

“HIV in my Day”

Interview #50

Participant: Mark Abbey

Interviewer: Ben Klassen

BK: Okay, sitting down this morning talking to Mark. Thank you so much for being here, we’re looking forward to hearing your story. So just to get started, can you tell me a little bit about when you started connecting with the gay community?

MA: Uh nineteen—nineteen-eighty—nineteen-eighty-nine. That’s a long time ago, but or I think eighty—eighty—I was positive in ninety-one so nineteen-eighty-nine, nineteen-ninety, when I was twenty-eight, nineteen—eighteen-nineteen years old actually. Isn’t that crazy? That’s long time. So nineteen years old in nineteen-eighty-nine, that’s about right something like that. Yes, and it was just a sexual encounter right? My problem—essentially well—do you want me to carry on? Or go ahead.

BK: Sure.

MA: I was just saying it was a brief encounter. I went to the bar, went to Love Affair which is a mixed bar, there were waiters with moustaches on roller skates in drag—drag queens with moustaches on roller blades. On roller blades, seriously skating around Love Affair which is on Granville there. Anyways I had an encounter and I didn’t really enjoy it, because originally I kind of came out loving my best friends all my life. Because originally my best—my first best friend got—well yeah my first best friend Paul he basically went into—he got hit in the head playing rugby and went into a coma for a year. And he was my best—I loved him almost—I remember I came out—I remember well I just remember looking at him with lust. But I was only ten years old right? I didn’t know what lust was! But anyways he played rugby, he was really good looking guy. And a sweetheart. And anyways he was playing rugby he got hit in the head went into—got a concussion went into a coma for a year and I went to visit him only once because—well I shouldn’t—I can’t really say. One thing leads to another, do you want to bear with me. Because I went to see him and I knew that he’d already passed I felt that he wasn’t there because I had previously had my own near-death experience, that’s what I’m saying. Because at three years old—bear with me—I—okay—I want to be able to do this properly, can I start at the very beginning? My mom was a stewardess my dad was an airline Captain she fell in love with my dad, he had two sons from a previous marriage they were delinquents but they—my mom looked like a—was a brunette Marilyn Monroe look-a-like even more beautiful than Marilyn she was gorgeous and she was Ukrainian and she was a virgin and she fell in love with my dad she didn’t care about the kids. My dad was a promiscuous pilot it was like catch me if you can he had girlfriends all over the world but she didn’t even know it. And the next thing you know they fell in love with her they calmed down they were good boys, so they were Mel and Neal my half-brothers. I just recently learned it’s half-brother not step-brother I’ve been calling them wicked step-brothers my all my life. Or wicked step-brother. And anyways uhm they were—then my dad—we lived in Richmond near the airport and then my dad we moved to Peru—because we I were we fought? ---- and had unlimited tickets to fly everywhere—and we moved to Peru—Lima, Peru for a year and this is when i—was not this was when I was—so what happened was, yeah it was three years later after they were married I was born. And all of sudden I started getting all the attention of course,

my mom's first born baby boy. And ultimately my step-half-brother now, the older half-brother started to get—well what happened was—one day three years later I'll get to you can make your own opinion about it—three years—so I was born and three years later we built—my dad was building—we lived in Peru—and while my dad was in Vancouver bouncing back and forth building a house in Richmond. So he built a house in Richmond it was a three level split-level at three-seven-four Lockhart Road. And so came we back—we moved back from Peru, my sister was born in Peru we moved back to Vancouver—bare with me—on my sixteenth birth—on my third, it was my third birthday three years later on my third birthday Mel was in the backyard—[inaudible] is in the back and she's Mel and he's—this is not HIV related—but he's—she sees something he's carrying a bunch of garb—wrapping paper for my birthday party, for my third birthday party to be burnt in the incinerator can in the backyard next to the garden there was a large incinerator can. He loaded it up apparently and lit in on fire next thing you know—she was looking at him going oh that's awesome he's doing his chores—next thing she turns around comes back to the window all the sudden hears this explosion and looks out—this is the beginning of my book, page one—the explosion looks out the window and uh it's like the sun is falling from the sky and is burning on her backyard. She freaks out runs out down the porch as she's running towards this fireball a little ball of fire bounces towards her screaming. The screaming of a child. She realizes it's me as it basically bounces into her arms, tries to put out the fire couldn't—wouldn't go out. The reason why I mention this is because it went on for an hour where the fire kept re-lighting it was a gasoline fire. Ultimately shock, hundred-and-seven-degree fever, body cast, near death experience, all the sudden heartbeat's stopping—out of body—I had a near-death experience. And the reason I mention that is Paul. So, I had to explain that because I have no problem with death—passing. And I knew when I would see Paul—my grandmother afterwards—she saw a white light on me—she called me her 'little white light.' And that I had this—I loved animals more than—god, listen to me! [laughter]. And she kept me calm, you know, and then as I fell in love with my best friend Paul, I didn't realize I loved him. And he went into a coma, and I went to the hospital once I didn't go back I knew he was gone. And that's how it repeated a pattern all through my life where I fell in love with my best friends. And ultimately in nineteen-eighties, I fell in love with my best friend Russ, Rusty Napoleon [inaudible] the Third, this hot Filipino guy, right? But he was just—we loved each other as much as you could love, right? And ultimately I didn't know what was going on and it became so passionate, all I wanted to do is hold him naked, whatever, hug, him you know. He loved me as much as he could but he was celibate, he was young and confused. We were all confused, right? And at the time we were just experimenting with pot, that's another story. So yes, uhm, that created—I'm very old-fashioned is what it comes down to. That made me conservative, unconditional love—and when I came into the gay community it was the most promis—that's why HIV and AIDS happened. It was filthy. I mean it was promiscuous. And I didn't—I couldn't get into it, but I could get into the party and the drugs. I think I'm the original cuddler in the West End. You know seriously, I give a wicked massage, very oral. But I could never get into intercourse. You know for years, it wasn't my deal. And I just wanted to—and I had sex with women, oh we don't want to go there. The last woman do you want to hear what happened—no you don't because you'll throw up. Because I threw up.

BK: I probably don't need to hear that.

MA: I fell asleep inside oh gosh.

BK: So connecting to the community, the actual community.

MA: Yes I came out, yeah I came out and I got into the gay scene, but it was party scene for me. And I never really got in—then I had sex occasionally, it was more while on vacation is when I would go crazy with sex, well not really every crazy but that's when I had it. And I actually—I never—that was my pattern throughout my—I travelled the world. I had ten tick—I had unlimited tickets, I filled out my own airline tickets. I've been all over the world, I've been to Peru over twenty times. So at twelve years old my mom and dad split up because my dad was a horn dog, and he moved to Peru. For twenty-five years my dad lived in Peru. I speak Spanish. Yo hablo español. You know and one thing led to another. Drugs. Sex. Drugs. House music. All kinds of music. And ultimately a lot of situations happened, my appendix burst, I had operations, health issues started happening. And then I—oh yeah and then I came back from Mexico. I hadn't—I finally had sex with a Mexican after not having sex for two years, going there with the purpose—there for two weeks, nothing and then the last night, yee-haw I was going gracias dios thank god, gracias dios thank god. And then I came home to Vancouver and I wanted to do is smoke some pot because Mexican marijuana sucks, it's like Cheech and Chong pot from the eighties, right. So I found my friend and smoked pot and all the sudden I'm feeling pain in my gut it was like giving birth. It was like ughhhh and it was every twenty minutes then every five, ten minutes, we got to the hospital and I was like screaming at the top of my lungs, keeled over. Finally a doctor came out, and said what's going on, who's check—and I was instantly put on a gurney, given morphine, Demerol, blacking out and screaming. And then I woke up and I—in a Demerol dream, twenty-four hours later or whatever. And I love the Demerol, it's my favourite medication of all, but you need to have—you need to pop an organ to get it right? You have to have an operation. So I just remember when I was going under something about the doctor saying, it looks like you have perforated ulcer we're going to do something. And then I didn't hear anything after that, I was too screwed up, groggy, to know anything after that. My friend comes by to visit me and I remember that's what happened, I woke up and there's Del the one who drove me there. Big guy and then, and he goes he's laughing at me and he's going Mark—because he's had so many, he was on Demerol before—he goes, 'you're—you're—you're a happy guy. You're flying man.' [inaudible 09:52] I had my button, I'm just pushing it way like every ten—every ten minutes getting a shot in the butt right. Just cruising along. For a month almost I was there. I was up—I didn't move out of that bed for ten days. That's how—they weren't meant to cut me open. It was an exploratory surgery. And I'm sitting there a couple days later having another injection into my butt, there's this angel of a nurse. I'm going god, something's bothering me. She's floating around the room in this angelic haze, right. And I'm going, excuse me? And she goes, 'yes, yes?' And I go, could you please—I don't know why I'm here, I-I-I don't—I-I-I haven't really talked to a doctor. I barely remember. And she goes, 'okay.' And she disappeared and she came back I don't know how long later. A moment. Because it was a moment. This is all a beautiful moment. A moment later and uh—I should write this, this is going to be a poem. I'm going to poem, I just wrote a poem about my dead mum, that's going to be a poem—she came back, and says well you know it's odd or she looks at me and says it's puzzling or something like that. 'I reviewed your file, and it appears that it's incomplete. The doctor who inscribed the information has left—never completed the report.' So it had an incomplete operation report, right. It said exploratory surgery, la-la-la, and that was it. No complete—it wasn't left complete. That's why I was still in hospital ten days later, because he—you normally—they would've had me standing up within a day, for anything. And there I was still overdosing on Demerol a week later and then they put me on a solid pill and it sucked. Because injections rule, that's why I can understand street drugs now. Because they have a pill, you want the real deal. [inaudible 11:30] is funny too, you can tell I'm very sarcastic. Okay so, you're getting it all you like it? Okay.

BK: So maybe to bring this around to HIV—

MA: Reel me in.

BK: --when did you first start to hear about HIV.

MA: So what I'm getting at is, so then, okay this is evil I guess, so yeah I had the operation all that stuff, and then I survived, I was released. And that was in Richmond, and that happened when I came back from Mexico. And then I went—I came and I went again—and I went to Australia, that was my last trip to Australia, ecstasy, party, mardi gras. I was one of the leading dancers in Australia can you believe it? My partner and I danced at mardi gras. I was the centre of mardi gras with the small, the main exhibition hall was eight thousand people and I was on stage with my little family, they had a dozen dancers from all over the world. From England, Kenya, Arabia, Kansas, you know. And I was the crazy Canadian. I'm a thousand miles an hour on ecstasy right, and I'm like this in the middle of—with people just bouncing around us. You know almost trying to touch us like Jesus Christ statue Nazarine festival in [inaudible 12:39]. Whoo-whooh the bass right, and I had like big Tarzan bouncing with me, it was awesome. But I got burnt out, I had a partner and it just ended up—the bubble burst. And my sister was having a baby in Vancouver and I decided to come back. And I came back and then I decided to be responsible and finally get a gay doctor. Because I really, I officially came out because in [inaudible 13:02] and he was really kind of like a boyfriend partner, but of course it didn't work in the end because he loved me too much, it was confusing. And that's another reason why I left. Right back in Vancouver, gay doctor then the next thing I see him and I look in his file—oh this also after previously I went, like I mentioned I had been going to bars etcetera. All my friends passed in the process. I had maybe less than a handful—a handful of friends left. Twenty in two months type of deal, they were just dropping like flies. And I knew—I questioned it all, it stunk. And I knew it was lifestyle, because I took care of myself really. I knew basically drink water, and sleep, try whatever—eat. But no one did that, and they all had promiscuous sex. You know they were all dirty that way in my—not really dirty, but that's the way it was, it was filthy really. Beyond promiscuous, and you know I'm not being judgmental, anyway that's the way it was in my observation. Just because I guess I didn't partake. And ultimately—oh, so, I had not had any sex for, I couldn't recall having sex. When it was—it was all of a sudden I get the bloodwork come back and he goes, 'oh you're HIV positive.' And I go—but I'm waiting in the—in his office, I'm looking at his files, no files. Like eight files are there. They're all dead, right? There's like twenty files in this whole wall of files, they were—you know, nothing there. And I'm going okay, and this is the beginning of me being a dissident as well, I'm going okay something's going on here. This is weird. This is nineteen-eighty-nine, right? Nineteen-ninety-one. And he goes, 'okay you're HIV positive.' And I go okay, but that—I didn't really know anything about it, right—and I go, but how? And he goes, 'well you obviously had sex with someone. Are you doing that?' And I go no, I don't. I drank then. I said well no, I haven't had sex, I've had oral sex, I had someone enter but I pushed them—didn't let them go in. I drink, I might've passed out and not remembered, I don't think so. And then I go, and then there's—I hadn't—that was right at the time the tainted blood scandal had just erupted. Nineteen-ninety-one. You check nineteen-ninety-one was the tainted blood scandal. It happened the month when I had my operation—I had an operation—and then he went, 'well the operation, let me check it out. Do you want me to check it out?' And I went no, I just want to get on with my life. I probably should've, I might've got a settlement out of it. But I just wanted—I said no, I just want to get on with my life. So I conclude that I very well might have become positive through the tainted blood. Otherwise, I had no comprehension or recall on this.

Like I said, I was a bit of a blackout drunk at the time. But I really didn't drink that much. So where are we now, are we catching up to what you want?

BK: Yeah so—

MA: So I became positive and I refused to go on any medication, my viral load was—no, what happened was—yes, so I was positive, but I didn't care about that, I kind of understood that, but my viral load, that was when the viral load test just came out. And the protease inhibitors just came out. And I was in the millions, right, and I had no idea what it was, they said in the millions, you're gonna—they said now or you're gonna die within six months. That's the old line. You're gonna be—you've probably heard this through these interviews. You'll be dead within six months. You'll be dead within—I've been told that so many times—you'll be dead within six months. You'll be dead within six months. Six months you'll die. Take the ARVs or that's it. So I said yes, and I went on first protease inhibitors. And the most nasty medication ever made which was called Crixivan, have you heard of it?

BK: Oh yes.

MA: It destroyed everyone's mouths. It was the most horrifying medication in the world. I was healthy, I was vegetarian, I worked out, I was at almost two hundred pounds. I was the healthiest person in the world and this because I had recovered from those drug days in Australia, and being single maybe helped me, motivate me more. But yeah I went on those drugs and Crixivan with by this time—oh yeah I should mention—by this time I, before my diagnosis I had become, or no just after my diagnosis I didn't accept. I didn't—I went okay, I'm positive, but I really—I don't believe this. It's more the—what it seems, like I already mentioned the doctors before, drugs—the water—lifestyle—promiscuous sex—drug—recreational drugs. But I started believing it was all propaganda as well and I questioned pharmaceutical—because I came to realize that my friends mostly died of overdoses of AZT. They were overdosing on the medications. And that's—I still believe that's the case back then, it's different today, but majority of people that died from HIV/AIDS died from I believe from lifestyle and overdosing on medications. They were mega-doses of medications. When I was on Crixivan, I was on nine-hundred milligrams of the worst, most horrifying medication in the world. I lost ninety pounds in two months. Like I went down to ninety pounds. I was a hundred-and-eighty then, I was about two-hundred when I was on steroids, we didn't know what said, we were on steroids it was deca-drog-in. I'm on—I'm jumping the gun here. I gotta drink some water, take a breath.

BK: Take a moment.

MA: No but I—this is good it's helping you should be able to get a lot of information I think here.

BK: Yeah, yeah this is good. Thank you.

MA: You are the sunshine, the light is just—I see the light. It kind of looks like that.

BK: We can move too, if it's in your eyes.

MA: Are you kidding? It's meant to be. Okay so uhm, oh yeah okay, I started protease inhibitors after the viral test confused me and my life eroded. I became a zombie. Dawn of the dead material. I lost ninety—no I lost all of, I lost seventy—I have no recall—I lost seventy or eighty pounds but I still had pot belly. My teeth were—I had to go to the dentist they were all starting to break. I then realize that all my roots were dead, from the Crixivan they ultimately realized. A decade—I had dental problems all my life

because of that. And I lost all that weight. I couldn't—I-I got anemia. I just fell apart. Everything happened to me. And then I got anemia, and I got a gut feeling I had to stop, and I quit, and I was one of the first people in Canada that I'm aware of that quit any HIV protocol. In nineteen—I'm almost about to cry—in nineteen—I am crying—in nineteen-ninety-one, I quit. And I was black sheep from that moment on. I smelt a rat. It didn't—my gut was going stop. Or god, inside or whatever and—and I stopped. And within that week all my friends started falling apart. Emery's liver blew up, another guy got dementia. Everyone started blowing up, it was horrifying. And I'm going—and then I became—I-I-I—okay yeah the last couple of my friends passed, from protease inhibitors. But mostly just—oh the buffalo hump. It was horrible like they—buffalo hump was nasty. Have you heard of buffalo hump? It was disgusting. You have a tissue? Actually I got some, I got one here I think.

BK: I should—

MA: I got one here I'm good. I come prepared. Here I'm good, thank you. You might want one. There this is good, this is healthy. So then I quit and I was black sheepled. Doctor said you're going to die. My doctor screamed at me. I fired her. I fired another doctor. I went without doctors for twelve years after that. I said screw all of you. I became aware of dissidents. Of alternative information. I became absolutely a vegetarian, spiritual, I read hundreds of spiritual books. Became a professional on near death, on all these experiences. When I was younger I had all kinds of peak experiences. We didn't even get into my peak experiences. Channeling. I channel light. That's how I write. I write writing through light. I mean it's all about light, love and life. Which means god I learnt later in my life. I used to go life, light, life, love, light. It came out repeatedly and then I realized that means god in many religions. I can go on and on from there. So I didn't agree, I went this is wrong, I knew what was going on, I suddenly went this is all overdoses. This is a nasty drug, they've created this viral test just to get people back on a protocol because everyone else died from the original—AZT overdoses and everything. From the original round and this is round two and now we're on round three where it's smaller doses, people are fine right. Now. But round two was just as bad as round one if not worse, because Crixivan was the worst medication that was ever made, of anything I could imagine. I tried everything. So I quit, everyone was afraid of me no one would be my friend it was horrible. I was bullied, because I didn't believe any of these people. They were all afraid because I wasn't afraid anymore. And then I discovered, I was in AIDS Vancouver I didn't go I—in the drug department I-I-didn't—I went there just to look at it and became very—reading something going nah, this is wrong. Then I came across a little skinny book called *What if Everything You Knew About AIDS was Wrong?* And I looked—I opened it up it was by Christina, Christina Mangiori. And she's pretty brunette woman and she lives in San Francisco. And I read it and it was all about everything I just talked about basically, it was all about misinformation propaganda from pharmaceutical companies, from medi—medi—every medicinal thing related to HIV/AIDS. And basically along the lines of lifestyle, drug use, insomnia, malnutrition, dehydration, insanity uhm you know, multiple illnesses, basically related to lifestyle, really is the biggest one of all. And the deaths relating to overdoses on medications mainly. And uhm, she was a negative woman with a positive husband and a positive baby, and then we brought her—we—we created a group, my friend Corey and I, and Jill Bear, the three of us created a group. No we—that was just when, really computers were just getting going, we kind of connected with a group, in the back of the book it had something about HEAL, we connected with a group and heal. And in San Francisco—in San Francisco chapter in San Francisco and New York, we became the chapter in Vancouver—in Vancouver. And HEAL meant Health Education AIDS Liaisons. And we disagreed with pharmaceutical companies, we even went to—they had monthly—they had—

every once in a while they had elaborate dinners at the century plaza, right there. And they had—in the ballroom—they had like smorgasbord, prime rib, whatever you know every month. And we went to these meetings at this point, at this point, that was our bible, and we had meetings at Corey's house down by beach avenue there. They started with three people, the next thing you know we have thirty people we can't hold them anymore. We're holding them at Gordon house, because we're getting bigger. And—and—and providing all this information and then they—through the computer as well everything's becoming, we're sending information it's all crazy. And then we import Christina into Vancouver and she stays at Corey's place with the baby and her husband. And we arrange for her to have a—to have a—to read from her book, with they do, the readings speakeasy or whatever at St. Paul's church on Cordero. And she stayed, she's beautiful, her child is gorgeous and yeah, she was an awesome young, she was only twenty-two or something like that. And her husband was twenty I don't remember they were young, I was probably young back then too I was I don't know thirties who cares. So we had her read in front of a church, St. Andrews and a hundred and fifty—over a hundred and fifty people showed up. They were out the doors, listening through the doors. And AIDS Vancouver, their drug advocacy, whatever her name was, Jill whatever her name was. There were three or four people from drug advocacy, screaming, heckling her as she—as she tried to read. You know everyone in the crowd was booing the hecklers. It was pretty cool actually, but they got booed back, they got disciplined after that. They never did anything like that ever again. And then after that I said okay I'm done, and I stopped. And I just—I just—no doctors, nothing, for ten years, a decade I didn't do anything except become healthy. I worked out constantly, I ate—I—I travelled. That's kind of a gap in that period, a decade went by. And then uhm, oh then I got viral anemia. Okay, okay so, I was healthy and I started when I went, well maybe I should go to a doctor, you know. And then I went to the doctor of course they got bloodwork, of course of now you got viral anemia. I went what? What's viral anemia? And all of a sudden I started to lose my breath, and viral anemia is low oxygen count in the blood. Your low hemoglobins. And a average hemoglobin's—healthy hemoglobin's are hundred-and-fifty, I was down to fifty. And it came to a point within a week or two I could barely breathe, I was like [throat sound]. Just could barely move, was basically paralyzed and ultimately the doctors were saying, you have to go onto ARVs. Antivirals, or you're—because it's a viral infection or you're gonna die. Or you could die. And I'm going I don't want to go on ARVs. But it came to the point where—and then spinal tap and another spinal tap, and every test in the world. And you have to do it or something's gonna, or you're gonna die. And it went on and I had horrible, horrible—I woke up delusional. My immune system crashed from going on the ARVs. I woke up destroyed. I had vomit everywhere. I-I-my immune system collapsed. I'm starting to cry again. And this is like, wow. This is like ten years later, back in the hospital ten years after saying—telling them all to go to hell basically and then uhm—so yeah viral anemia, spinal tap. God this is crazy. You just wait, okay. So yeah, I'm delusional. But I'm—my doctor's convinced—I come out of it, and I'm completely delusional, I got blister packs because of it to this is day which is wonderful because it makes it easier to have pills. But I couldn't take my pills, I couldn't do anything. And my doctor was convinced I was bi-polar, for a month she was trying to commit me to a mental institution. And I'm going I'm not crazy! I'm happy, leave me alone, I'm just energetic, I've always been hyper leave me alone. You know. Fuck. I think I fired her again, I've gone through so many doctors. And then—then uhm, okay where I gotta lose my track here. Do you want to ask a question or how we doing?

BK: I think we're doing okay. Yeah uh—

MA: Okay so—

BK: Because you're kind of talking about getting onto ARVs now.

MA: --so I went on the ARVs. And oh yeah my immune system crashed, my doctor thought I was delusional, I—she gave me MRI, every test in the world. Like, I had three CT scans, I had everything and we're so lucky being HIV I get everything instantly. I get an MRI the next day. I get results three days later. Boom boom boom, especially when it's everything at once. So within a month of that—so my doctor's calling me delusional, etcetera, the next thing you know my appendix burst. I'm serious, my appendix burst. And that's another story, I nearly died, what I'm getting at—wow it's all the sudden it got really quiet, it's like uncomfortably quiet, don't you think? It's the fan going off?

BK: Yeah it's the fan going off.

MA: But anyways we'll get to that okay, let's get to, I gotta catch my breath. We can tie this up soon. Uhm, help me again? I just went on my ARVs—okay, my doctor felt that I was bi-polar. You probably think that I am too the way I'm carrying on right now. And she was convinced I was—well I was delusional when I came off all the medications my immune system crashed. Little did I realize that my CD4s had dropped to seven, and my viral load had gone into the millions. We never realized that until bloodwork came a month or two later, and it wasn't until I had a second MRI. Only through a second MRI can you determine whether an individual has PML, which is an opportunistic brain infection, caused by my immune system breaking down. It's not around anymore, it disappeared around five years ago. But when it first happened, so we're talking about eight years ago is when it hit me when my immune system crashed. Everything happened, delusional. Second MRI, six months later my doctor committed me once to the psych ward, I fired her. I was in the psych ward in St. Paul's. Fired her. Ultimately the second MRI there disclosed that I had PML, which is poly multi-focal about twenty-seven letters opportunistic brain infection. Only determined by—you can only determine it by a second MRI, you need two MRIs to determine it. It's a shadow on the brain. I actually saw a neurologist and he showed me it, it looked like an alien on my head it was vibrating. This shadow on the brain. And it kills you. And people were die—were dropping dead from that left and right. Unless they went—again you have to go on ARVs. It's a viral brain infection. And apparently it would go dormant, or stable whatever on ARVs, because it's a viral infection it doesn't matter—and I went well can't I go on some other kind of antiviral medication. You know I didn't want to go on Crixivan or AZT or something like that, right. No. So I said yes. And it basically stabilized. No, I was on the psych ward when that happened. That's when I was in psych ward. I'm on the psych ward and within a week of that, I swear to god, within a week of that I had a spinal tap because I was still having reactions, I was delusional or something was happening. Or no, because I was such a great candidate for the original spinal tap by doctor Hall, who's an awesome doctor and the head of HIV at St. Paul's. Him and Montaner who I don't care for but doctor Hall's awesome. He asked me if I would be a candidate, because I had no problem. Most people find it painful, because they put the needle right in your back in the vertebrae and suck liquid out. Most people get headaches but I have it—I find it very relaxing. So he saw me again and then after that test the next day it came out that I had neuro syphilis. I had syphilis of the brain. Along with my PML, so I had two killer brain conditions, syph—neuro syphilis, syphilis of the brain which is not a venereal disease but it's another v-v-vvv—it killed Al Capone! Did you know it killed Al Capone? Isn't that nuts? It almost killed me, right. So now I had to go through IVs for ten weeks on ten C, they had no room, they had to move me to the psych ward again after that because I had been in the hospital for I don't know how many months. This is all nuts. Okay so, we're almost up to date. So I'm in the hospital, the doctors realize I'm not a crazy person, but I'm still recovering on that floor. Ultimately I'm there for a month on the psych ward after—I don't

know there was other complications that happened. They moved me into a SRO, [inaudible 32:39] down the road, the worst SRO on Granville Street. I'm recovering, I'm going up four flights of stairs, and uh—I-my-I-I'm almost finished, and we're almost up to date. I could catch my breath. This isn't necessarily—this isn't HIV. So I come upstairs, I'm recovering and I have a small tiny room, SO room, with a toilet next, right at the head of my bed, and I open up the toilet at midnight and all of a sudden thrown across the room by a wave of sewage. Comes up—it's coming out of the ceilings, the sinks, the floors, everything, throws me across the room, covered in sewage and ultimately uhm—I don't know, this isn't HIV related we should just stop there. Yeah I call that holy shit. It's a chapter in my book, one of the closing chapters right. And till dawn there was two staff on, one was trying to get permission for an emergency plumber while Fraser, this awesome Coast Mental Health guy he found two mops and that was it. Nothing, the mops are doing anything so we use it to block the crap from going under my bed, and we found a garbage bag full of—of—of sheets. We used those to soak them up, going downstairs one flight to the laundry, wash them and dry them up and down over and over again all night long. Next thing you know the cleanup crew came in at dawn, or the plumber came in at dawn, ahhh! I'm alm—and he goes, oh my god, what do you—and I go yeah, and I'm going holy shit. He goes no look at this—it's summer time, we're running around in bare feet and sandals, we don't know what's going on. Chalk, right. Put some shoes on. So, that was that, he fixed it, the next day cleaners came for two hours for three days of work and actually the whole hotel blew up. Every floor had the toilets flooded. It was a shit hotel. It was Saint Helen's became hell. And they never—they cleaned up the floor for two hours and they never cleaned my bathroom they kept it sealed for week. And I got sick. I got incontinence, the worst non-stop diarrhea you can imagine. I couldn't stop. I couldn't leave. I couldn't go down an alley without going to the bathroom twice. So I was basically shut in. I was on Immodium, and antibiotics they didn't know what was going on. And then ultimately I could've sued, they found me a place to live and I'm living there happily ever after. So I'm stabilized, okay so then I get throat cancer. Serious? This is not HIV related but did affect my viral—my counts. So next thing you know I'm fine, I'm healthy, I'm getting my life back together after a little crack attack. I finish drugs and then getting it together because my knew home helps, that's all I really needed was new awesome home, which I have now I love it. And then I started exercising again, everything's coming together again. And the next thing you know I had a crack attack, just one after two years. I did three hundred dollars worth in one night, because it wasn't any good anymore and didn't get high. Next thing you know two days later I wake up with a lump in my throat the size of a golf ball and hard as this [thumping sound]. Throat cancer. Diagnosed, you got stage A throat cancer and I ended up having to need radiation. I went to radiation for two months, every week day for twenty minutes. I'm lucky because I didn't get side effects until about the last five weeks, and most people get it within the first week or two. After a month my throat became one giant blister inside and out, I couldn't eat anything. I couldn't even eat a slice of banana it was like third degree burns in my throat. I couldn't—I could only drink liquids, and ultimately, three chemos, two months of radiation in the last two weeks I lost thirty-five pounds. And I couldn't eat, and I then—they—I finished, I'm almost done, we're almost at the date believe it or not. And we'll get back to HIV. And I-I survived. I had a positive attitude throughout. You can't kill me, I'm a cat with ninety-nine lives, that's my line. Maybe we're at nine-hundred-ninety-nine lives. And uhm, can't kill me! I'm a tough—oh I forgot to mention when I was getting diagnosed, get a load of this. This is my book, it's my last chapter, one of the last chapters. It's called *Radiator*. I think the chapter's called *Radiate*. So when I got diagnosed I got diagnosed at doctor Peter, they got me to go to the—right there, there's a office right there. There's a hot brown ear nose and throat specialist with a long, Arabian name. Almost as long as the name for my

neuro syphilis. No, no, the PML, poly multi-focal with twenty-seven letters, his name was almost as long as that in Arabian and he was hot. And his—bare with me eh, I tell it like it is—and his office was like fifty shades, fifty shades browner. Like, fifty shades browned. Like his office was like black leather and chrome and metal which I like because I've got steel everywhere. My apartment especially, silver and steel. And next thing you know he's got me in the chair, and he goes, looks at, 'oh yeah you've got stage A, we'll scoop your mouth.' I went okay. 'Well you need to have a biopsy, a tonsil biopsy and something injection.' And I go okay. And he turns around and comes at me with the scalpel, just like that no freezing nothing open wide. [mouth sounds] And aaahhh that was big ahh, quick and painless right? No. And then he comes look and I see his assistant she's getting this big needle, I swear it's a bull—I used to work at a—be a farm where the prize winning steers at Playland, you know Pacific—is this fun, are you having fun yet? Pacific national exhibition the steers' as big as this room. A two-tonne steer's, five hundred, uh five-thousand dollars for a shot of sperm. That's how much they used to charge. And I don't know why I'm thinking about these damn cows, oh! Because this needle. Looked like it was going to go in their gluteus maximus. This needle is this big, it was like a foot-long needle. And I'm looking at it, and he picks that needle up, and he's coming at me with this needle, towards my golf-ball throat, and he put it against it and he goes—and starts sticking it in—aaahhhhh. And he's going, 'you're a tough guy. You're a tough guy. You're a tough guy.' And that wen on for like a minute. It took, I don't know how long it took to just break the flesh and I was like ahhh, it went on forever, right. And that was the worst of the whole cancer deal. And so I survived that. Yeah and then I went every day, to cancer institute every weekday for fifteen minutes at nine-thirty in the morning. They were awesome there. My cancer angels. They were—I love them. The brown guy there was just a sweetheart too. Anyways eight weeks later I started feeling, like I said having effects, I couldn't eat a slice of banana it was like shingles of the mouth. It was on fire, second-degree burns, one giant blister. Week six I lost thirty pounds within a week. Within two weeks because I just started five pounds a day, I was going boom, boom, boom. I couldn't eat anything I could only drink. And I couldn't even drink an orange juice because it was too bitter, too tart. Then the blister went outside my throat, and I had like a giant blister on my throat. I couldn't go out in public because it was just a [inaudible 39:38] it wasn't liquid but it was like, horrifying looking. And I had to bathe it in saline solution every day and wrap it in gauze, and put special creams on it. And my mouth, my taste buds got destroyed and too this day I have dry mouth. Permanent dry mouth. I have, I can't live I need it right now actually. This—anyone who has dry mouth this is the most amazing stuff. I wake up I need this. So yeah. But I had a positive attitude throughout. I had the most positive attitude you could imagine and they loved me there, and I loved them. They were my family. And Asmir, this brown guy almost invited me to his wedding. They loved me. Oh what kind of drugs—I told them about mardi gras, and I'd been to mardi gras and all this stuff. I said well I'm gay but I'm celibate I don't know what I am anymore. And they go, I thought mardi gras—if you ever go what would you do, ecstasy. Oh yeah! This radiologist is going oh that's my favourite drug too. Wow! Can you still get it? Oh yeah. And then he goes, have you ever done down? Yeah, I go yeah, but I threw up. Anyways, next thing you know the radiologist then informed me when I was having all these side effects I was just about to be finish—just finishing my treatment, they said it's probably going to take me at least two months to recover, and I probably won't regain my taste buds for months, if not years. And that it at least going to be two months of recovery. And they told me, by the way do you realize that your treatment cost, the radiation costs over eight hundred thousand dollars. With the chemo you're a million dollar man. A million dollars to treat me right, to treat a cancer patient. Three-hundred average of, between three-hundred-and-eighty and four-hundred patients a year, that's half a billion dollars. And the machine only costs five

million dollars right. The machine's bizarre, it's like an alien operating device it just wraps around you and then it comes and stops at my throat, and this red radiate light goes radiation through me. But I found it all very relaxing because I like sunbeds, and it's like who cares it's a radiation bed. So there's a reason why that was HIV related. I finally get bloodwork back I don't know after how many years, and my CD4s again have dropped right down to seven. And my doctor's not concerned. I'm going well, because now they're not concerned about CD4s. Not really. You know we want you undetectable again. I went okay, and he put me on new pills. They figured out that I was resistant to—might've been resistant to the medications I was on. I just probably didn't want them, my body was kicking them out of my system. But I'm fine with the doses now today, don't get me wrong. Yesterday I was dissident, although I was still—oh! Oh! Oh! My my new discovery, new realization okay. So my CD4s everything dropped, my CD4s dropped, my doctor felt that I need to switch my medication. And I said no I think it had something to do with radiation. He goes no, I think you've become resistant to your medication that's why your CD4s have dropped. I have the best doctor in the world. My intuition rules. I've studied health for years I'm in nutrition right. And I've gone through every medication there is, you know and well not, you know what I'm trying to say. I'm going nah, I'm not are you sure it wasn't two months of radiation every day, basically, and chemo therapy? Oh no I don't think so. I said well I can't taste anything. So he put me on new medication. And I went oh, I disagree, I disagree with all of you again. And I—two months, it didn't take me two months it took me three weeks, to recover. I gained all my weight back within a month, thirty pounds. I now weigh heavier than I've ever weighed. I-I worked—I began working out again. This is almost a year ago right, time flies. And I've been—I-I went on those new meds, no problems with them, minimal amount. I only take three pills a day compared to a handful before. And no side effects. And I'm okay with it, it's okay. Not that I really believe in them but I'm happy with my protocol. And so then uhm—oh! Then uh, never a dull moment. Ben, ha ha ha. And whoever, SFU special. And okay so, okay so present—okay so! Recently so I gained my weight back and I actually I'm doing so well I took a few weeks off from the gym. And I'm actually going to go work out right after this treatment, after we meet, after our little appointment here. And I took a few weeks off and I in the process I realized you know, I realized it's been almost a year since I was diagnosed with cancer. And they haven't even followed me up for one follow up appointment. That's very suspect again. Now I'm being a dissident again. Don't you think that like two or three months later they would request for me to come in for a check up? No connection at all to the cancer institute on tenth avenue. Isn't that highly suspicious? After a million dollar treatment that's all they wanted out of me, was get their million dollars. That's why they're so happy working over there. They're not necessarily cancer angels, a little bit. But they want their bucks baby. As possible. Even I've heard other nurses at doctor Peter they go well how are you gonna deny that. I don't want really to accuse them, because they doesn't sound good, but if it turned out I had another diagnosis I wouldn't do that again. I'd go screw you, I'm going to breath, I'm going to drink lots of water and breath light. Whatever. Nah it's all about love and healing yourself and it's about vibrations, about a lot of stuff. But I don't think it's about being over medicated or radiated. It's a great way to learn things but no pain no gain I'm over all that thank you very much. And I'm currently I just got bloodwork—I just saw my—then okay, now okay so being HIV positive I—they put you on medications that they never take you off of. And Seroquil was a big one, I had problems with insomnia for a decade and I never realized until recently again, I've had all these realizations again lately. That my insomnia was related mostly to the sleeping medication I was on! Because really, you're not supposed to be on any sleeping medication for more than a few months. But with HIV they keep you on everything for always. Ten years later, I got a new doctor I fired that one

doctor who was convinced I was bi-polar, I fired her I got a new doctor. And she said, you're—I'm taking away your sleeping medication, Zopiclone or Immovain. And I got off, I went off of it and I went through withdrawals and it took me months to recover, to come off of it. And I was on a dose of Seroquil, which was increased to crazy amounts. Seroquil again I started overdosing. They just sneak them up on you, the next thing I'm taking five-hundred-milligrams of Seroquil and I gained fifty pounds and the gut, and I'm looking at myself going oh my god what the hell is going on. And again I'm going this is bullshit. And then I-I-I started cutting my Seroquil without talking to my doctor. The nurses at doctor Peter I love them so much, they worked with me. I said don't you tell them. So we started reducing it by half every week kind of thing, and I got down to two-hundred milligrams. And it took months! And then I uhm, started sleeping again, on two-hundred dose. And then, to tell you something really short, okay we're almost to the present day again. Oh I need to pot, to smoke to fall asleep as well. It's a combination of factors. Because I'm very anxious and obviously a hyper person by the way I'm babbling on right now. I'm a happy hyper person I'm not bi-polar dammit. But I'm HIV bi-polar perhaps, thank you. So okay present day, I write poetry. I just finished writing, I wrote *Radiate*. I just wrote, oh I'm writing okay uhm let's think okay so, cancer recovery, questioning cancer, questioning it all, letting go of it all. I'm fine, into the present moment now, accepting HIV status, not and accepting protocol regardless. Like, I don't take much. Well I'm obviously doing it. I'm not—oh how do I put it, I'm accepting protocol? I've adjusted to protocol. And I'm beyond protocol, I'm beyond protocol, that's what it is. And I'm healthy again. But it's beyond the physical connection, it's more mind, body, spirit. That sounds cliché. But you know I, my new—I've written all kinds of like I said, short stories. My book is called *A Fire*. Now if you recall, here this is going to sum it all up okay. If you recall I was lit on fire. I never mentioned it but it was seventy-five percent of my body was third-degree burns. And my mother put out the gasoline fire, she said it—this is my second page, paragraph four. Second page describes my mother putting out the fire. The little ball of red and turquoise flames that was screaming towards her and she realized it was a child as it bounced almost into her arms, she realized it was me her three-year-old baby boy and on fire. Dripping—my—I was dripping—my skin was dripping off me like gasoline—like melting plastic she said. And the gasoline wouldn't go out. Because it was gasoline, she kept trying to go out and it was just skin was melting off of me. Ultimately, to make a long—ultimately finally in Vancouver general an hour later it was only one hospital in the city Vancouver general this is Richmond, they showed up an hour later. Shock. Two-foot-long body, it was feet back then. Baby. Child. Infant. Three-years-old. Somehow that small. But leaping nine feet in the air. They couldn't strap me down, gripping my arms because I was in shock. Then I went into hundred-and-seven-degree fever. Dying. Salt water bath. Warm one. Cold—cold bath—it was a warm bath. It was odd you'd think with burns. You'd think it was cold. Warm bath. Body cast. Bandages. Mummy. I can hear her. Recovering from fever. And then I'm in that cast, I remember looking out at holes, my mom was saying, 'peekaboo, peekaboo I see you.' And then I hear my heartbeat, and I can hear my heartbeat going ba-bum, ba-bum, ba-bum and then it stopped. And then everything went black. And the all of a sudden wwhooooooop I just plopped out of my body cast and was floating around laughing and giggling and having a great time, just my little three year old happy—seriously, having a fabulous. I can see it right now I visualize—as I describe to you this is what a near death experience is, and this is why I wrote all this, so people can—Diane at doctor Peter's I mean I'm her biggest fan, I don't mean to brag. She says I can visualize everything, and you can probably, perhaps you can. I can visualize it as I read all this. It's amazing you know. I wrote all this so people don't have to go through any pain, or they can, if they you know they don't have to skip steps and trip, or whatever. This is inside information. And if it's not for them, they'll leave something out, they won't be able to

absorb it. It's about attention and absorbing things as well. And breath. It's all about breath and love. Breathing love and life. And light is the big deal. Whenever I talk about my lived experiences, that's why after this I'm going to give you—I'm going to email you my writings, and then you'll really get into the light part of it. And so, I'm almost done. And uhm, god these really I'm really this has really come out well hasn't it. Barely any stops. Okay so, yes it turned out the seventy-four degree, seventy-five percent of my body third-degree burns I had the near death experience I recovered. The body cast came off, I had gangrene in my leg, it was covered in it looked like frostbite my mom said. It was a giant puss pool. And they wanted to chop it off. And she went no way, you cannot do that, he's gone through too much, he'll die with no—and so they just came out with new super band, antibiotics, really it was in the nineties, the early nineties, they had come out before but now they were coming out with really strong ones. And they saved my leg. And I'm covered, all my skin grafts they said he's going to be scarred for life he's never going to be able to walk. And I walked—my mom had me walking within weeks. And I came out and I was supposed to be completely scarred everywhere head to toe, my scars started healing up I had very little scar tissue after I came out of this. My baba stabilized me, she kept me stable. She believed in god, she actually claimed after her husband died, my Ukrainian baba which is a Ukrainian grandmother. She claimed that after her husband died, she cleared out their bedroom and claimed to communicate with god in her bedroom. To pray to god, in her bedroom which is a white light. And then she—as I got older uhm that's another story but you'll get into it. But what I'm getting at, is my book, my work is called *A Fire*. A-F-I-R-E. So when I was writing, when I was finishing my initial drafts of *Grace on Fire* is what I called it. And I went, is that a TV show or something, and I googled it and went no it's not. It's similar, but *Grace on Fire* was not and I used that, and that was my working title. And when I finished my original drafts, Shirley doctor Peter's mother, doctor Peter's centre—doctor Peter his mother who I adore, we hug each other. She's the best hugger in the world. She read one of my original drafts, and it was rough, and she sent it to Tom Hanks. She knew Tom Hanks' assistant and he read it. She sent it to Hollywood and I went no, I haven't even edited it! But I cried. And I went okay. And uh so then, I'm rolling here. I said I got compression socks, that's why I'm serious. Check em out, compression socks are crazy. I'm not crazy. And then uh, so this is cool. So I went *Grace on Fire* and then I was just starting script, which is awesome, which is another trip because you're going from the past into the present. It's like changing your brain around. I went through a confusing period of how to adjust. How do I do this? But the script is easy as pie after I got it going. So the book, so I got the book down from two-hundred-and-forty pages, I edited it down to a hundred-and-forty pages, I got down from a two hour read to an hour long read for the average reader. Got it, finish it, and then start the script and then I discover then the New York Times bestseller for the last two years had been called *Brain on Fire*. And I went *brain on fire* written about a woman with some kind of mental illness, probably nothing compared to the two that I had, the two killers, poly syphilis and PML. But it had been the New York Times bestseller two years in a row my god. I thought brain on fire, and I'm going *Grace on Fire* I'm going a fire, a fire. A fire. And I go, a fire. A-F-I-R-E. Google dictionary. A fire, heart on fire. And that's the name of my book. So my book and my script are called *Heart on Fire*. My writings and my poetry which is turning into lyrics, today I'm just on the verge of writing a song. I just completed *Love Is In The Air*, a short song of that. You'll receive them if you'd like. And uhm, I just finished, I'm spitting these amazing poems out in five minutes. I can't believe they're just right—coming right out. Three o'clock in the morning last night. I don't really sleep. Oh yeah back to sleep. I'm finally sleeping, been back to Seroquil. This is the conclusion. So that's my healthy, I'm going to start working out again after a couple weeks off. I finally got, I was on sleeping a before to help me sleep, I realized I need pot before to help me sleep. I got some really good pot

today, I'm looking forward to smoking it later. And I am on it, back on Seroquil which I didn't agree with large doses, I'm on a nice small dose. They only gave me a hundred. You wanted a hundred a night I took two last night. I'll take two hundred I can handle two hundred doctor! He wanted to give me fifty but I was on five hundred before. So that's all good. So I'm going to get a good night's sleep tonight. And you know, I just got bloodwork done. Oh, when I did get bloodwork done before remember I said after cancer it crashed, it crashed, we're finishing now. And I said I know it was the radiation that caused not a reaction to the medications, because I'd been on those meds forever and never had a problem. You know hello it was the radiation. Hello every day third-degree burns. Immune system gone why. I'm not the only one, other ones lose hair. Thank god I didn't. And uhm, so yeah, now that's under control, everything seems to be under control. Tonight I'm going to get back into sleeping patterns. And yeah I think I have a hot roll with a Latino this weekend, but I might have to pay a few dollars but that's okay. I used to do that but you know what happened to me, because again I said I've never really been promiscuous etcetera. I actually had a [inaudible 56:39] name Alejandro and I saw him for two years. We had a relationship. It was so hot we were so good together. And that's all I needed, I just need once a month, good roll, safe sex, hot Latino, wapo, Alejandro. And here we are, then he took off to Rio left me confused without anyone for over a year I've been single, confused ever since. Because I don't want any of these promiscuous people I don't, I'm not into that. I watch porn maybe that's about it. Even then it's like oh god it always ends up ugly. And I turn off the volume, please shut up! I don't do that anymore. But I just happened to turn on Rent Man which is the old site, that I had my Rent Man Alejandro from two years ago who took off to Rio. And if found an Alexandro. Alexandro. I went Alexandro! Who heard of that. And he's hot, he's a wapo, and he's a top, excuse me but, I can't believe it. Alex and I talked to him, I'm meeting him on Friday. I'm paying a few dollars but hey it's worth it, I deserve it. I paid before, I was—it's—there's no bullshit, it's instant, passionate, that's the way I like it. I don't need a—for me, a relationship will come perhaps after my success, whenever, it'll happen when it happens right. But you know the nice thing about being HIV positive it doesn't really matter what kind of relationship I have. Right now I have relationship with my life and my work. Which is again life live light, remember that one. Yeah and so again like, you're gonna love, there's a section, ah okay. HIV positive, no before I was HIV positive was the craziest time of my life that's another story altogether. You'll get it in there. I think we're done for that part. I actually had [inaudible 58:32] I channeled, people sharing light with people in my teens actually, late teens. Was pretty crazy stuff. Mind-talking. We called it mind-talking my sister and I we committed—my mother actually but she denied it. We would communicate telepathically, I called it mind-talking. It was all through breath. It was pretty fascinating stuff. Breath is important, it's one of the most—that's why I guess yoga and that stuff. It's all very interesting. You're very good, you're got great, I-I-I usually have a hard time looking at people in the eyes but you're an awesome interviewer that way. Your eyes do all the talking. You're welcome. I do all the talking actually, but I think I'm almost talked out.

BK: Yeah I mean you've shared a lot with us, thank you.

MA: That covers everything I guess.

BK: Yeah I don't have a lot of additional questions. That's good for me.

MA: Okay awesome. No bloodwork either.

BK: Yeah that's nice. I'll just stop this then if that's okay with you.

MA: And if you want to do it again sometime maybe I'll videotape it.