first started with Theatre Positive, we got a hold of this tape of a list. Every year there is a memorial where they read off the names of the dead. It was very powerful, just in itself, because it started out – I forget what years – let’s say 1981. Fourteen recorded deaths, three names: Fred, John, Henry. And then it would go on.

Eventually there would be a last name and then there would be a woman's name, but the death total and the names were always different. It was a very very powerful tape.

JH: The amount of deaths increasing, how did that affect the HIV community and their feelings or their positive outlook, if there was one?

JT: Oh, it was very difficult because there seemed to be no end in sight at the beginning. People just kept dying and dying, and people also started committing suicide. I had a friend who jumped off the Sun Tower. I knew another lover, or another lawyer, who killed themselves because they didn't want to go through everything they had seen their friends go through. It was very, very difficult, watching all these people die. And then the – after that first wave of losing members of your community and you're still standing and you've got this guilt of "Why did I survive and why did they have to die?" And then you look at the holes that were left by these people – huge holes in the theatre community, all across the arts, and families. It just devastated – there were so many holes.

JH: You mentioned burnout, and I am thinking about people like yourself that were involved in living a long time with HIV. How do people around you cope with burnout? How do you cope, Jake?

JT: Well, I've had some very, very good luck. I've had very good doctors, as I've said. I had an addiction problem that I managed to get over and advance from, and just recently I met an old lover and we got back together. He knew all the bells and whistles. I had absolutely no intention of having another lover and he walked into my life at a point when I needed someone to care for me at home. I can't bend over and put on my socks, I can't do a lot of things physically that I used to be able to do. And this man came into my life at that exact moment. Not only that, he had come from a relationship where his lover had died from cystic fibrosis, a very crippling lung disease, and I have COPD, so he knows all about all of the drugs I have to do, and is very, very supportive. The other day, we had spent – I had gone to emergency because I had been ill, and because my doctor is retiring, I get whatever doctor is available at IDC. And this particular doctor, he had put me on a course of antibiotics for a week and I still wasn't better, and so I went back and did an x-ray and the x-ray looked clean. And so, I think he thought I was a bit of a hypochondriac, so he told me to go home for tea and honey.

Well, three days later I was still sick, so my partner said, "You are going to emergency," and we went to emergency 10:30 in the morning. We got out of there at 5:30. They did tests on my heart, because I had recently had an operation of the removal of the lower lobe of my lung for cancer. They did a cat scan with a dye to see if that was what was happening. They checked for blood clots to see if that was what the problem was. But anyway, eventually, I got some antibiotics and some prednisone and did very well, but the great part of it was that my lover stayed there all day with me. I was on my scooter and he had to guard my scooter, so he couldn't even come into the examination rooms with me. And he ended up being a hall monitor in the waiting room. Everybody that had to go to the bathroom, would say to him, "If they call my name, tell them I have gone to the bathroom." And my doctor said how wonderful it was to have somebody there. And as a senior and somebody who has lived with HIV for a long time, isolation is a very, very

difficult – we need somebody there for us to look out for us. And I am so blessed to have this man come into my life right now that’s willing to take on all of that responsibility.

JH: Other men in your situation without someone to help them, are there services in this city? Are people, in your experience, isolating?

JT: I think there is a lot of loneliness in the community and it is hard to get around it ‘cause people are proud, ‘cause they want their own little life and they’ve always had their own little life, and they don’t want someone to come into their life and tell them what to do or how to do it. But at the same time, you worry about them because they are all alone, and if they fall down, will they get up? Who will be there to look after them? Who is there to make sure they are eating properly? Who is there to make sure they are doing their meds properly? It is very difficult. There is a buddy program, I believe, that is offered through AIDS Vancouver or Positive Living – I’m not sure where – where they can team you up with someone, when you take a complete stranger and they are going to be your new buddy, and help you dress or help you feed or help you take your meds. So, it’s very difficult.

JH: So, there is a need in this community for senior care.

JT: Very big need for senior care, very big need for some kind of space where we can all get together and not be isolated – where we can play games like bridge, or we can dress up, or we can play bingo, or we can sing, or we can do whatever it is that we want to do in terms of socializing. We need a community centre and a senior centre and senior housing. All of those components, really, and the gay community, or the HIV community, it would really be lovely to see some kind of archival centre where you could go in and press a button and say, oh, this is what it was like to have AIDS in 1980, and this is what happened in 1985, and this is what happened after this drug that came out and these are the organizations that came out of all of this. It would be wonderful, if all of that could be – you know, if somebody brand new, getting the diagnosis, and walking into a room where they could access all of this information, it would be wonderful. I hope to see that.

JH: I do too. What would our lessons learned be for new people who are diagnosed, like you just mentioned – what can we teach them?

JT: A positive, that it isn’t the end of the world, that contrary to my diagnosis – that you have two years to live – I don’t think that the medical community isn’t that glib anymore. That you can still work, you can still function, that you can adapt your sexuality to fit in with this disease. It’s a much easier world to navigate now, and the older gay community certainly has a responsibility that the younger community knows the risks of unprotected sex, of not being tested, of not having good nutrition, or good housing, the problems that addiction can cause, all of the pitfalls that can get in the way of a healthy life.

JH: Do you think we are doing a good job of that today? Do you think that is going on?

JT: I think both are going on. I’m not very involved with the younger community, but I understand that they are pretty – that that is the most at-risk people now are young people that

think they are not going to get it, that this disease is over, and that they will not get tested and have unprotected sex. I think that is happening.

JH: And there are some new drugs out there that people can take prior to having sexual intercourse or sex that are supposed to be helpful. Do you know about that?

JT: Yes, a friend of mine who does dates for money in San Francisco, they get the drugs for free, and if you take it every day you don't – can't get this disease. I believe it costs a lot of money here. I was amazed to hear it was available for free down in the States.

JH: Thinking back at the points we have touched on this afternoon, is there any area you would like to add, or you would like to talk more about? Take your time and think about that. Any political actions, any programs that were very supportive?

JT: Well, the programs that I've personally got the most out of – the Wings Housing. I'm so grateful to not have to worry about having a roof over my head. That's wonderful. I love working at Polly and Esther's and giving out free clothing, 'cause it makes people so happy when they come in and get a new coat or a new jacket or a pair of pants, and that there's not too many strings attached – you are allowed so many articles, and so that's a wonderful program.

JH: Looking back, how has this been for you as – looking back at your life, the time being HIV positive?

JT: Well, as I said, I've tried to view HIV as a gift. A, it has opened my mind and my heart a lot more than I would have if I had just gone on living this life without knowing all of what I know now. It has allowed me to share a journey with some remarkable people, it has allowed me to do the theatre that I wanted to do. It's allowed me – it's given me bridge, which is fabulous – I never thought I would, I took it up later in life and it is something you need your whole life to really understand it and would not have had that without HIV. The retreat program at Positive Living was a wonderful thing. People would come there and come back and feel so clean, refreshed, and ready to start again. And it was so important at times to, you know, have that ability to go away and think only of yourself and how you're going to get through all of this, and these retreats were wonderful. Everybody who came back from them were magically touched.

JH: Thank you, Jake

JT: Well, you know, it's the truth. It was the most fabulous program that we did. It had the most impact. People weren't expecting it. You organized it so completely perfectly that people – even I remember, I did a little, the Loom Like Opera Company, where I took what you thought were people who weren't going to fit in with anyone else's programs and gave them a space. It was wonderful, that everybody found some way to participate in those things

JH: It was, spectacular. [Laughs]