

Interview with Avida (pseudonym) for the Boston Hemophilia Center Oral History Project, A Gift of Experience, by Christine Harland, October 20, 2004.

AVIDA: So do you combine oral histories for people to make like books or tapes? What is the final form?

HARLAND: Of this group?

AV: No, what you do personally.

CH: I talk to families or individuals and put together those interviews to create books on families. They're anecdotal histories of families. They're not genealogies, and I work with cancer patients. I do a whole spectrum of history.

AV: Oh, good, so usually in the context of disease, you mean?

CH: No, some of them, but certainly not all of them. Then I do family businesses. I've done that for many years.

AV: Oh, sweet. My uncle's just selling his business and I asked him if he wanted to do a history of it and he's like, "No." He has no desire to do that.

CH: Family business histories are very interesting.

AV: Yeah, totally.

CH: And they tell a lot about the people. They're really about people, not about business —

AV: Yeah, right. The dollar.

CH: Not about the dollar, no. I'm going to start at the beginning and I'm going to ask you about the onset of hemophilia for you and your memory of that.

AV: Okay. All right. We're already going?

CH: We are.

AV: You didn't tell me that. So the onset. I don't know. The onset

was when I was an infant and I have no memory I can verbalize.

CH: And your family lived where?

AV: Lived in Watertown, Massachusetts.

CH: You had brothers and sisters?

AV: Sister, two years younger.

CH: And was there a family history of hemophilia?

AV: No.

CH: So it came as a surprise.

AV: Yeah, I'd say so. To everyone involved.

CH: In your parents' telling of the story, what happened for them around that discovery?

AV: I really don't know the details. I guess they noticed I was getting bruises and took me to the doctor and somehow they made a diagnosis based on that. I don't have more information than that. I think it was pretty simple. There was the concern of why am I bruising? What's going on? I don't know if I had any joint bleeds. That would have been painful. And someone figured it out, but I'm not a child. I'm an infant when this happened.

CH: What year were you born?

AV: 1964.

CH: What did your father do? What was his work?

AV: He was a chemist.

CH: A college graduate?

AV: Uh-huh. Yeah.

CH: And your mother, did she work?

AV: She did before I was born. But when I was born, she raised a family.

CH: The two of you.

AV: Yeah, did child work, family work, house and home work.

CH: What was your earliest awareness of your condition?

AV: It's difficult because the disease is part of you and there's no differentiation. It's not like added on after the fact, that you have a sense of self or identity and then something's layered on—like a head injury. So this is about as much a part of me as my eyes and my breath, I don't know any different. There was no real awareness, except an awareness of the things going on, but it wasn't like 'this is hemophilia'. It's really 'this is me'. So I guess the awareness as a child was of pain. It must have been.

CH: Was of pain?

AV: Pain! I mean, it's only a disease of pain or trauma. It's not like it's a disease of laughing or pleasure. It's a disease of discomfort. So I must have noticed that in different ways. Bruises are nothing and didn't bother me, but bleeds in the joint are painful. So I'm guessing—these are childhood memories, not infant memories—I'm guessing I just noticed pain in my joints and I remember that, but the infant stuff, I have no memories of that I can tell you.

CH: Of course.

AV: Right, my first memories of acknowledgement are icing the joints. We're talking the 1960s, there was a different form of medicine than now. Before that, people got whole blood, and before that, you just suffered. So people of my generation are a little more impaired. Kids today when they're forty are going to be much better off than my generation is at forty, in terms of joint disease. So we're probably just on the cusp of—I don't know what you'd say. It's not quite a cure, but a manageable disease now.

CH: There are much more effective management tools.

AV: Yeah, so the way diabetes is far from cured, hemophilia was far from cured in the 1960s, particularly when it related to treatment and the politics of getting the medicine.

CH: How did your parents approach the problem? Were they very protective?

AV: Right, so my parents. I really haven't gotten into it too much. My father died in 1978, so I was thirteen. Old enough to remember him well, but we didn't get into discussions of hemophilia, but that said, I'm forty and I really haven't talked too much with my mother about it. My sense is that it was traumatic for everyone involved, and how they dealt with it? They were not over protective at all. Far from being, you know, smothering, mothering, smothering. Far from that, and far from being negligent. I think they tried to let me have as much of a so-called normal life as possible. I didn't play football, but I was never really interested in football. But maybe if I could have played, I would have been. I don't know. But I played baseball. I ran around. There's pictures of me in kneepads as a kid. My father rigged some stuff to protect me, naturally and functionally. I don't remember being limited in anything I could do. If I cracked my head open, then it would be bad, whether I have hemophilia or not. So I don't remember any sense of just being reeled in or an extra watchful eye. It might have been out there, but I didn't feel restricted at all. I rode my bike around. Fell off it. Treated when I had to, and the main thing is that cuts and bruises and scrapes aren't going to do anything. Benign. But in terms of the actual stress that was on the family, I think it was great, particularly on my mother. She's the one that had to bring me into the hospital. It was always to the Emergency Room. It was always slow, and I was already in pain. The bleed's going and

growing, as I waited for treatment. It wasn't instantaneous treatment. So that always led to problems. That's why my joints are as bad, or as good, I don't know, as they are. I think a lot of that waiting had to do with it. Before home infusion, you were kind of at the mercy of the system, and there wasn't much mercy in the system.

CH: Tell me about that. Where did you go for your treatment?

AV: I think I always went to New England Medical Center. I'm not positive, but my memories are I always went to the same place. It was the city and I think it was there. That was where my care was. If that's a hospital with an Emergency Room, that's where I went. I left here in 1973.

CH: Left where?

AV: Left Watertown. We moved to Michigan, when I was nine. So in those first nine years I think it was always there, and my mother was active with the Hemophilia Chapter in Boston.

CH: She learned quite a lot about it?

AV: Yeah, she was involved. I mean she became, I don't know if it was her—I don't know how you gauge these things. It wasn't her passion, but she became passionate about it and put a lot of time and energy into I guess advocacy, fundraising. So it had to be life transformative for her in that way. Maybe as a healthy way to deal with the situation.

CH: Was it divisive at all in your family?

AV: Not that I can think of it. I mean, economic issues I think crept up—my mother said something once. My father took certain work so we could have insurance for everyone, but I don't think that—I never heard anything negative about me or the situation that made me feel belittled or guilty or less than the full human I am. But I'm sure as the

two adults, my mother and father, talking, I don't know. My father had diabetes, so they were familiar with disease, hospitals, treatment for better or worse. But in terms of me as a child, I think it was—I felt—I guess it's bad. I wouldn't say guilty. Sad, hurt. It was obvious the inconvenience of having to go to the hospital and get a treatment. The time, the energy. It was always a pain and I was never put down or ridiculed or like, "Not again." Never like, "Don't be so active, so we don't have to go." Nothing like that, but it was still obvious this was a challenge. It disrupted our lives and it was never a positive thing to go to the Emergency Room. So I took on some of that and I know I waited sometimes to tell my mother, hoping the bleed would go away and not knowing better. So that was on me, mostly.

CH: What was the Emergency Room care like in those days?

AV: Hmm.

CH: You said you had to wait a lot sometimes.

AV: Well, yeah, it wasn't—it wasn't bad, like negligent per se, but this was, I was, sometimes low on the list, I think, for taking in. You could look at me, I was fine but I have a bleed in my joint. Plus, there's other people in greater need. It's probably just a less efficient version of what there is today. Dealing with people as flesh and bones, and not as people. That hasn't changed much, I don't think, from my experience. That's just the tragedy of modern medicine. They're good doctors because they're good people and they meet you first as a person and not as a patient. But a lot of that wasn't there, particularly in the Emergency Room. Just like, 'strap him down and get the medicine in and get him the hell out of here,' type of thing. That was never vocalized, but that's really how I felt. It's just

probably the way you milk a cow.

CH: Get him through the system.

AV: Yeah, get him through the system. So as a child and as an infant, I don't even know. I've done some therapeutic work and have a little more access to some of the early medical events in my life—just things I never really thought about, but it was scary and traumatic. I'm not saying anyone was purposely scary or purposely mean, but an infant, a child, doesn't understand. Right? It's like if someone just yanked both of us out of here and put us in a strange space with strange sounds and sights and started doing intrusive things to us. You don't know what's happening and there's not necessarily a calming and loving person within reach. You are small, alone. You're in pain and someone's helping you, but you're still in pain and you don't totally know they're helping you. You don't understand. Your mother's there sometimes. Your mother—your protector, your caregiver, your intimate, your love, your creator—yet she brings you to such a horrific situation and you only feel better—hmm, a good time later. It's far from instantaneous. The medicine, even when it was slow, when it was done, it's not like, "Hey, I feel good. This is better." It was hard to make the connection between the traumatic treatment and the relief from joint pain.

CH: There was no Novocain shot?

AV: Not that I remember. But my mother recently reminded me that I sometimes received a shot to temporarily and quickly relieve the pain before the treatment for my joint bleed began. This was also scary because the drug restricted my sense of my body, my felt sense. So I don't think I really understood at first that the treatment, the medicine, was making me better. Not because I was slow or stupid, it

just seemed like a brutal procedure. I can't even imagine what it was like as an infant. It just had to be—I just have ideas of like, “Stop,” and “No,” preverbal fear and anger. So I know I was strapped down. Sometimes my arms were held down, just to get the needle in. I mean, functional, but not necessarily done in the most humane way. The same way it's probably not done now in the most humane way. So my sense is, unless there were exceptional parents and exceptional medical care, most people with hemophilia back then and maybe still today were really traumatized as infants. I don't know. I don't think that's a reach. So all of us are living with that in one way or another, whether we realize the degree of it or not, particularly since it's an infant situation and the treatment is invasive. So it's not like you're born with no legs. Then there's no treatment. You just grow, deal with the situation. But every so often you're brought into a situation and kind of you could say ritualistically assaulted, because that's all you get out of it. When my mother was there, it was probably more comforting, but just confusing, the mix of love and pain. I needed to be held, not held down.

CH: People have mentioned how cold the blood often was. They put it in quickly and it would be cold and very uncomfortable. Was that true for you?

AV: Oh, yeah. I remember that. That never bothered me.

CH: It didn't?

AV: I mean, it was just because it was—hmm, it was cold.

Sometimes when I give Factor myself, the water is cold. It was more like a sensation. Maybe as a baby it did, or an infant, it was scary.

When you mention it, it sounds right, but it didn't seem it.

CH: It didn't strike you.

AV: No, because you're getting the shot. Even though the pain of that's over right away, but you know, if your arm is held down, you can be fighting that. I think it's that immobility, that kind of claustrophobic stillness. I mean, try to tell an infant to be still or a child to be still. I mean, it's like, "Shut up. Be still. Sit in the corner." It's kind of the same mentality you get in school, except in the hospital in many different ways. Yeah, but that sounds right, the cold. I'm sure—it definitely wasn't welcoming and pleasant.

CH: At what point did you begin to develop, an attitude towards the pain and ways of dealing with it?

AV: Hmm. Is this the time to say like world peace in 2004?

CH: Anytime.

AV: And can it include some healthy propaganda/truths?

CH: Anytime.

AV: An attitude towards the pain? [pause] The pain—wow, I don't know. It's so hard. The pain is—when it's there, it's there. I have only a few memories and I don't know, one in particular where it was just brutal—and that's what I remember. Crying, painful, just hurt and that again is another claustrophobic thing, that you can't escape the pain. It's everywhere. Even though it's in the joint, it's just in you and you can't work with it, or I wasn't able to at times. But there seemed to be a point—I don't know how old I was—less than nine. It was before I moved, where all the damage was done psychologically, in a way. It wasn't. I mean there was still more to come—but it was like I had this understanding. It's kind of like maybe the first time someone gets mad at you or you fall out of love, someone breaks up with you. There's an understanding and wisdom that comes with the experience. So I got to a threshold or a level where it became routine.

You know, I have a bleed, I go to the hospital, here's the pain, it's coming on, and at some point, I think just before we moved, I believe home infusion started. I think this was one of the first areas in the country. That made things a ton easier. It was also the new Factor. It was more concentrated. It was still less concentrated than it is now. They've been shrinking it down, like everything gets smaller. All technology moves toward miniaturization and invisibility. So that made it easy. And at some point I gave it myself. It was very different, but in terms of dealing with the pain, I don't know because it wasn't a presence that was there all the time. Just when I had the bleeds. The reality of hemophilia is, at least for my generation is that I think the worst may be yet to come, and no one prepared me for that. No one even mentioned and it seems kind of again, I don't want to say incompetence, but some degree of just arrogance and ignorance. Because so much hope is placed in the medicine and everything. No one ever said "Be happy you're alive," but there's that sense that everything is taken care of now, but the pain that I have now in terms of arthritis, is significant.

CH: No one ever said to you, "Get ready."

AV: No.

CH: Would you have done anything differently if you had known that?

AV: I don't know. It's hard to answer a question like that. I don't know if I would have. I've been told to exercise, you know, to keep my joints strong, but probably—I mean I would have done something differently maybe a little earlier.

CH: What would you have done differently?

AV: I probably would have—my guess is I would have—the only

thing I could have done was exercise more to maintain strength and mobility.

CH: Does that help you now?

AV: Uh-hmm. Yeah, it does. I notice a difference. Even if there was nothing I could have done, the inevitability of the physical course is unknown to me. Kind of like most people by the time they're teenagers know they're going to die, unless they have lived very sheltered lives. I guess you can be unknowing up to a certain point, but I feel like the establishment kept me pretty unknowing of arthritic changes in the joints. Yeah, this should be a major emphasis of hemophilia treatment and care. I can't be alone, because I've just seen people growing up as a kid that were my age and younger and they were worse off already. Worse than I am now, thirty years ago. I was lucky growing up in Massachusetts. Some people, when I was in Georgia and Missouri, I mean they really damaged their joints. I don't know what they're like now. So anyway, it's just strange that—I was thinking about that the other day. The disease is as active in me in some way now as it's ever been, but it's all secondary. I'm not having joint bleeds as regularly, but the damage done when I was a child and older is like it's here, loud and clear.

CH: Do you think it was that they didn't know or was it that they were so focused on immediate treatment? Were they thinking life and death?

AV: No, not life and death. You'd really have to be hurt to be at that point. It was never a life and death situation for me health-wise. Someone should be knowing, but I think the focus was on maintenance and day-to-day care, week-to-week, without acknowledging the changes that will come. Maybe other people are

really active and they're doing well in their fifties and sixties, but my gut sense is no. If you want to be hiking many miles, do it now. That's always true with everything in life: Now is the moment in which to live. There's no reason to expect that you're going to get joint problems with aging, but it seems like this is in the course of the disease. Sidetracked. Everyone's sidetracked. HIV. Hepatitis-C. I think that took some focus away from hemophilia, specifically. It's only recently that it really sunk into me that my joint health is degenerative. I think about these changes and I am told, "Well, it might not get worse. It could stay like this," and I go, "Yeah, okay, cool," but I realize it's getting worse. This is, I don't know—I call it arthritis. The cartilage is gone. These are secondary effects of hemophilia.

CH: That sure sounds like arthritis.

AV: I mean, I don't know where it can go. How bad things can get.

CH: Do you think about that a lot?

AV: No, I don't. I never thought about any of this a lot. I hope I never do, but if I'm immobile at some point, I mean, that wouldn't be pleasant for anyone, obviously. But knee replacements. I know these things are common. You have eighty-year-old people getting two knee replacements. So what. That doesn't make it good. That doesn't make it less traumatic.

CH: Have you thought about knee replacements?

AV: Oh, it's been talked about, yeah, in different ways for the last ten years. I'm not touching it until I have to.

CH: Much the same thing happened with polio and post polio syndrome.

AV: I'm not familiar with that.

CH: And part of it was that they didn't know a lot about it.

AV: Okay.

CH: Part of it was that the information didn't get out there. People thought they had polio and got over it, but in fact now they're often suffering the consequences of Post-Polio Syndrome. And like hemophilia, it isn't the issue it once was.

AV: Right, it isn't.

CH: That isn't where the attention goes.

AV: Yup, it isn't. In that sense it's a dying issue. As my generation dies, or maybe the one after it. I don't know. You're going to have home treatment. You're going to have some changes, but it should be a lot less unless you have neglect in the family or abuse in the individual. In that sense things are better. I don't know how people my age and older with hemophilia deal with these issues.

CH: What was your doctor like? Did you have a primary care doctor for your hemophilia?

AV: Yeah, I had a great—I had Dr. Britton. I believe he had hemophilia. He was great—in terms of all the negative things I said about medical care.

CH: Was he British?

AV: I don't know. He was a character. He was a good person and caring, sensitive in contrast to the Emergency Room visits, but these people you see relative infrequently. You're not there every week, even every month. I don't know. He was—I just remember him being kind and gentle. My mother spoke highly of him. My sense is he was well regarded as a rare person, let alone doctor. So that was good.

CH: He must have been a great help for her, too.

AV: Yeah, right. Yeah.

CH: Maybe more than for you.

AV: Uh-hmm. Yeah, to have an adult on your side and understand. Yeah, and I know I had an orthopedic doctor, Dr. Zimbler, who I liked. He was kind when I got casts. He was good. Dr. Levine took over. He wasn't the same. Nothing bad to say about him, but not really—

CH: Dr. Levine?

AV: No, nothing really good to say about him. So my care is always, the people, you know, they ranged. I feel like the best care I ever got was when I was in Massachusetts as a kid and it's been in different ways since because, also, the hemophilia issue's kind of dissipated in my life. It seems like there's the childhood and adolescent needs, and then they kind of go away. You're on top of things and it's almost like you need middle age and beyond hemophilia specialists. I don't know. I mean the doctor running the Boston Hemophilia Center now is a pediatric specialist. So that's indicative of the problem, in a way, whether it's political, bureaucratic, financial.

CH: Well, the light is focusing on the young and the newly diagnosed.

AV: The new life. Yeah, that's good and it needs to be—I mean I don't feel neglected, per se, I guess, but I just feel I want—the latest information and best care out there for me. I just think that's the reality of the disease and maybe a lot of diseases are really like that. I think diabetes is considered cured and yet it chips away at you slowly. Diabetes is managed, not cured. The same is true with hemophilia.

CH: What did your father die of?

AV: He had a heart attack. He had heart disease. I don't know to what extent it was related to his diabetes or not, but, yeah, it didn't help.

CH: You started school in Watertown?

AV: Uh-hmm.

CH: And what was that like?

AV: I remember I used crutches in elementary school. I'm sure all the teachers knew, at a certain point. But they didn't know in college. Did they know in high school? I don't know, but in elementary school they knew. The kids? The ones I was friends with, I don't know what it would mean. They must have known in some ways but I don't feel—

CH: But you don't remember it being a bad experience?

AV: No, it's probably like, "What happened to you?" and I'd just say, "Hurt my leg today." I'm sure a wise kid would go, "Why are you always hurting your leg?" I don't remember that. I don't remember really being ostracized, but there's a sense that you'd get—you'd almost ostracize yourself by the disease changing your persona. I was more withdrawn, quiet or doing other—less active things.

CH: Fearful?

AV: Fearful, right. So it's not that anyone would say anything, but you undergo those changes. So I've always been kind of quiet, I think. I really have no negative experiences. No like what you call 'isms' such as racism or disease-ism from my contemporaries all through my life.

CH: I guess I'm a little surprised, not negatively or anything, that your parents didn't talk to you more about it. That it wasn't more a

topic of conversation.

AV: In the family? The disease?

CH: Yeah.

AV: Well, it is in a way. You're always treating and up until a certain point my mother and father gave me the Factor. There was a point at which I did it myself, once we went to home infusion. So there was always an opportunity. I mean it's not like hidden. I was on prophylactic treatment where I'd take it every other day. A little too late in my life, as so much damage was done. It started maybe when I was nine. I don't know. Discussed in terms of, you mean it's actuality?

CH: In terms of the things you've just described. The ways in which it might affect you in your development.

AV: Oh, that kind of stuff. No, that's just the tragedy of emotional life in my family. That's not necessarily out of the norm at all, the way people deal with emotional issues in this world. Don't speak about them. Talk about them in a tangential way. I don't remember specific conversations. I was always encouraged—it was a positive environment. It's not enough to not be abused, to not be mistreated. You want to be fostered and nurtured and enriched and supported in your growth.

CH: And you were.

AV: I was in part, but not in a way that I mean—parents do the best they can, obviously. They give you the—

CH: You were sustained.

AV: Yeah, and I was given a lot of love, but I was also routinely traumatized. It had to be brutalizing for my mother to witness what happened to me and the pain I was in. So we haven't discussed that as

a child I don't remember discussions. I'm sure at some point it came up, you know. "These are some things you might not want to do. If you're going to do this, be careful." I mean it wasn't like things were totally ignored, but things about like—you can call them psyche and body issues, were not addressed.

CH: How you were feeling about it.

AV: Yeah, but knowing me—or this is the way I am now. I'm not too—I was not one to be very open. I mean, I can. I have the capacity and with certain people I do, but in my family, I don't have any memories—I mean the conversations are different when you're a child, but there still can be right to the core issues of fears and sadness. Can be nothing more than "I'm sad, hold me." That's the same thing you can have as an adult, all through your life. That same conversation. "I'm sad, hold me." I was encouraged to be a strong boy, good boy. You know, like a dog, good boy, and I rarely let those feelings through, as in "big boys don't cry." I know I was scared at times as a kid, and I know I was angry a lot of times. I mean, I don't know if I ever trusted the medical establishment, once I realized what it was. What it is. Just this is pre HIV. It's not—it's not a kind institution, really, and that's this—

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AV: —people out there that just can't do it, the way there are counselors out there who can't counsel.

CH: They can literally do it, but they can't do it—

AV: Yeah, right. You don't want to end up with a bruise from getting a needle. I've never had a bruise, giving needles myself, even when I miss the vein, but I've had bruises getting my blood drawn numerous times. Bad technique. You see stuff with doctors. You go

to PT sometimes and they force the joint. It's obvious. You feel it the moment it happens. You know you're going to have a bleed. You don't want to get a bleed from PT. It's difficult work, but it's just that unqualified people creep into the system. They're not bad, but they just don't have the sensitivity to be working at restoring and maintaining health and wellness.

CH: They're not the right people for the task.

AV: They're not. Exactly.

CH: For what they're doing.

AV: Right, exactly and we find that in all professions.

CH: You do, but it matters a little more here.

AV: Yeah, because it leads to pain or—

CH: You can't walk away from it.

AV: No, so I've never been trusting of the care process and always questioning, but in terms of your question about the discussion, yeah, it is kind of surprising, and I think it's probably just across the board. No one regularly asked "how do you feel?" I don't know if I was given the space for emotional release, but the thing is I cried as a child and that's in some ways good. I've been sad or depressed in small bouts, but it's never really gotten me functionally down, but I don't feel like there's been many heart-to-heart discussions and emotional sharing in our family historically, and there still haven't been.

CH: What was your sister doing throughout all this? She's younger or older?

AV: Getting neglected.

CH: Was she? The focus was on you?

AV: Yeah, not like she wasn't fed or clothed, but she got the short end of everything for the first—

CH: By the way, would it help you just to stand up?

AV: No, this is good. Thanks.

CH: She was younger?

AV: Two years. Two and a half. One parent's working, one parent's there for us two and when I had to go to the hospital, someone had to take care of her, or she had to go to the Emergency Room with us. I realize this must have been hard for my sister. It's not like this was a good way for me to get attention. I was in pain. It's not pleasant, and she suffered from some of that exposure.

CH: Was she resentful?

AV: I think in a way she's been. I know she feels I'm favored. As the first child, I think I have been. Independent, probably, of the disease. She's ended up hurt a number of times or her needs were not met, even if her need was just like acknowledgement—hold me or play with me—so, you know, these small things can lead to lifelong neuroses in a way.

CH: Or sickness.

AV: Yeah.

CH: Tell me about realization.

AV: Right, yeah.

CH: It doesn't have to be anything that your mother would have seen necessarily. It just is one of those things.

AV: Yeah, and I don't know who my sister was left alone with. I think my grandmother, at times.

CH: Were your grandparents around?

AV: Yeah—all were alive. My father's father wasn't. I was named after him, but my grandmother remarried. They were all around, but the only one I really remember helping much was my mother's

mother. She came and did a lot of stuff, whether it was taking my sister or helping, going to the hospital. I don't know, just being there. She was present. My father's mother was present, but we made the trip to her. She lived in Nantasket, so those were all good trips. I don't remember the dynamic of when I had to go to the hospital, which was often. My mother probably took us both there and they had to be scary for my sister. So that in and of itself, just being in an Emergency Room? You don't even have to be sick, just hang out in the Emergency Room twice a week as a child. It's almost cruel.

CH: When you went to Michigan?

AV: Uh-hmm.

CH: Was it because of your father's job?

AV: Yeah, uh-hmm.

CH: What was it like to change venues? You left your doctor. You left what you knew.

AV: Yeah, well, hemophilia—this discussion is probably the most I ever talked about it in my life. It's never been much of a discussion with friends because to me it's kind of matter of fact. Like I said before, I don't know anything else. It's just present. So, yeah, a change in the doctors was—I guess it must have been strange, but by then it was routine.

CH: You were used to things.

AV: It was routine. Yeah, there wasn't much happening. Treat at home. There was a point in which once you treated at home, I thought it was more of a nuisance seeing these doctors.

CH: Being able to treat at home made all the difference, didn't it?

AV: Yeah. I felt there was no reason to see them. They were not offering much. Once you've got your treatment down, they do a

blood test and everything's basically good. That's why I think the whole Hepatitis C and HIV thing must have just been for those people, well, "Whoa, now there's two other diseases to deal with." They're still grappling with it.

CH: And that didn't touch you?

AV: Oh, yeah, it touched me. Both, one, two. Uh-hmm, yeah. I got both of those from—yeah, the Factor.

CH: I want to come back to that, but I had asked you about Michigan.

AV: Yeah, right. It wasn't good.

CH: You went to high school.

AV: Well, it wasn't good. The move wasn't good. You have your roots, your family. As much as now I don't like the northeast, the northeast being the megalopolis. Yeah, everything you know is transplanted and we moved. New friends. I had friends that lived across the street. It was the kind of—it wasn't idyllic, but it was in a way. Playing in the street.

CH: It was?

AV: Yeah, okay.

CH: Where did you live in Watertown?

AV: King Street, by Cuniff School. Those are my two landmarks. I remember the crossing signals made sounds.

CH: It was a nice town.

AV: Yeah, I've been back. My sister and I went to the old house a couple of years ago just looking. The neighborhood looks great. We moved to what you'd call a subdivision. Not knowing it at the time. But it was, in terms of a vision, a dream for a growing family. So I adjusted. The main thing that I gleaned from all of that is we moved

to an extremely conservative town—it's a Christian country, but we moved to where there were very few Jews and to be Jewish was to not be Christian. Not that I'm—

CH: What town were you in?

AV: We were in Grand Rapids.

CH: Grand Rapids.

AV: Right, so it was a pretty—

CH: Very WASPY town.

AV: Closed-minded, closed-hearted. Just, yeah, sad. Stiff and intolerant and not like I was walking around declaring my “chosen people” attitude. Far from it, but people would impose the fact that you are Jewish upon you, or that you're not one of them type of thing and it was just different from the northeast, the mix of people's and feel, the attitude. Culturally.

CH: Imagine how your mother must have felt there.

AV: I don't know what they were thinking. I know about my father's work, but it didn't make any sense to me. I would never bring kids there. It's not like it was fascist, though it was in a way. It was a good move for my father work-wise, and the house was nice, but it's just pretty empty. And it's not like the Midwest is empty. There's a lot of vibrant places in the Midwest, but Grand Rapids was not one when I lived there.

CH: It's very conservative.

AV: Yeah, it still is, for all the goodness going on there. I could live in Grand Rapids now and be satiated, in a way.

CH: Very social. Upwardly mobile.

AV: I didn't realize all this commentary at the time. It was just emotion—it just was less fun. I made friends and always have, kind

of through my life, and my parents had friends. So it was once we got in the swing of things it was good.

CH: Did you have any plan for your life at this point?

AV: I never have had a plan for my life.

CH: Did you know what you wanted to do?

AV: At some point I wanted to, believe it or not, be a doctor and I think just because part of me felt like I could do it better than a lot of people that had touched me in a cold way. But that ended fast, when I went to college and just saw all the requirements that I needed. I didn't want to—I wasn't interested enough.

CH: You didn't have the passion.

AV: Yeah, if this is what it meant to be a doctor, I don't want to go through this.

CH: Where did you go to college?

AV: To Wesleyan, so it was—that was intense.

CH: Was that a good experience?

AV: Yeah, overall. It wasn't—it was far from negative and I guess maybe everyone wishes they could go back to college, but my approach was very timid, I think, coming out of who I was and coming out of Grand Rapids. It was all—it was a lot of new stuff to me that wouldn't have been so new if I grew up here. It didn't freak me out overwhelmingly, but I approached things very slowly and it's by my fourth year that I was ready to embrace college fully. Yeah, it was good. Yeah, it was a good living experience.

CH: And what did you do after that? Or what, your father died—he must have died around the end of college for you.

AV: He died my freshman year of high school.

CH: Freshman year of high school?

AV: Just going into high school, yup.

CH: So this was 1978.

AV: Yeah, I was fourteen.

CH: Fourteen?

AV: Yup.

CH: And that was sudden?

AV: Yeah. One minute he was there; the next minute he wasn't.

CH: That was difficult.

AV: Yeah, that was—that was huge, obviously.

CH: I'll bet.

AV: Uh-hmm, for everyone. He was like the center of the family, the emotional core. He generated and gave a lot of love. Gave and received, so it was a huge loss for our nuclear family and the extended family. Obviously—I don't think people ever really recovered in a way. It was so long ago.

CH: Do you think it's hard to get over it when it's so quick?

AV: Yeah.

CH: When it's so untimely, unexpected.

AV: Yeah, right in his prime, in a way.

CH: You lose heart in a different way.

AV: Yeah.

CH: You lost confidence?

AV: Yeah.

CH: Did you come right back to the east?

AV: No. we stayed. We stayed.

CH: Your mother stayed there?

AV: What was she thinking? Oh, I know what she was thinking.

My mother, and she really doesn't admit it, but I've said it, she was

happy to get away from her family—

CH: From her family.

AV: Yeah, it was just too—

CH: Claustrophobic?

AV: Claustrophobic. I said that about my father giving love. He gave love in a healthy way. My mother's family gives love sometimes in an unhealthy way.

CH: I understand.

AV: And, yeah, my mother was ready to get away. My mother was ready to I guess grow.

CH: Be her own person.

AV: Uh-huh.

CH: And how did she fare after your father's death?

AV: Wow.

CH: Or did she?

AV: She did. I don't know how. She managed to thrive. She started working part time.

CH: What did she do?

AV: She worked in retail—a buyer in a clothing store.

CH: Do you think she enjoyed that?

AV: She did. She loved it. She's a very social person, not in a chit-chatty way—she's a great woman.

CH: What's her name?

AV: No, I'm just thinking. [voice is breaking up] I can't imagine. [pause] I don't know why she stayed.

CH: I think you're right in what you said.

AV: Yeah, but just so alone. I mean she had some friends and us. I mean she didn't move.

CH: Maybe she didn't have the energy.

AV: She didn't move anywhere else.

CH: She didn't move?

AV: No, stayed in the house for another six years and then she moved, but just to another part of the town. But she's the type—she'd be happy anywhere. She's that type of person. So she makes friends, meets people. She's another giver, so somehow, yeah, she made it work.

CH: Did she remarry?

AV: Yeah, like 11 years after my father died. Yeah, and she's not moving back—

CH: She's still there?

AV: Yeah, as much as the family is important, it's just not that important.

CH: So she went and she stayed.

AV: Yeah, it's not healthy to be by the family. My sister came back after college and I just came back two years ago, but I have little to do with the family.

CH: You had pretty regular dramatic changes, with the move and your father dying.

AV: The move, yeah. That's true.

CH: The fabric was fairly steady, but then there were these very serious blips in the screen.

AV: Right. That's true. The move was all right. It had to be. My father dying was huge, though. I mean it was just like he had vanished, and then I started high school just two months after he passed away. Yeah, it was challenging. There were problems. Now I had to listen to everything my mother said, instead, of you know,

“You must talk to your father when he comes home.” My father was just a big bear. I was scared of him, though. He had a big voice and he was authoritarian.

CH: You respected him.

AV: Yeah, but also he scared me just because of his voice. He could just raise his voice and I'd start crying, type of thing, but no, I didn't get hit really or anything like that. So it was hard. The first couple of years were hard with him gone. I teased my sister more. It was just a mess. It wasn't—it wasn't a pleasant place. I think I immersed myself in school. I had friends. I don't know. I guess that's it. It's weird. I don't remember. As bad as it was, it wasn't like the fun was gone. Far from it. Still had a lot of fun and I think that's always happened.

CH: In the family and outside the family?

AV: Yeah, my sister and I could be fighting one minute and the next playing ping-pong. So there was a time in high school where we were at each other's throats, but with my mother, I didn't get along well with my mother the first couple of years after he died. That's my memory of that.

CH: No surprise.

AV: No. I don't know how well I got along with her before that, but it did just seem worse. In some ways I just felt like there was less freedom once he died. I don't know if that's true. It just seems that way. We were all grieving for a couple of years, and everything with the hemophilia just kind of—basically not much happened.

CH: You were infusing at home.

AV: Yeah, and—

CH: And it was status quo?

AV: Yeah, it was status quo until HIV and I think it would have been status quo up, if that never occurred, aside from the arthritis.

CH: What was happening with the HIV experience?

AV: Oh, the HIV experience. Well, the HIV experience is another example of the blind allegiance to medical science and pharmacology. My first experience, actually, was in college. I remember reading something about it. 1985, maybe 1984 and for some reason I thought I had HIV. I didn't even know what it was.

CH: You read that this was beginning to appear.

AV: Yeah, but I had like a fever or a rash. I don't even know what it was. I remember going to the student clinic and telling the doctor and he was like, "No, you have none of the signs. Everything's fine." I didn't think about it again for years. At some point it became a reality that people with hemophilia were getting HIV. I don't remember what year that was. It was obvious and the main thing that impacted the issue was just my need to explore and engage sexuality and love. Love, really and mainly. That's the way I responded, with fear and like, "I can't get in a relationship. How am I going to meet someone? How will this person deal with the situation? I don't know. I still don't know." It was almost like being celibate, denying that part of myself out of fear because there was all the stigma and lack of acceptance. The history of that disease in the world, in this country tells much about how people treat, that is mistreat, each other. So I was at the clinic in Georgia and when I got there, they were surprised I hadn't been tested yet. I went there in 1987 when I started graduate school. Every time I went to the clinic, "You still haven't been tested? You haven't been tested?" and the doctor who ran it, Dr. Stein, said, "You ought to get tested." I'm like, "Why do I have to get

tested? What's it going to tell me?" "Then you can get on therapy," you know the whole spiel. So at some point, just to get this doctor off my back, I said, "Fine, I'll get tested. I don't care," because in my mind it made no difference. It's not going to change a thing, but now I'm going to know, so I have to live with that knowledge, even though I know anyways, kind of. I mean, just statistically most people with hemophilia got infected. So I got tested. I went in—this is 1991. The way they made it sound, by 1991 most people with hemophilia had been tested. So I hadn't, and I got tested, and went back to the clinic and got the results. It was positive, and they were kind of long-faced and I was like, "All right." Just hearing it and then dealing with it was scary. In the same breath, Dr. Stein is offering me AZT. "So you can go on AZT. Here's how it goes. I'll write you a prescription." He had no sense of heart and soul.

CH: Was he hard because he had no empathy.

AV: That, yup. So casual with the news. I mean, it could have been—

CH: Cold.

AV: Yeah, exactly and in some ways it's very devastating because of longevity. I thought I was going to most likely die soon, whether it's five years or ten, it's in the mix. But he was just matter of fact, routine, start taking this drug and you'll get through, and I'm not exaggerating any of that. It was just really fast and formal. I was like, "No, I'm not taking this drug. This drug is a joke," and he was a firm believer. He tried to push it on me and I had read a little bit, and from my reading it was obvious that this was the drug not to take. I don't know if the story's been finally written on it.

CH: Were you right?

AV: That's what I mean. I feel like I was and I wasn't lucky to be right, it just seemed the knowledge was out there already about AZT.

CH: Did you take anything?

AV: Well, at that time there was nothing to take.

CH: But since then?

AV: No. I mean, I've been taking vitamins for years, but I didn't pursue any alternative therapies or anything like that. I just kept saying no to him every time I went to a clinic. They referred me to an HIV specialist, Dr. Steinberg, who was good. But there was little coordination. Someone's writing you a script for AZT. The other one's saying, "Well, that's okay. You can wait. Your numbers are here. Da, da, da, da, da, it's fine." Dr. Steinberg was not aggressive with treatment. The hemophilia doctors had factor VIII to offer their patients. Some people could say no, but it's very unlikely. Whereas, AZT, it wasn't offering the same type of health restorative effect as factor VIII, yet they were still excited by it.

CH: And when you said no, did you feel he withdrew his interest from you?

AV: A bit. How can I deny this? I'm being offered help and I'm saying no so what's my problem, not acknowledging my intellect and my knowledge and my opinion. The doctor is not God. It wasn't very clear about AZT. I mean, I didn't just have this opinion for the hell of it. It just seemed to be that's what was being stated in the journals. I was training in psychology, so I was familiar with going to the journals and reading and learning.

CH: It has other implications, where you have doctors who determined that it was the thing to do, and if you had reservations, they really lost interest in you.

AV: Yeah. I never listened to this hematologist, but the infectious disease specialist was good. He never really pushed anything. Just informed me on the state of the art and for HIV treatment. So I found out and it was 1991.

CH: Did you tell your mother?

AV: I told my mother eventually. It was strange because right after finding out about being HIV positive, I met this woman and we grew a love relationship together and I obviously told her from the beginning. Well, actually, it's not obvious. You hear about how messed up it is. I've heard some stories that people have HIV and don't tell the person they're with. It's sad, what people do to each other. I mean, constantly. So, yeah, I told her from the get go.

CH: And what did she say when you told her?

AV: I was amazed what she said. She was concerned about my health, but it didn't really impact our love relationship. I mean it did and it didn't. She didn't retreat. So that was a huge awakening for me because—it's not that I don't value myself or see who I am, but there are only so many things you want to take on. We were both young. There's everyone out there and I can see not wanting to deal with it, like anything. Alcoholism or something that's not terminal, never mind something that seems to be terminal. Yet this disease is such a stigma, so it impacted her, you know, safe sex and she was tested every year for HIV. The hemophilia center encouraged the testing just to be certain, even though there was little chance anything was going to happen. So that was good and every women I've been with since, three other women, two and the one I'm with now, no one's withdrawn—they're amazing beautiful people. Every time I have to tell someone I think they'll run away or retreat and it still

blows me away. I don't know what that means. If it means I would run away and not want to deal with it. I don't feel like I would, but because you see so much fear and running away in day-to-day life, when you're confronted with the opposite, it's a little mind boggling and inspiring. So they've all had huge hearts and gone with their love, not retracted from their love.

CH: I think you've been with good people because it is very rare that people take on something that big.

AV: Yeah, I guess you're right. Yeah, they've all been good people.

CH: You'd have to have a very generous heart.

AV: Yeah, that's true. That's a good point.

CH: When you're older, you can do that more easily.

AV: Yeah, yeah, and I was a little older, I mean because—so I'm twenty-six and she was twenty-one, but still, it's young. We're both young. So yeah, and Hepatitis-C was just in the mix and didn't really mean anything, yet.

CH: Did you eventually take something? Did you go onto some medication for the HIV?

AV: Oh. No, I still haven't. I may in the end succumb, I have no idea, but it's like I have no detectable viral load. No one knows why. There's so little virus in my body that I'm not rushing towards anything. I'm one of these people who have a different and controversial view of HIV. HIV dissidents. I think there's a growing population of these people asking is HIV the cause of AIDS, and a good amount of data suggests that HIV is not the cause of AIDS. So there's obviously a lot going on. It's not as clear as most people think. I don't think HIV will kill me. I think what's going to get me is something else. Hepatitis-C, possibly. I think I've cleared HIV.

CH: I know someone for whom that's true. It's been twenty years and it just never went anywhere.

AV: Yeah, that said—my T-cells, they're not normal, but why? This is what people don't really want to talk about or admit—that I am treating with Factor twice a week. It's not water. It's not pure. It's not healthy to do and few people want to really acknowledge that, still.

CH: Even though it isn't the really rugged situation you had before, it's still a foreign substance.

AV: Yeah, right. No one's going to take this on just for fun. You put these foreign products in your body so many times a week, so many times a year, and that takes its toll on your body. It does something. It doesn't help your immune functioning. So I'm still doing this and I'm still, in a way, mistreating my body while I'm treating this disease and so is everyone else out there.

CH: And you have to.

AV: Yeah, you do. Right. I mean in terms of acknowledging the reality, there's a sense that things are safe as they ever have been. That's true, but a bullet's still a bullet, you know, and any disease could creep in at any time. So—

CH: Have you made mental adjustments that you can pinpoint that have helped you be who you are and functional?

AV: That's a good question. I have this understanding. Whether it's reality or not, this is what I think is happening. I thought I'd be lucky to live ten years, and that was the psychology I was living with, which was at times devastatingly sad, but most of the time it's just a reality. It didn't—I don't think it brought me down, but it changed things. So I was going to retrain in clinical psychology, which would have been a three-year program, which was awesome. It was three years and I

may only have ten to live, so why am I going to do this. It didn't make sense to me. I totally changed my life course in a way because of that and this was still under the belief that I was going to die from HIV. So that was a huge impact and change in my life thinking and feeling.

CH: How long did you go through—

AV: Well, I stayed in what I was doing, which was neuropsychology, doing work with people who had Alzheimer's Disease, Parkinson's Disease, and traumatic brain injury. I worked in memory disorder clinics. Meanwhile, I'm in the midst of standard medicine. I just stayed that course without retraining. At some point in the last five years, I realized, I'm not going to die from HIV, so I guess I could still retrain.

CH: Is that a bit along the lines of what you described in high school where it's hard to say whether some of your psychological states, if you will, were a result of the hemophilia, or defensive positions? Is it really hard to know?

AV: Yeah, totally. Yeah, that's good. Yeah, you're right. Yeah, it gets very intertwined.

CH: Were you happy with your choice? The change you made, working with the Alzheimer's and Parkinson's?

AV: I entered in a graduate program in cognitive developmental psychology, so I just continued with that. When I was graduating, I was going to retrain in clinical psychology. Yeah, it was good and I'm happy now because it's not the model I would want to work with. I recently became interested in alternate forms of psychological work, body work and somatic therapy, and that would be the realm I would work with and not just talk therapy.

CH: Retraining is really admitting a whole new way of looking at things.

AV: Yeah, it's true. I don't know what I'm going to do in that sense. Right now, I've put away the degree I got, in terms of working in a traditional hospital setting.

CH: Are you working now?

AV: I'm not formally employed in the field. I am working with a couple of people setting up a community arts center. It's a non-profit, music, poetry, theater, somatics. It's things I've been interested in and never really pursued. So that's what we're doing. Yeah, it's good.

CH: And you're still here.

AV: Yeah, still alive.

CH: Your five year plan became a ten year plan.

AV: Right. So that's—

CH: Or your ten year plan became a fifteen.

AV: Yeah, I've known for fifteen years I've had HIV.

CH: Can I ask you, given the things that have happened to you, do you feel it has had some value?

AV: Yeah.

CH: Maybe more because of it.

AV: Yeah, I'd like to think no one would say no because then they've not engaged their life.

CH: I guess you'd be a depressive, if your answer was no.

AV: They had been beaten down, in different ways.

CH: Hopeless.

AV: Yeah, hopeless and damaged, for whatever the reason. Yeah, it's never—it's always—it's just like I said, a part of me. I'm not denying or ignorant. It's limited me in many ways and you can say

there's always things that limit you. There's things I'd love to do that in some ways maybe I can't. There's so much to do, so I got a fairly positive attitude somewhere along the line. I think I've always had that. I'm not like—I don't know, compulsively happy. Far from it. I mean, at times I'm sad, serious, angry, but I've always been able to see the beauty and engage it.

CH: They are emotional states.

AV: Yeah.

CH: Which is different from a psychological state.

AV: Uh-hmm. It's hard to be hopeless, I think, but I've had it so—but now let's say I've had it easy. People have said that I've had it hard, but it's all relative in some ways.

CH: And what would it be relative to? What makes you say that you've had it easy?

AV: Aside from my childhood traumas, which you can't discount, and my infancy traumas, which I can't even begin to imagine, nothing terrible has really happened. I deal with joint pain regularly. It's not that bad. My father died. I grieved and got over it and I miss him and I miss all the opportunities engaging him in my life, but I don't know. I don't know. It's not that these things don't impact me, but it's like I'm alive and I'm vital and I'm feeling and sensing and being and growing constantly and changing. So unless that stops, that's when it gets hopeless. However, I must admit that I have healing work to do from the traumas related to having joint bleeds and being treated for joint bleeds when I was an infant and a child.

CH: I understand.

AV: And I don't know. There's nothing that's been able to derail

that, or take that away from me yet. Not that I fight to keep it. It's just there. Just like every day I wake up anew.

CH: It's your nature.

AV: Yeah, so whatever that was or how I got that, I don't feel like it's been choices I've made. My mother always told me, "You make the choice to be happy." Maybe, I don't know. I do choose to see and look and make efforts to engage my passions actively. I'm not trying to fool myself into happiness.

CH: It's an attitude, in a way.

AV: I guess what could be more devastating is knowing, you think you're going to die soon. Well, I guess being dead then would be more devastating. It's all very navigable.

CH: It's a challenge, but it's navigable.

AV: Yeah, it's a challenge, right. I don't mind a challenge. I mean, there's no alternative really.

CH: Is there anything you'd like to say that I haven't asked you about?

AV: Hmm. I don't know. It's good asking questions. I don't—

CH: Your website, loveknowledgeandwork?

AV: Loveworkandknowledge. Yeah, it's—"Love, work and knowledge are the wellsprings of our life. They should also govern it." It's a Wilhelm Reich quote.

CH: Has your faith played any part in your outlook?

AV: That's good. My mother was upset to find out that I never believed in God.

[end of Side B, Tape 1]

AV: I have things deep inside that I need to work through and get to. Anger, fear, hate—I've worked in therapy through some of it. It's

beautiful and wonderful that we can be alive and vital and change, constantly. First of all, you grow up and become an adult, whatever that means. That's just institutionalizing. You grow and you're not done until you're dead, so change is possible. Some people may be unable to change. But there's definitely movement in the body possible for most people. What little I've learned from body work, you have got to want to take it on. And it's scary and it's sad and tragic. It's a process and it leads to freedom and liberation, a fuller engagement in living. You're an organism. You're a biological being.

CH: It's a risk.

AV: Yeah, it is a risk. [phone rings] It seems, though—I've never sensed like, I don't know, just total dissolution of my ego or breakup. So knowing that this is inside me, some of it's just fear and anger and letting it out and acknowledging it in small amounts and different degree is very doable, but you have to want to do it. And it's not very good that most of the world has been traumatized such that therapeutic work like that would help people but there's not resources devoted to such societal healing. The system is more interested in wealth than in health. Just like resources are not devoted to getting existing food to people. There is food everywhere, yet people are hungry.

CH: Hungry for lots of things.

AV: Yeah, right. Food, love, right. So the faith thing, I'm still with it. I was, probably like most kids, not being acknowledged fully as a person. You're fully formed every day that you're alive in a way, right? You're still growing, but that state where you're at is all you can be on that day. I was never given a choice about going to Hebrew

School. My self wasn't acknowledged in that way, so I was forced. So I went to Hebrew School, got Bar Mitzvahed and then when I was thirteen, kind of dissociated and played around in college a bit with some classes in religion. I went to Israel for a semester to learn about Israeli culture and Judaism, but I've always been fascinated with faith because I've never really had it. It's always been a little confusing to me—out of reach, out of mind, out of heart. I'm fascinated by religions, but particularly ritual. I like ritual, whether it's a song or just a hug or anything more elaborate. So I've never had faith to guide me, lead me, sustain me, support me. But I don't feel at a loss for that. My mother feels it's a loss, but I've had a faith in a way to guide me, lead me, sustain me, support me—a faith in being, a sense of living.

CH: Since what point?

AV: I've had it just in living, in what's present in my being. That's where I've centered upon the most, rapport and harmony, the web of life.

CH: Why is that so?

AV: Yeah, because it just seems readily apparent, but it's hard in this world that doesn't acknowledge, support or nurture the living. The world is life-denying in so many ways. You're constantly challenged to maintain your gut sense, when the rest of the world is saying that you have no gut sense. Common sense is just not so common.

CH: Instinct, common sense.

AV: Yeah.

CH: All those things.

AV: Yeah. But I haven't felt at a loss for that. I've been pretty self-

reliant to maybe my detriment at times. Well, not detriment. To my lack of contact with people, sometimes, in a deeper way. I search for that, and still am. Community. It's almost mythical. Church and temple is good for that, to provide community. It's harder outside that setting. I think some of my darkest moments were really just the beginning of the acknowledgement with HIV and changing what I was going to do for work and love. My father died at forty-two and before HIV it has always been a goal, kind of half joking, but real, to live longer than my father. Why? I don't know. It makes no sense. It's two more years away, but I didn't think I was going to live longer than my father until about four years ago. Now I don't know, just like anyone doesn't know, but I don't think I'm going to die soon. I'm not making decisions based on that. So in those darkest moments it's like grieving. It's a sadness or reality you work through and grow through and at some point it was less troubling. I just had to go on with my living, because I thought I had about ten years to live, once I was diagnosed with HIV. So that was good. Some people don't have ten years.

CH: Your father didn't—he didn't know.

AV: No, right. Exactly. I've been pretty much in the moment type of person a lot of my life and never had big visions. So knowing this ten year thing was kind of strange when I was casual about just being. It seemed like I almost needed a plan or focus more than I usually did.

CH: Well, it was brutal news to get.

AV: Yeah.

CH: And anyone would be angry.

AV: Uh-hmm. It was also helpful right after that, being with someone. My first love relationship.

CH: Life transforming.

AV: Yes, uh-hmm.

CH: At a very important time.

AV: Yeah, it was. It's terrible that I don't have contact with that person.

CH: Did it end unhappily?

AV: The reality of the situation is that we're not in contact which suggests to me it did end unhappily. We were starting to have problems, issues. We split up. I connected with someone else. I moved. We maintained some contact and then I ended up getting married to this other person. But when I told her I got married, that was the end of our contact. That was what she wanted. It should have been enough that I was with someone, instead of this compulsive morality about marriage. Because I was with this other person for a number of years before we married.

CH: But she was very special.

AV: Uh-hmm. Yeah, totally. I have only positive things to say about all the women I've been able to live with and love. I'm not a hateful betrayer type, so everything's ended in a kind of natural dissipation—love grows, love transforms, love withers.

CH: No cataclysms.

AV: Yeah. So I've maintained contact and good relationships with people still. So that's awesome. Hope it stays that way. Yeah, I don't know what else in terms of the disease.

CH: I think it's been a wonderful interview and I appreciate it.

AV: Oh, thanks.

CH: I appreciate it very much.

AV: Oh, good. Well, thanks for giving me the opportunity. [tape

off/on] 'Disease does not have to be dis-ease' one, and the other one is going to be 'better living through living better.' That's it. So—when someone reads it, they won't know the difference, but I know it does. [tape off/on] It's very neglectful to not talk about the whole class action, the whole lawsuit stuff.

CH: I wondered about that, yes.

AV: Yeah, so just in terms of the complete—

CH: I should have asked you.

AV: It's hard to remember things. I didn't write it down.

CH: Sometimes it seems odd to bring up money.

AV: Well, money, it's not—this culture is so sick about and obsessed with money. Someone just said they escaped communism of fascist Czechoslovakia. I just met her the other day and I was like, yeah, now what are you going to do? Escape consumerism of fascist United States? She was like, "I know. It's depressing me," and it's like only people from outside this country can readily see how distorted life in the USA can be. But anyway, the point—so I don't mind talking about it.

CH: Tell me about the class action suit.

AV: The story—so the whole class action crept up. I don't even remember the dates. It's the year I traveled, 1995.

CH: I thought it was 1994-1995. Somewhere in there.

AV: I was traveling that year and there was the class action in all different ways, and I hooked up with the Mull and Mull law firm. You could opt out of the national class action. So I opted out as much as I could because I didn't really care about the money. It seemed like a joke what was being offered in compensation. The whole thing was absurd. So I just felt like I'll add my number and power to the opt-out,

and if money comes, it most likely would be more anyways. It was the correct thing for me to do, to not to be part of the class settlement. This was independent of the federal Ricky Ray legislation. I've never been active at all with other people with hemophilia. It's just like go to the clinic and that's it for me. So I'm pretty ignorant of what goes on with the support and the people and their issues. I don't know. I just have my own issues, which are probably similar to other's issues. Anyway, so I was one of those people who opted out and eventually they settled. It took about six years before they eventually got a settlement. It was a whole process back and forth. It was very strange in terms of dealing with the hemophilia because you were supposed to get all your medical records. So I had to contact hemophilia treatment centers and get this information and saw how much I treated in my past. This awakened some ideas, "Wow, I was hurting my knee a lot." It wasn't once a month. It was twice a week for six months, and different things like that. In the end, as part of the settlement I was one of the people who got some money. This allowed me temporarily stop working in the field of neuropsychology and I came to Massachusetts to work setting up a nonprofit community art center. So I used that settlement money as an opportunity to make a change that I didn't need the money to make, but it gave me the sense—

CH: Of having a little freedom?

AV: Yeah, a freedom and security. Yeah, to do that. So that was huge. I can't—

CH: Do you think it was the correct—did you feel positive about the drug companies being confronted?

AV: Right.

CH: I didn't want to say good, because it wasn't feeling good, but—

AV: Well, through all the people I dealt with across the whole board and what I read, there was one of the aides at Mull and Mull.

CH: At where?

AV: At Mull and Mull, the law firm. They were in Louisiana. I think the lawsuit was based there because Louisiana has these blood shield laws. It has nothing to do with the truth or what's right, justice. She was humane and we could engage. So I talked to her a good amount and exchanged—I wrote them letters, sharing my knowledge. No, the drug companies are still all about the money. The only reason I'm alive is because it's about the money. At some point someone discovered something that wasn't about the money. Maybe they made a discovery, "Hey, this could help people with hemophilia." I don't know the actual story of how treatment for hemophilia developed, but they knew blood solved it, giving blood. So there's a good lead, right. There was a financial incentive to offer treatment to this population. And the treatment is overpriced, and society—the people—burden the cost. At other times in other countries it wouldn't happen. I just try to be as good as I can as a life form. Somehow we got off the goodness and love and into badness and hate. Money drives the system. Profits over people. It's tragic and there will be some other travesty. Vioxx, for example. I don't know how much was known or not, but the drug companies made their money and continue to make their money and the people continue to be unhealthy and in need of relief.

CH: And now they can afford to let it go.

AV: Yeah. So I don't know, but people suck it up, too. They offered me Vioxx, I didn't touch it. I wouldn't touch anything new, unless you know you're going to die and you're willing to take the experiment. I mean, the first major test on the population is the first

major test. Everything else is clinical trials, small numbers.

CH: And it takes time.

AV: Yeah, the drug companies got off sickeningly easy.

CH: Yes, they did.

AV: People should—I don't know what really should happen, but some people probably should be in jail, if you talk about crimes against humanity. That was a crime against humanity. And financially it was a joke. They got off low, but people accepted it. We accepted it. The law firm accepted it. In another sense, it's amazing we live in a society where people get financial compensation.

CH: That's right, it's both sides. It's both ways.

AV: So I understand all that, but it's been extremely important and it's given me the freedom to engage other passions, and I wanted to discuss the lawsuit against the pharmaceutical companies because it's a big part of the picture for a lot of people.

CH: It is a big part. I'm glad you did.

End of Interview