

Anonymous per patient's consent option #2

Interview with Andrew Flagg (pseudonym) by Christine Harland for the Boston Hemophilia Oral History Project, March 17, 2005

CHRISTINE HARLAND: And you probably know that this is a history of your experience with hemophilia, how you felt about it, what it has meant for you, how it has affected your life. I'm going to start at the beginning. Where were you born?

ANDREW FLAGG: I was born in [name of town], Mass.

CH: In what year?

AF: In 1959.

CH: Tell me a little bit about your family. How many siblings were there in your family?

AF: I have two older sisters.

CH: What did your father do?

AF: My father was a plant manager for a plastics company.

CH: And your mother?

AF: My mother was a bookkeeper and various related activities.

CH: Did you have much extended family? Grandparents? Aunts and uncles?

AF: Yeah. Actually, my grandparents were also in [name of town]. Most of my immediate family is still in [name of town] and—which is good but also sort of makes my wife and I feel like we need to stay here, even though every winter we wish we could move. [laughs] But with everyone here it's kind of hard to do that. But my grandfather, who was a hemophilic, died when I was eight, I think. So I don't really have a very strong memory of him, since I didn't see him that often. But my maternal grandmother I saw quite a bit.

CH: Did he die of complications from hemophilia?

AF: I—I think he actually—so the answer to this is no. I believe he actually died of a blood clot, which was probably transfusion-related, so I guess it would be a complication of treatment of hemophilia, to be specific. But I—I presume at that time that was the only option available, to have a whole blood transfusion. And I’m not sure of the details but he was, I think, 68. So that was fairly advanced for a hemophiliac born in 1900.

CH: So your mother was familiar with hemophilia.

AF: Yeah.

CH: How old were you when she discovered that you also had hemophilia?

AF: Well, she tells me that at circumcision she was suspicious. [chuckles] But she would say that for that generation she was told that she was “being hysterical,” and, “Let’s be sure that, you know, he’s really a hemophiliac.” I think she suspected, obviously from her father and then when she saw the complication from the circumcision that I was, in fact, a hemophiliac. But, you know, she did say that they were sort of telling her to—that that might not be the case. [chuckles]

CH: So they didn’t respond right away to her anxiety.

AF: Yeah, and I guess—and the way she’s phrased it, that wasn’t atypical in the late ‘50s. [chuckles] But I can imagine it would be pretty hard to dissuade a mother who was the daughter of a hemophiliac that she knew more what she was talking about.

CH: Did she ever talk to you about her decision to have children, whether she considered not having them, given the possibility of hemophilia?

AF: I’m sure she has and I can only tell you that, since I was the

third child, it didn't seem as if that was a concern. I don't—I've never really asked her whether she felt any kind of relief the first couple times around to have daughters. But I do know that my two—one of my sisters, the one who is married, has decided not to have children. And that was a leading factor, although not the only one. And my other sister has never been married and so it wasn't really a choice for her. But I'm not sure how she would have leaned.

CH: Did your mother ever describe her experience of growing up with her father's hemophilia?

AF: No, not that much. I don't know whether he had a less severe form than I had, but I don't remember hearing a lot about the implications that I had for the family life. She came from a family of six kids so there's probably plenty of stuff going on all the time [laughs] regardless of what the dad may or may not have been able to participate in. And that would have been—in her case it would have been sort of around Depression time.

CH: Yes.

AF: And, you know, I think—I think a lot of people were limited in what they could do [laughs] compared to—I always think of physical limitations. But obviously there are the other kinds as well so I'm not exactly sure.

CH: The focus was on survival.

AF: Right. And in an economic sense and everybody working and I believe he worked for the—either the state or the city, and this was also in [name of town] so whatever—you know, so he was able to have a job and—with minimal impact—

CH: Yes.

AF: —in that regard. I'm sure I'm—I'm sure it was much harder

than that but—

CH: Do you have cousins who have hemophilia?

AF: I have one cousin so—who is a hemophiliac.

CH: Where does he live?

AF: He lives somewhere in Brookline. He's around here too.

CH: Has that been a source of support—

AF: Yeah.

CH: —for you at all?

AF: Actually, yeah, it's kind of interesting. He is—his mother, my aunt, is 10 years older than I am and he's 10 years younger than I am. But the difference between those 10 years is pretty dramatic in terms of hemophilia treatment. So that's a very interesting thing to have been aware of. But he also has some different problems with different joints because he received a different treatment than I did in a different—you know what I mean? So even though in some ways it's been less of a problem for him from a management point of view, it has turned out that where you get treated sometimes can make a big factor in—in how that comes out. I've always been going towards—to Children's or Brigham, and he had some more regional treatments that maybe didn't work out as well for one or two of his joints.

CH: Do you think that made the difference?

AF: I think that it did and also just response time, you know, in terms of—I don't know that he has a less severe form. I suspect that he does because his infusion regimen is nothing at all as demanding as mine. So I think maybe there was an occasion where he had a bleed that was more serious than he or the physician he went to see might have thought, whereas I know it would have been probably much more aggressively treated at one of the hospitals here.

CH: Your mother had a suspicion from the very beginning; how did the awareness of your hemophilia develop from there?

AF: Oh, I don't think there was any doubt really after a couple of days of—and then just—I—I do know I had a fairly serious cerebral hematoma when I was a baby. So [chuckles] I guess—you know, I'm sure the diagnosis was before then. But I do know that that was quite a worrying concern—to the point where people that knew me as a kid are surprised that I am sort of doing as well as [chuckles] I am now, which is a weird way to put it. But I think you know what I mean.

CH: Mm-hmm.

AF: That they remember me as being a very unhealthy kid. And I think in general I don't give that appearance, other—at—other than, like maybe stiffness of joints and such, but nothing like when I was a kid.

CH: Did the cerebral hematoma affect your cognitive or learning capabilities for any length of time?

AF: Not as far as I know. [chuckles] It when I was very young and I don't know that there was any—any effects of that.

CH: Did you think of yourself as unwell? You said some people perhaps perceived you as unwell.

AF: No, I would say not, except I was acutely aware of being physically limited. And I think for a boy in the '60s and '70s that's more of a problem than it might have been for a girl. And maybe—I'm not sure. I can't quite decide whether it would be less of a problem now or not. There's a—you know, I mean, there's a lot of emphasis on fitness now.

CH: Yes.

AF: On the other hand, there's just a lot more awareness of gender

roles and that not every boy wants to do x and not every girl wants to do y, and all this other stuff. But I was probably more aware of feeling physically limited and a little bit out of place because of that, and the expectations for a boy in that—in that era.

CH: There are probably more options now.

AF: Yeah.

CH: You can work out in a different way and that would be a perfectly acceptable alternative to, say, football.

AF: Yeah.

CH: It is acceptable to not play football.

AF: Right.

CH: Describe your mother and her approach to things. Was she very practical? Very pragmatic?

AF: Mm-hmm, I think she was very pragmatic because she had the familiarity from her dad. She knew things were improving from management of the disease. Both she and my dad are, I think, very intelligent and I think that goes a long way in terms of understanding if you have options, then maybe things are manageable. And that's the word that I probably hear more than any other one, thinking back on this.

CH: You heard that from your parents?

AF: Yeah, and, you know—and also as a big factor in any kind of clinical treatment is—you know, this is a—something that you wish wasn't happening but maybe it's manageable. And I specifically remember her telling me that people used to wonder how she could let me run around in the yard or do this or that. And, you know, she said she was always around and she was watchful but she had to let me learn my own limits and not put too many constraints on me. So I

think she was pretty pragmatic from that point of view.

CH: Proactive.

AF: Yeah, yeah.

CH: Did your mother decide right away that she would take you to Children's Hospital?

AF: Yeah, absolutely.

CH: So she decided on the venue.

AF: Yeah, I don't know that there was any—ever any discussion of that.

CH: That was the best venue?

AF: Yeah.

CH: What were your first encounters with care like? Tell me about the caregivers and the environment in terms of providing information and of being sensitive to your needs.

AF: Well, I think I've always felt fortunate that I was born here and knew that it was an option and was able to take advantage of it, even though it meant my poor parents dragging me in, and ungodly hours and, you know, some of the—[chuckles] not the best trips you want to make in the hours of darkness and all of that. But, so I know that in—in the hospitals here there's fairly good awareness with specialists but even back in the '60s there was not really with hemophilia. So even though I knew my options were better than had I grown up in many other places, there was still—it was not uncommon to have to go to the emergency room and be asked, "How long have you been a hemophiliac?" which, you know, I just—I guess that really does let someone know that they don't know about the disease itself, even if they're trying to find out, "How long has it been a problem for you?" You know, I've kind of thought about it—are they really trying to ask

another question? But basically, I think the bottom line is they just don't know.

CH: Yes.

AF: And I know even—probably even today there is still—they are—hemophilia centers try to encourage that—it may not seem like an emergency situation and it's not life-threatening per se in the way some are. But the longer a bleed goes unattended, the more damage will be done. So that was a big problem.

CH: So you found that there was a lot of delay while they asked traditional questions that weren't pertinent.

AF: Yeah, I think it was possible that the potential severity was not recognized. And in looking back on it, and because the bleeding is largely internal, which is the biggest thing most lay people wouldn't ever know, I never have any way of knowing whether I'm actually—have any internal bleeding I can't sense yet. So I can usually tell when I've hurt an elbow or a knee—ankles not so much. But if I did something that—did something, you know, to one of the organs or nearby, I wouldn't necessarily know. And so that always seemed like it would—that concerns me a little bit in terms of if I fall or something, that—make sure I haven't done any damage that even I can't tell.

CH: And of course when you go into the emergency room, nine times out of ten they can't see the bleed. You look fine.

AF: Right, they can't see it or they don't—they can—you know, you can convince them pretty much by if they feel the heat around the joint; that would certainly get their attention, or if it had swelling. But it's not as obvious that it's, if not emergent, then it's a potentially serious situation.

CH: May I ask you what a bleed feels like?

AF: It—you get a little bit warm—well, the first thing you notice is you lose range of motion. And that's a constant problem because all the joints can be affected, and it will vary. Just a few days ago, without knowing how, I hurt one or two fingers. I must have bent them back or something shoveling, but enough that I noticed I couldn't move it quite as well as I wanted to. And so those little things happen all the time, even the need to reschedule this interview, because on that day my ankle was not good. That is probably the biggest—the second biggest impact I have right now is that on any given day there's something that's a little bit annoying to very disabling or—you know, that won't allow me to walk, for example. That's rare but there's always something that's probably limiting.

CH: And it's unpredictable.

AF: And it's unpredictable. I do have a sense that I can't go out and do many things that I'd like to. What I don't have a sense of is if I do this x number of times, or if I walk this distance, is that too much? I know when I've gone too far, because aside from the loss of motion, you can feel a little heat. But the biggest thing is it will start to actually—because it's bleeding in the joint, it will be painful because you're pressing on nerves. And it can get very painful—surprisingly painful—very quickly. And for instance, these two fingers, even though they weren't really that bad, hurt quite a bit, which was kind of strange. And it's annoying to have a—

CH: Did you have to do anything about it?

AF: I usually infuse twice a week so I was close enough to an infusion that I knew that it would probably take care of it. It was when I was going to take anyway and I didn't have to do any sort of

follow-up. I just tried not to use it as much over the next couple of days and then actually ended up—the next infusion sort of worked out as well. But I didn't feel it was that big a deal. It was just sort of an annoyance that two fingers are really being quite painful. [chuckles]

CH: Was pain a big issue growing up? How did you manage it as a child?

AF: Just being—bed rest was the biggest one. Pain's been a huge problem because it's—it's, I guess it can be—it's isolating—

CH: Yes.

AF: —because even now, even fairly recently, if you're in pain, you're just not open to a lot a things. So that was the biggest problem, aside from not being able to physically do things, or being confined to bed, or needing to rest, is just being in a lot of pain. Most of the time—there are very few times when I'm not in some kind of pain. It's almost a constant thing.

CH: And has been all your life?

AF: Well, since I can remember, yes.

CH: Since you can remember?

AF: I don't remember a whole lot about being a young kid, to tell you the truth. But I know that it's—it is noticeable to me when I am free of pain. And those have been a very few occasions that have been enjoyable. [laughs]

CH: And when you say isolated, you mean from your surroundings and the people around you.

AF: Yeah. Even your family because you just sort of don't feel up to—you don't really feel like making the effort to be social when all you're really trying to do is not—is trying to be physically more comfortable. And I guess maybe in my 20s or 30s and even in the

Hemophilia Center, they were very aware that addiction or dependence to painkillers could be a problem for the hemophiliac population. At least, that's what I'd always heard. So they were very hesitant to give out anything, even like a Tylenol with codeine or any of those matters. It took awhile of my sort of asking about that to get around to getting a prescription and basically saying, "Well let's—can I—let's see how I do, you know." [laughs] "If I run through it"—

CH: And did that make a difference?

AF: —"in a couple of weeks, then we've got a problem but"—it has made a difference, because what I was really looking for is when I have the bleed, then, you know, just to have something on hand—

CH: Yes.

AF: —to help—because, if it's bleeding at first when it's really swelling up, you won't be able to sleep. There's no way you can sleep from any sort of over the counter drug. And I—so I think the concern was—and this is something that I would watch for and be mindful of is that, if I'm not taking the painkiller because my knee hurts this much during a bleed, am I going to take it when it hurts a little bit and I'm going to work? So I could see where they were going. But eventually I think they came around to saying, you know, let's have it for the—for the bleeds and see what comes of that.

CH: How long have you been able to take painkillers?

AF: It's been awhile now. I'm, you know, 45—6—45 now.

[chuckles] I'm not sure. So it's been awhile but it always—it seemed a little odd to me and I recognized their concern and the reason behind it. But it seemed a little odd to—to not have it available as a treatment option for a bleed.

CH: Particularly as a controlled substance.

AF: Yeah.

CH: Where they can control the prescription.

AF: Right.

CH: How would you say having this constant pain has affected you and your philosophy, your approach to life and your nature?

AF: Let's see. I guess the first thing—I guess my initial reaction to being asked to do something, and it's just pure reaction—no thinking about it involved—is “no,” because I'm starting from a—I'm already in pain and I don't want to add more to it. So there's that element. It has—the pain and the limitations though have forced me to slow down compared to most [chuckles] of the people out in Harvard Square—

CH: Yes.

AF: —and on the subways and all that. And I think that has some benefits in terms of my—the way that I look at life and just trying to be more aware of what's going on at the moment. And some of that—from dealing with pain, I did get moderately interested in meditation a long time ago but I've never bothered to follow up on it. But it's that sort of just being aware of what's going on. And so that's been a benefit of it. But overall, it's probably been more the other of really already feeling pressed upon physically that more is not necessarily welcome.

CH: I understand.

AF: It's just something that I know that I need to not react to at first.
[laughs]

CH: You went to school, obviously.

AF: Mm-hmm.

CH: Did you go to the public schools in [name of town]?

AF: Public schools in [name of town].

CH: How did that work out?

AF: It was okay. I missed a lot of school. I honestly don't have much memory of any school before—a couple of vignettes from the second grade, one or two from the sixth grade. But I missed a lot. In fact, I almost didn't entirely go to the fifth grade, I think.

CH: Was that just a particularly bad year?

AF: Yeah.

CH: Is that unusual to have a bad period? Was it something special you were doing or was it just that—

AF: I think you can get into cycles where it's just impossible to recover entirely because when one joint hurts, you tend to compensate with the other joint. And then that can get sore or lead to a bleed. So it's a constant sort of push and pull. And one sets up the other and then all of your balance is thrown off. I mean, as we speak, I have a couple of joints that actually hurt and won't work that well for me. So my balance today is different than it was yesterday and so you always have that. It's hard to get back to fully being recovered. But I don't recall what it was specifically. I just—I remember I had a tutor for one year. And I do remember that my mother decided not—they asked me if I wanted to skip a grade, which I guess they used to do way back then. They—I don't think they do it so [chuckles] much anymore for social reasons.

CH: No.

AF: And she just decided that I'd missed so much school and probably would that that wouldn't be wise from a social point of view. So I really thank her for that because I would have been a very young kid going off to college, et cetera.

CH: Tell me about your time at home. You had a tutor who came every day?

AF: I—I think so. I don't remember now. But that was just for—

CH: Did you keep up scholastically?

AF: Yeah, I wasn't—

CH: Maybe you maybe did better.

AF: Yeah, I think I probably did. I think I did better because I didn't have some of the distractions, which are usually the fun ones. But also, when I was in school I was happy to be there from the social point of view.

CH: Were you in bed most of that time during that time at home?

AF: A lot of it, yeah. And if not in bed because of any kind of real fatigue, but just from the need to keep joints that are sore and bleeding elevated. So to this day I always look for things I can do [chuckles] while I'm in a recliner or some other, you know, ridiculously elevated situation, because that makes a big difference.

CH: Apart from cousins and sisters, what did your mother and father do about socialization? Did you have friend who came in to see you during those long periods?

AF: Yeah, I had friends from school that came over. I had, you know—it's fairly typical where I'd have one or two friends that people would think they almost lived there and, you know, that kind of thing. Our house was more of a—was kind of a hangout for me and my sisters' friends. People would come over all the time.

CH: I was thinking that if you were absent a lot, you might not have had the opportunity to make those friendships—

AF: Yeah.

CH: —that then were durable during the times when you weren't

there.

AF: Yeah, I always had one or two really good friends and then people that would help me keep up with what the assignments were and things like that. And then in school—particularly in high school—if I needed—one advantage for this other friend would be that I would need to leave class a little bit early to get to the next class so I was always very popular.

CH: They could help you and leave class a little early, too.

AF: Yeah, they dug that because I went to [name of town] High School and at the time there were 6,000 kids. So can imagine I needed [chuckles] a little head start when the bell rang so I wouldn't get trampled with the crutches and all of that.

CH: So you didn't find prejudice amongst your classmates?

AF: No, not really.

CH: Did they ask you much about how it felt?

AF: Yeah. [chuckles] Kind of. I did—this was, I think, in high school. One kid was asking me about it. He said, “So if I punched you right now, you would bleed?” And I said yes and he punched me.

CH: Oh, no!

AF: And so I show—you know, and fortunately, he just punched me in the arm. So muscle bleeds are not a big deal. They hurt but they don't—unless they hit a nerve, they're not any problem. So it was just, you know, I showed him over the next couple days what he had done and [laughs]—

CH: Was there a hematoma?

AF: Yeah.

CH: Yes.

AF: Just enough that—

CH: I bet he was sorry. He probably had no idea.

AF: Yeah, because I think if anyone has any preconceived notions, it's that if I cut myself I'm going to bleed to death.

CH: Outwardly.

AF: Yeah. [chuckles]

CH: Yes.

AF: As I keep reminding people that, as a grownup, you don't actually cut yourself that often.

CH: No.

AF: Generally speaking, it doesn't come up a lot, whereas all the joint bleeds are continual because you break little vessels—

CH: Yes.

AF: —all the time, going upstairs or down, or doing repetitious things.

CH: And we as observers wouldn't know that.

AF: You break them—right, and you would clot them right back up, generally speaking, whereas I would not. So because you really—you bleed longer internally—it's not something that most people would be aware of.

CH: Did you have any other illnesses growing up? Did you have any surgeries?

AF: I don't think so.

CH: Teeth? What happened about the dentist?

AF: Oh, until—until fairly recently though, it's a big problem. I just had my wisdom teeth out, like, within the last year and a half or so, I think.

CH: That must have been traumatic.

AF: It wasn't that bad.

CH: It wasn't?

AF: They really—they really—

CH: What did they do? Did you go in to stay overnight?

AF: No, they—they really know what they're doing now. They know if they give a prophylactic regimen of factor, they know how to do the procedure to minimize the trauma. And if I—if the patient then follows up in the way that they should, it should be okay. They really in advance made it sound like it wouldn't be any big deal and it really—it didn't turn out to be a big deal at all. But we'd been putting it off forever and ever.

CH: I bet.

AF: Yeah. And then I had one dentist as a—when I was a kid who would use nov—would use nitrous oxide and that was pleasant. But after that I've more recently seen dentists who did not want to even use novocaine. So until within the last couple years or so, if I had drilling or something, fillings, I would just deal with it. I'd just sit there. Just [chuckles]—

CH: More pain.

AF: Yeah, and I would—I remember telling one dentist, "Just tell me when you're halfway through. So then I can see it." And as it turned out, it would be painful. But some of the other cues, like the sound and smell is—

CH: It's worse.

AF: It's more troubling than the actual pain, you know.

CH: The sound is not nice.

AF: Yeah, exactly.

CH: It's ominous.

AF: And—but again, since even management from a dental point of

view is so much better within the last few years—now, I will infuse prophylactically, have novocaine, and that makes it a lot nicer.

[chuckles]

CH: I'll bet.

AF: Yeah.

CH: Your parents, presumably, envisioned and encouraged you in a normal career path. What about college? Did you go to college?

AF: I did and I was expected to go to college. And I think a concern was where more than for what. And that tied into hemophilia because it would have been '77 or so. And even at that point it might have—I initially thought I might go to law school. So given that, and knowing we have decent schools here for that, I applied to local schools here. And that seemed to work out okay. It never occurred to me really to think about going somewhere else and I do think—you know, another part of the country—I think a big part of that was the hemophilia options. Because I don't recall right now, but I think that was probably still—you either had to go into the hospital to be infused, or if the lyophilized product that you could have at home was available, it was relatively new or—it just wasn't as—you know, as routine as it is now. So that was a big part, I think, in deciding. And then again, as I said, for law then those schools would have been fine.

CH: Where did you go?

AF: Well, I ended up going to [name of university] here in Boston. But over the summer—the preceding summer I changed my mind and decided that I—as much as I thought law school might be kind of challenging and interesting, I couldn't imagine being a lawyer.

[laughs] It was kind of a good thing to figure out in advance. I never—I didn't make that connection until I thought, 'Well, what

would my day actually be like? What would I be doing?’

CH: There’s often not that synapse. People think about law school and being a lawyer but they don’t wonder what that’s going to be like.

AF: Right, and I guess because I sort of liked to argue [chuckles] and was fairly verbal, people encouraged me to go to law school and which seemed like the thing to do at the time. But I switched to biology.

CH: You did?

AF: And so I got a degree from [name of university] in biology and then my—

CH: Did you live at home?

AF: Yeah.

CH: Did you enjoy college?

AF: I—yeah, I enjoyed it but [name of university] is an all-commuter school.

CH: Yes.

AF: So that’s a very different experience. Fortunately, I got to go to graduate school so I had the living away from home experience.

CH: Yes.

AF: Although in graduate school it’s not really quite the same. You actually have real responsibilities, [chuckles] just not that fun aspect. And the commuting—commuting is just a drag when you’re going to college. And to this day I commute at least an hour and a half each way.

CH: Back to [name of town]?

AF: Well, yeah. I live nearby now in a different town now. But wherever I’ve lived—all of—wherever I’ve worked, with one exception, has been like an hour and a half away. So couple that with

commuting, and it's a lot of—

CH: It is a lot.

AF: It's a lot of kill time.

CH: It is.

AF: Yeah.

CH: Where'd you go to graduate school?

AF: [Name of university] in Ohio.

CH: So you went quite a ways away.

AF: Yeah.

CH: Was that partly a product of the transformation of care, that you felt more comfortable going away?

AF: Yeah. Yeah, it—I mean, it came about from contacts at [name of university]. But the thought that I could probably be okay going off to Ohio was definitely related to more freedom. And that—by that point, I'm certain medicine could be shipped wherever you were. And that was probably the case in college but I don't know.

CH: That must have been a wonderful experience to go to Ohio, to be away—

AF: Yeah.

CH: —from the environment that you'd been so tightly leashed to for such a long time.

AF: It was fun. I liked it and I had a good time.

CH: Your parents were encouraging, I assume.

AF: Yeah. Yeah, they definitely were.

CH: And you studied biology.

AF: Mm-hmm.

CH: Did your parents have health care insurance?

AF: Mm-hmm.

CH: So they didn't have a terrific burden financially because of the hemophilia. Do you know what the financial implications were for them?

AF: I—you know, I don't really know. I suspect that they did, not to the extent that they would without the insurance coverage. But I imagine that there were deductibles and such that they would never—even to this day, I'm sure my mom wouldn't tell me about it. The insurance part though is—is actually pivotal because I was covered—they both had insurance and they were complementary. And I was covered as long as I was under 25 and a full-time student. So even though I had intended to go to graduate school, I probably wouldn't have minded taking a break right from college. But that was, in my mind, not an option.

CH: So you needed to jump from their health insurance to your own.

AF: Well, I needed to either find a way to do that or be a full-time student.

CH: Until you turned twenty-five.

AF: Right, and then—and as it turns out, and this is where things get really silly is after I got my master's, I was still 24-ish or something when I came back to Massachusetts. I actually enrolled in a—in a junior college just to sort of bridge that until I could get my own coverage. That was very weird.

CH: That must have been.

AF: I literally started at junior college the day I came back from getting my master's. And there was some—you know, it was—obviously, I was doing it for a particular reason. But I always thought it was funny that the school—not only did they think it was weird but I was taking completely different classes. So to me it was sort of like,

“Well, why can’t I just take classes that are in another field?” You know? [laughs] They weren’t buying it, though. But I—yeah, that insurance—

CH: Did you take classes in a completely different field?

AF: I did.

CH: What did you take?

AF: That sort of helped me out. I took as many writing courses as I could, took some sociology classes, a couple of psych classes, things like that, because I think I went for a year. And fulltime student, you know, you used to get 10 good classes in there. [chuckles]

CH: Was it beneficial?

AF: Yeah, I think so because one of the classes I took was technical writing and I’m now a medical writer, and it didn’t hurt.

CH: No.

AF: It just surprised me that the school was reluctant to even let me do this.

CH: It was a junior college?

AF: Because I had a Master’s.

CH: Yes.

AF: Right, you know, it’s the same expression you have. It’s like, “So. I mean, why can’t”—

CH: Why can’t you study this?

AF: [laughs] It’s one of those things where you think, ‘Aren’t you a school?’ They were—you know, they were not encouraging me to take classes for my own edification, it seemed like, [chuckles] which is very odd.

CH: It is odd.

AF: I’m sure they just hadn’t run into it.

CH: No.

AF: But the insurance coverage is the biggest determinant of anything I do, I would have to say.

CH: Because you can't be without it.

AF: Can't be without it and I either have to find it or get lucky. And the—aside from going to the junior college, I got a job at a supermarket because they didn't have a waiting period. So it's kind of a non-traditional post-graduate [chuckles] but—

CH: You worked at a supermarket?

AF: Yeah. [chuckles]

CH: And you went on their health plan there?

AF: Right, and then—then I was set sort of because of COBRA and other possibilities.

CH: So you could bridge the supermarket to your first job.

AF: Right.

CH: Was being accepted into the new health plan a complication?

AF: Not retrospectively but no one—at that time, so now it's '84 maybe—you would never hear over the phone or certainly not in writing that you were covered. You probably were. And, as it turns out, I always was covered. But you would not be able to hear that in advance because it was too—it was just too technical. You could look—you, as the consumer, could look through all their information and see they cover this for health care. It's—but you could never really get someone to say, "Yes, we will cover you for home infusion of factor VIII." And as I said, it never really became a problem, with one exception. To this day, whenever I switch, I'm figuring if I'm not covered there's enough expertise in the hemophilia centers now to sort of help you figure that out. But it always feels like it could change at

any time.

CH: But they were never saying, “Yes, you are covered. Don’t worry about it.”

AF: Not—yeah, to that specific—and because part of it is the people you would actually be able to contact don’t—you know, they’re sort of first or second, third line.

CH: They don’t really know.

AF: Right. They’re not going to be able to commit to that either, that—that specifically.

CH: So the issue of health cover really did have a determining effect in lots of ways.

AF: It’s sort of—it is actually the biggest thing.

CH: Yeah.

AF: And it’s probably the thing I worry the most about. You know, aside from salary. I mean, everyone worries about salary. Anyone’s job could end the next day and all. But for me, I—you know, with COBRA, I know I have time so that’s good. But it’s a big deal.

CH: Is it two years?

AF: I think it’s 18 months.

CH: Eighteen months.

AF: Maybe it’s changed. That’s a good—that’s a good, long time but I was—a company I worked for closed and I was out of work for about four or five months, which wasn’t really that long. But I was starting to feel it.

CH: Yes, of course.

AF: You know, I was starting to think, ‘Hmm.’

CH: Have you ever had any difficulty getting jobs because of the hemophilia?

AF: Oh, no.

CH: You've been up front about it?

AF: You know, I don't—I'm not sure I bring it up, to tell you the truth, unless I think it's really relevant for the job. I've only worked in three places so I've been lucky in that regard. But I did interview with someone; this was for a lab position. And I must have mentioned hemophilia or it must have somehow otherwise came up because he called me back. And he says, "You know, I was just thinking about this and you're a hemophiliac. We use a lot of glass plates in our lab work and sometimes we have to score and break them." And I just assured him that wouldn't be a problem. But in my head I was thinking, 'I didn't go to all-plastic universities.' You know what I mean? [chuckles] I sort of had been—

CH: You got the job?

AF: I appreciated his concern, you know, because he was real—

CH: You got the job?

AF: Yeah, I did get the job and he really—it was really a personal concern more than trying to screen someone out as an applicant.

CH: Yes.

AF: He just sort of thought, 'Oh, what about this? I hope'—

CH: Of course.

AF: —'he'll be able to do this.' But it just kind of cracked me up. It has just more to do with the whole external bleeding—versus internal stuff. And—

CH: Is it true that if you declare a condition to the insurance coverer, they can't divulge that to the employer? Is that how it works?

AF: I'm not sure how it works. I've just been fortunate that in my other two jobs it never came up during the interviews.

CH: Yes.

AF: One job—one place I worked for 14 years so that was easy. And then this new—I've worked at this new job (I call it new) for almost three years. And it was a phone interview and I showed up as a contractor and then got hired. And it wasn't until I had my first real bleed that they knew I was—even knew I was a hemophiliac.

CH: Did they respond all right to that?

AF: Oh, yeah. They—they—they were very accommodating. [chuckles] Almost—almost a little bit too much because they were concerned, should they get someone to type for me? Or should they—dictation? All this other stuff. And I was really just trying to say, "I'll be okay probably. I'll know in two days whether I'll be okay. So let's not go to the—I appreciate it but let's not go to the big, heroic efforts so I can continue to work when—if I can just sit for a few days, it might be okay." [laughs] I also didn't feel quite up to it myself, you know. That sort of while you're having an emergent knee bleed, trying to figure out contingencies to continue working when you hope in a couple days you'll feel a little better. [chuckles]

CH: Have you missed much work?

AF: Hm-mm.

CH: Do you like what you do?

AF: I like what I do. I don't care for the pace of it, the structure of it.

CH: In what way?

AF: Well, I'm a medical writer so it combines—

CH: Textbooks?

AF: It's for—

CH: Or structure manuals?

AF: For a pharmaceutical company.

CH: I see.

AF: So it combines my interest in clinical research and writing. But in a pharmaceutical industry—I'm sure there are other problems in other industries—just it's more driven by timelines and resource issues and less writing, per se. And it's—this is my first job as this so I don't really have that perspective to really say beyond that. But the pace of it it's a bit much.

CH: Fast.

AF: Yeah.

CH: Yes.

AF: Things change constantly. And as much as I can keep up with that to some extent, I'm not looking for that beyond what's necessary on top of the physical limitations and the long commute and all of that. It would be nice if, you know, things were a little more settled. The converse of that though is I really need very little physical ability to keep working. [chuckles] You know, a couple of fingers and a computer. And I can—I don't do it that much but I can work from home sometimes.

CH: I should think you could work from home doing this kind of work.

AF: Yeah, it's just not part of the culture at the moment. But I think it's something I could push for a little bit just to get a—to get that physical break. And I think as we work more with this—some of us have been there for a few years together. I think people see that we're not working from home to goof off; we're working from home to get stuff done.

CH: Do you need to interact very much with other people?

AF: Yeah, just constantly. It's just constant. [chuckles]

CH: So you do need to do that?

AF: Yeah. A lot of it—

CH: In order to do your job?

AF: A lot of it's e-mail. You know, but it's mostly e-mail, over the phone and then meetings. But you could certainly—you know, a day here or there wouldn't make a big deal but, you know, it's constant interaction with people.

CH: It would be nice to have relief from that commute even one day a week.

AF: Right, and that's probably—I'll probably pursue that. It's been—I would have liked to have done it this winter but the time didn't work out. This has been just a terrible winter for that. Between the cold and the snow, it's not really what my joints want to do. [chuckles]

CH: So you're staying where you are, around [name of town], primarily because your parents are still there?

AF: Oh, in this part of the country, you mean?

CH: Mm-hmm.

AF: Yeah, because our family—my and my wife's families—everyone's within 12 miles with one or two exceptions. And it would be nice to move somewhere south but I don't see that happening.

CH: Probably not now, anyway.

AF: Yeah.

CH: Tell me what happened for you in the '80s when the crisis arose around the transfusions and the HIV and so forth.

AF: Well, that was obviously—the reason I said that the health insurance or something else was the second biggest concern—

CH: Mm-hmm.

AF: That was obviously the first because I am HIV positive and have been probably since the late '70s—I forget now exactly—and have known about it since the early '80s. And it was just huge. There was no way to—hmm—no way to estimate the amount of concern that it's caused me, even though I personally have not had much difficulty as a result of it. I haven't had complications from it. But I don't know that there are too many days, if any, where it doesn't cross my mind. You know, whether—because there's always the feeling like, “Well, okay. I seem to be doing okay but I'm one blood test away from finding out that I'm not doing okay.” So the—it was a huge impact. I think we knew in advance that, given that—my age and that I'd grown up in an urban region, there was a pretty good chance that I'd be positive. As—and so I wasn't surprised that I was. I've had lots of factor over the years because I'm severe, so I've needed lots of factor. So that—so that frequency, coupled with geographic location, just wasn't a surprise at all. And I honestly can't remember much more about the initial reaction than just like [unclear].

CH: Can you remember when it first dawned on you, through your reading or hearing about the possibility?

AF: Not really. It's been too long now. I do remember—this is unrelated—but a “Time” magazine article when I was in high school about the average age of hemophiliacs' death was 21, or some ridiculously low number. [chuckles] And I remember mentioning it to my mother and she said something—she's like, “Oh, are you feeling sorry for yourself?” Looking back on that, that was the right answer. And my grandfather was 68. You know what I mean? So it

was like—and also, it’s made me suspicious of what you read in the mainstream press. [chuckles] You know. So that was a double lesson there, as you probably have experienced, when you know something about something and you read about it in the mainstream press, they don’t quite have it right. And that was certainly the case. Even their number was right, it was kind of meaningless.

CH: And that misinformation can be very destructive.

AF: Yeah.

CH: Very dangerous.

AF: And I guess I was hearing—you know, just sort of primed to being more concerned about what other people might think because of the Ryan White stories. Before that, you just had kind of the charming Nicolas and Alexandria, Rasputin stories and people might have thought that was kind of cool. And I think an initial reaction, aside from being concerned about my own health was I no longer felt comfortable saying I was a hemophiliac, at least during those initial days.

CH: The HIV issue changed things.

AF: Absolutely. To this day, even. I mean, I work for a pharmaceutical company so most of the people I work with would be aware that it’s a possibility for me. I think none of them would have a problem with it just as individuals. But, you know, I don’t know that I need to—to be out there with that information.

CH: No.

AF: And—but it’s clearly something they’d be aware of.

CH: So you were told that you were, in fact, HIV positive in the early ‘80s?

AF: I think that’s when the actual—the first sort of blood—

definitive blood tests were available. And retrospectively, people realized it must have been in the '70s—late '70s, I believe, that most people were infected.

CH: And where were you in your life at that point?

AF: I think I was physically in Ohio and, you know, that's about it. I was in graduate school.

CH: Not married?

AF: Nope.

CH: Dating?

AF: Yes. And I don't know. I seem to be blocking this out.

[chuckles] I'm sure I was dating. I don't remember it really being a problem though because I'm sort of a serial monogamist. I mean, I've always been with someone for awhile and so it's actually—it's possible now maybe that I may not have even known until—for sure that—until I was—had known my wife already, my—the woman who would become—you know, the woman I was dating. You'd think I'd remember that but I don't. [chuckles]

CH: And you had a test at some point? Did you decide that you would go and be tested, or were you tested routinely?

AF: Oh, I have been at least a yearly visitor to the Hemophilia Center. So I'm sure I got tested there. And maybe it was as late as '85 or so. And I just don't recall when I first knew that because I think my expectation was, as I said, that it wouldn't be a surprise. I mean, I've had everybody's blood all my life. I have, as far as I know, all of the things one might be exposed to.

CH: Did your parents have a reaction that you can define or remember? Was there anger?

AF: No, I don't remember being angry about any of it. I guess

that—not upon first hearing. Subsequently, finding out that some additional safeguards could have been put in place, or (I think I have this right) that some of the factor we get was specifically from high-risk people that was pooled, because they had good titers of other things. So none of us, certainly in my family, knew that that was going on. Had I known that, then I would have been angry because that’s a form of risk that I was not aware of. I don’t recall ever—anyone ever saying, “You know, this plasma come”—you just knew it was pooled. All right. So you—I would—I had assumed—never really thought about it—that it was general population and not a specific—what we would now call high-risk population. I think now that would not—it’s hard to say, with all the FDA stuff going on—I think that would not really fly as easily now with the awareness people have. But—

CH: We hope not.

AF: Yeah, I know.

CH: But we’re never sure.

AF: Yeah, it just doesn’t seem like something a group of people would decide to do anymore after all the troubles but

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AF: when I learned more about the risk that I unknowingly was put in, and others, I felt it was justifiable in the sense of it is essentially the only thing that companies respond to, if not governments. But also because I knew—excuse me—that if I couldn’t—it just was a way to have some money available if I got sick. And I have to say that it has made a difference in terms of feeling some level of security

from that point of view. It's obviously not enough money for anyone to change their life. But even to have some kind of cushion to—as a result of this was something that seemed—seemed to make sense.

CH: What about Hep C?

AF: Hep C—I've not really done much about it. I have a viral load to that, you know, for the last five years or so. People have been asking about whether I should have biopsy and just see where I am. It all makes good sense but I never get around to doing it, because I know, or I suspect at this point I really don't imagine I would go through any kind of treatment regimen for it. So unless there's [chuckles] some real sign that I'm in trouble, I just can't imagine that I would with, you know, work and everything.

CH: You wouldn't do chemo?

AF: To do any of the—from what—the little I know about them, they're not easy thing—not—they're not easy treatments to go through. And I had been on retro—anti-virals—

CH: Retro-virals?

AF: —for quite awhile. Have been off them for awhile and they're not that easy either but those made sense. [chuckles]

CH: And what sort of an effect did those have?

AF: Just general GI disturbances. You can feel a little nauseous or unwell. I was in one clinical study a long time ago. And those were—those were—those pills were awful. You would get mouth sores and it was just very hard to tolerate.

CH: Yes, and hard to work through. As you say, life goes on, doesn't it?

AF: Right, and then I've been lucky that any—even when I had the anti-virals, they were “Take with food.” Take them out of the cabinet;

they weren't—didn't need to be refrigerated. It wasn't the cocktails and all these other elaborate things that people talk about. And then just—it was either this July or a year ago in July I just asked, "Well, I'm doing really well. Can we see if I'm doing well because of these or despite them or"—so, you know, I went off them and there's—they monitor them. And I do have detectable viral load and my CD-4 counts are low but okay. But, as I said, you know, they monitor them so maybe the next time I have them done it in a few months they might recommend I go back on them or maybe, you know. There's that—

CH: In the meantime you've got some time off.

AF: Oh, yeah. Which was, I thought, really worth doing as long as I didn't—they assured me that I wasn't putting myself more at risk, that something might happen that you couldn't recover from. And that seemed to be okay.

CH: You weren't going to slide.

AF: Yeah, to a point where you sort of regret letting it get that far.

CH: Would you mind if I asked about your relationship and getting married? A large number of people in your position eschew relationships. They prefer not to go there either because of the issue of children or HIV—all of those things.

AF: That's why I'm starting to think that—that I must have known my wife when I found out, no matter how long I suspected. So it might have been really even later than I recall when they had definitive measurements for this, because it wasn't really ever an issue for us. She—I met her about 20 years ago and she had two kids. And so I—actually, for unrelated reasons, never really thought about having kids to the extent of—that I must have my own children. You

know what I mean? And it sort of kind of worked out that I was never really forced to make that decision. [laughs] I always had this kind of idea that I can understand why people want to have kids, obviously. But there are a lot of kids already here and maybe they can use some help. You know what I mean?

CH: I have none.

AF: It's—I—

CH: It's not a burden for you.

AF: Yeah. So I guess I—I'm not saying this very well. It's like—a little bit like creating need when there's already a lot of need around, like, there are plenty of kids around that could use someone now. But I certainly see the desire to have someone that's part you and part her and then all that stuff. And then there's, you know, plenty of people that don't have kids. The guy I mentioned that didn't—who was worried about me breaking glass used to refer to it as being childfree [laughter] whenever—and this was, like, you know, the '80s or something. When people talked about being childless, he'd go, "Oh, no, no, no. Child-free." [laughs] So—

CH: Were her children young when you met?

AF: They were 10 and 8, so fairly young, yeah.

CH: Did you ever have any reactions from women, from partners, about being a hemophiliac?

AF: Yeah.

CH: Did you have any issues around that? Did you tell girls right away that you were a hemophiliac or did you just wait and see how it developed?

AF: I guess the second one. I've really only dated women that I knew from school [chuckles] since I was in school most before I met

my wife.

CH: And you were in school twenty-five years.

AF: But, you know—[chuckles] yeah, exactly. So it was pretty obvious that there was something going on. And then, as I said before, the HIV stuff. I actually preferred people knew that I was a hemophiliac because in some ways, I'm actually a little bit proud of what I've done despite that. And so—and it also made me feel better if people understood why I didn't do this or that, that it's because—it's not that I wasn't interested or that I didn't enjoy it but that I probably couldn't. And it also impacted quite a bit what I could do, how much activity and all that stuff. So the—generally speaking, the women that I dated knew me anyway and then we started dating, as opposed to just sort of meeting someone.

CH: Let's assume that you were seeing your wife when the HIV became a fact for you. Did that that complication your relationship? Has it ever been an issue in the sense that you haven't been able to work it out together?

AF: It is—well, we've worked it out and I'd be curious if you could ever actually be honest with yourself or another person, how much of a concern it has been. My wife has never really expressed that it's a concern. She's been tested a couple of times. I continue to ask her to be tested. She's always been negative. We were careful at first and all that stuff and—but I can't imagine that it's not a concern, in the same way that in the back of my mind it's a concern, that it wouldn't be one for her. But it's just not and—you know, on the day to day conscious level. And 20-something years later it seems borne out that it shouldn't be a concern. So when I go to the clinic visits she's not expressing anyway that she's as worried about—as I might be on an

unconscious level. But one thing I do worry about is I have a fairly stressful job in terms of all the pressure that—that can't be healthy and I keep trying to remind myself that I maybe should be a little more aware of that than I am. And, you know, instead of just continually going through the next step and the next thing, and the next pressure and the next pressure, well, maybe I should do something about that but—

CH: Is there a way to wind that pressure back? Do you have any choices? Can you say, “I can't do this much?”

AF: I haven't yet, to tell you the truth. Part of it's being new.

CH: Is it the environment?

AF: I don't think it's that environment. It's just that it's—everyone works all the time, you know. It's that kind of mentality. It's—clinical research is 24 hours a day, right. Not—it doesn't impact me in the same way it does people that deal with the sites or the patients, obviously. But the people we deal with are sort of “on” 24/7, you know. [chuckles] So that's part of the pressure of that.

CH: We talked earlier about how the hemophilia affects your life in that you can't assume day-to-day that you're going to be able to do something. Do you think that's been difficult on your marriage, the fact that she's had to accommodate some of that uncertainty?

AF: Absolutely. Yeah, it's—it is very limiting and that is a problem. I do kind of think as we get older now it's less of a problem. [chuckles] I actually feel like if I can stay in the same kind of shape I'm in now I'll be pretty much with my peers.

CH: You can play shuffleboard.

AF: [laughs] Well, I don't know about that but I look around at guys my age and I think, ‘Yeah, I'm probably doing okay.’ You

know, if I can just hold steady. But, you know, that is a problem and especially something like the winter where if I could ski, I'd ski. I don't know that she would but we'd probably try it. We went cross-country skiing once and I just couldn't do it at all and—

CH: Yes.

AF: And I have to be real—more careful in the snow and the ice all that stuff. So that—I think “drag” is the appropriate word there. But as I said, as we get older it's less of a problem. [laughs]

CH: So you just accommodated for your condition. Did you as a couple ever get counseling or did you—

AF: No, we—

CH: —talk much about it?

AF: No.

CH: You just worked it out.

AF: Yeah, I guess so. [chuckles]

CH: You are unusual in that. It would seem to have been a very durable marriage through some very complicated—

AF: Yeah, I know. In fact—

CH: —times.

AF: —this literally is the—we met 20 years ago, had our first date 20 years ago a couple of months ago. And it's hard to ignore that; that's a lot—that's a long time—

CH: It is a long time.

AF: —through a lot of things. Part of the reason maybe it wasn't as limiting as it might have otherwise been is when I—when we got together there were already kids.

CH: Yes.

AF: So she had plenty of things to worry about other than whether

or not I could go skiing. You know what I mean? [chuckles] That's really—that's one thing about—to generalize about single moms is they have a lot on their mind and usually seem, you know, very competent and have perspective on whether this is a big deal or not a big deal. [laughs]

CH: The kids are coping.

AF: Yeah, exactly.

CH: So coping is a place they go.

AF: Yeah. And then one of the boys—she had two boys—has a daughter. So now we have a grandkid running around.

CH: Oh, my goodness!

AF: So, you know, that—there's plenty to do from that point of view, although it would be more fun if she and I could be more active in terms of even—

CH: Does she work?

AF: Yeah.

CH: What does she do?

AF: She used to work for an agency for retarded adults called [name of agency], and she did that for almost as long as I was at my other job. And now she currently works for [name of agency]. So she's either worked with [chuckles] retarded adults or small, screaming children. I used to feel bad for her about coming home to me and two boys. [laughter]

CH: Three boys.

AF: Exactly, yeah. [laughs]

CH: There was a lot on her plate, wasn't there?

AF: Yeah.

CH: But you got through that and raised the boys.

AF: Mm-hmm.

CH: What do you do together, given that you can't ski and so forth? What do you share in particular that enriches your life?

AF: Well, we do both like home renovation-type things. So we do stuff—projects around the house and obviously, I'm limited in that too. The usual stuff, go to movies and things. We don't really have any specific, like, club or group or something that we belong to. But I do work a lot so there's not a lot of free time. [chuckles]

CH: I was married to a man with emphysema and it was extremely limiting in the sense that he could only walk a very short distance. That was just how life was; you got used to it.

AF: Yeah.

CH: We did other things, went out to have a meal or something. I think he minded more than I did.

AF: I hope that's the case. I would really like to just be able to walk more though because that's just key. There's just something about just you and her just walking.

CH: Something so simple.

AF: Yeah. And it's—I'm not sure. It's probably the rhythm and just the fact that you're taking time away from everything else, you know. There's—and you're just out together somewhere. So that would be great if I could do that more. But right now, if I do it it's very likely I won't be able to walk the next day if I go—any great extent. If I have a couple more surgeries, then that might change. But that's a kind of a scheduling nightmare. [chuckles]

CH: Surgeries on your joints?

AF: Yeah, I've had my right knee replaced and my right ankle fused and I could really use the matching surgeries on the left side at this

point. And that—

CH: It was helpful?

AF: That speaks to the compensation I mentioned earlier, that now these two joints are worn.

CH: Right.

AF: It was great. Yeah, I've had—it's made a world of difference.

CH: Much less pain?

AF: Yeah, the pain in my right knee, in particular, was just constant. And now my left knee's getting there. But it's just—I think part of it's psychological in the sense that you've seen it before; you know it can be fixed. If you've got to fix it, you'll fix it. And it's not—it's more painful and it's stiff but it hasn't been a lot of bleeds, although I'm concerned about it all the time. So until it gets to the point where it's bleeding or there's some sort of other weird opportunity to take three months off from work, I'll probably let it go another year or so.

CH: So once you've had it done, the bleeds are fewer?

AF: Yeah, yeah.

CH: Why is that?

AF: Because part of the bleeds come from—you lose the cushion between the joints. The bleeds erode that so you then have bone on bone. So that's where the pain comes from, but it's also where the bleeding comes from because things are making contact that shouldn't be. But that's specifically where the pain and the range of motion come from. When they put the new stuff in, it's just gone.

CH: Would your job be willing to accommodate those three months off?

AF: I think I could make a [chuckles] case that they don't have any choice, to tell you the truth. It's one of those things. And I'm sure

they would and if it were longer than that we—I'm sure we could work something out. But, you know, having been through it once, I know that—I know that I wouldn't be able to work for awhile and then if maybe we wanted to figure out some way to phase things back in, that would probably be okay.

CH: So it would be more than three months out of work?

AF: It could be. Yeah, really, I—

CH: But you might be able to work at home.

AF: Yeah.

CH: Do you think a warmer climate would help?

AF: Yeah. Yeah, there's no doubt that—and that just the joints being warmer but also, just the difficulty in walking on snow or ice. I fell a couple—

CH: Oh dear.

AF: I fell last week in my own—slipped in my own driveway. And I didn't get hurt much. It was kind of a slow motion fall and I managed to land on my arm and then my back, right, rather than my head. But then I was worried about my arm. So as I'm falling I'm not—I know I don't want to land on my arm but I don't really have any choices, you know. [laughs]

CH: No.

AF: Right, because this—this is one of the range of motion things. This arm doesn't straighten any more than that. And it doesn't move—

CH: The joint is so stiff?

AF: —any more than that. So I—I do as many things as I can with my left arm. But—so as I was falling, I remember thinking, 'Well, I

don't really want [unclear].' [chuckles]

CH: You must be so aware of your body all the time.

AF: Mm-hmm.

CH: Are you?

AF: Pros and cons to that.

CH: Yeah.

AF: The awareness part I like; the having to be, not at all. But I definitely think I'm more aware of where everything is going on [chuckles] than a lot of people around me. And maybe it's just my perception of that.

CH: And do you espouse eating a particular way? Does that lead to fitness consciousness in terms of your nutrition?

AF: No, not really. I think, all things considered, I'm in pretty good shape and I could obviously eat healthier and weigh a little less and be in better shape. But it means giving up a lot of the food that I like.

CH: Yes.

AF: And I really am limited in terms of how much exercise I can do.

CH: Yes.

AF: That has to almost be scheduled. I have to keep in mind that, you know, I don't have any factor at the moment so I better not. So, given that, I actually feel probably not too bad.

CH: What about swimming?

AF: Swimming's good. It's more difficult than I think people think when your joints aren't necessarily aligned the way they should be. Like this arm in particular, the one that doesn't straighten is not great with—well, it's actually pretty good for swimming because it's bent at a useful angle. [laughs] But—

CH: It's all ready to go.

AF: It is. It actually is in that position but it won't put up with it as long as it would. We have a pool now at home.

CH: Indoor?

AF: No, sadly. [chuckles] So it doesn't get—that, plus a work schedule, doesn't get much use. And then it's just hard to find a pool that has decent hours for working people. Usually—it's usually not long before some six-year-old's jumping on your head [chuckles]—

CH: It isn't easy.

AF: —if you go to the Y or something but—

CH: You said earlier that you felt proud of the way that you've managed your life and your condition. Could you tell me a little more about how that feels? Is it primarily the fact that you pushed through it and are a balanced human being?

AF: I wouldn't go that far. I don't—I don't know that I feel balanced. But I do think that, despite all of the physical limitations and the dealing with things like HIV and the unknown Hep C—who knows all of that—I do think I'm relatively okay and that I should be proud of that, rather than afraid of people finding out my limitations. I know it's obviously easier when you're 45 than 25 but that's sort of the way I've been thinking of it lately, and the same with a relatively new career. Despite being new at this, I think I'm doing okay with everything else that's gone on in my life that people may or may not know about. I know they have no idea how—how difficult it is.

CH: I'm sure they don't.

AF: And because they don't know about the HIV, when I do mention that I have to go to a clinic—you know, I tell them I go to a hemophilia clinic—

CH: Right.

AF: But someone actually asked me just out of curiosity, like, “Well, what do they act—what can they do for you?” So I just told her, you know, some stuff but I don’t tell her they’re actually drawing bloods and all of that thing. [chuckles] So that was a big impact of the HIV part, aside from the concern of getting sick, was really feeling I needed to put it underground again.

CH: You had to pull back in your honesty?

AF: Yeah, and there was an article that had stuck with me for a while. And I think it was the “New York Times” magazine by a hemophiliac who had essentially the same initial reaction. He was really starting to feel more comfortable as a guy, as a man and then, person. And then suddenly it wasn’t something he wanted to tell anybody anymore. And he didn’t know when he should bring it up and how he should bring it up and all of that.

CH: That’s too bad, isn’t it? Because you grow and you reach that point when you are who you are.

AF: Yeah.

CH: You’re not a person with hemophilia. You are a person.

AF: Yeah, and then—

CH: And suddenly—

AF: —the—just the, I guess, irony. There’s the factor. Here’s the thing that can give us life and might take it away at the same time. The new irony in the making for me is that if you have hepatitis C to the point where you need a liver transplant, and you get a liver transplant, you may no longer be a hemophiliac, because the transplanted liver will make factor VIII. That’s happened at least once that I’ve read about. It should theoretically work. But that—I can’t even begin to think about that because that just blows my mind

too much. [laughs] One of—the whole HIV from the product that you need, you can understand because everything comes with risks, right? But that one is too far out for me, that—

CH: 360 degrees.

AF: Yeah. If this eventually does enough damage to you that you need to get into this really life-threatening situation, it might cure you, which is—

CH: A bit late.

AF: I like to tease one of my brother-in-laws when we go out that— not to drink too much because I might need a little bit. You know, need a little liver. [laughter] It's like, "Hey, put that down."

CH: How are liver transplants working out these days? Is the life expectancy from a liver transplant very solid?

AF: The last time I asked, the mortality rate was 10 percent, which is not great. So it's not something that you're going to consent to unless you really, really need it, because that was an initial reaction that people had.

CH: That you should have the transplant?

AF: That they'd ask me about, "Well, why don't they just do it?" And I'd say, "Well, are you going to take a 10 percent chance of not getting through the surgery?"

CH: Not if you don't have to.

AF: Never mind a complication from an unrelated event from the surgery. Just from the surgery itself was a 10 percent chance. And that's a little—a little bit high.

CH: Not to mention how complicated surgery is even with the new factor.

AF: Yeah.

CH: So that's a real difficult one.

AF: Yeah, but—

CH: Have you suffered depression? Do you have times when you feel black?

AF: Not for very long.

CH: No?

AF: No, not really. I mean, actually [chuckles] start most of my days in a very good mood. And I sort of watch at work to see how long that lasts. But left to my own devices—

CH: So your problems are primarily a physical thing; I imagine that you just hurt and that's depressing, and by that, I don't mean mentally depressing.

AF: Yeah, just—

CH: Spiritually depressing.

AF: I don't really think I've ever had that because, I don't know, I've just been lucky to always be around good people or people that I want to be around. And maybe we can't do what I'd like but I'm still happy to be with that person. And that's certainly been the case for quite awhile and even before that.

CH: Do you have a spiritual life? What was your parents' faith?

AF: Oh, everyone in my family, with the exception of me, [chuckles] is Catholic. And I was raised Catholic but it never resonated with me so I don't follow any practice. Did—the only—the closest I get to anything even spiritual is knowing that I probably should pursue meditation or something along those lines, because I—I can feel it. I'm just too lazy to do anything about it. And I did have one specific experience related to pain that I was in so much pain—I can see this as we speak—from my knee that I was just sitting in a

chair. And I was just sitting quietly and thinking about the pain but not thinking about that I wanted it to go away. And I can tell you that I've never—only one other time I've ever felt so calm in my life.

CH: So you were thinking about it but you weren't fighting it?

AF: Right. And so something like that and one other event—I just—I feel like there's something else that I could be in touch with and I'm just too lazy to do it. So whatever—whatever that is, I don't know.

CH: Could you tell me the other event?

AF: The other event was—I think this is a coincidence—going over to my parents' house on Easter Sunday. That's why I think it's a coincidence. My wife and the two kids and I were going out, getting in the car. And I have never in my life felt a sense of calm like that before or since for a very brief—you know, it just—and it stuck with me all these years—that every single thing was okay. And I don't know if it's a sort of, you know, when the weather changes in April and you can think of a lot of things that might contribute to it.

Sometimes it just feels good out but I've never really felt that level of calm ever. And so that kind of tugs at me a little bit that maybe that's still around somewhere. It didn't last too much longer once we got to my parents' house and we started eating and the kids were the kids and all that stuff but [laughs]—

CH: I think when I first asked you how you handled the pain, I was looking for the sort of moment that you described where, in fact, you stopped fighting the pain. A point where there's some accommodation in you that—

AF: Yeah.

CH: —overrides the pain to some degree.

AF: I did kind of mean to go back there because when I had mentioned about the physician's hesitancy to give me painkillers—they say, “What do you do now?” I say, “Well, I sit quietly and I just try to recognize but not fight the pain.” They said, “Well, that's what we want. That's what we're trying to get people to do.” I said, “Yeah, but I can't do anything else but that.” So there's sort of a tradeoff, like you can sit quietly by yourself. But you can't do—no—you can't talk to anyone. You can't be involved in anything so that—it's—it can be an okay feeling but it's not necessarily how you want to manage something on a regular basis.

CH: You can do that when you're by yourself.

AF: Yeah.

CH: But you can't do that at Easter dinner with a lot of people, for example.

AF: Or you have to go be yourself. You have to go be by yourself, be a little more active than just if you happen to be.

CH: Most meditators will probably tell you it becomes so automatic you can do it anywhere, anytime.

AF: That's the part I suspect and that's why I chastise myself for being lazy. But, you know, I'm sort of a real typical American, [chuckles] the attention span of an American. If there's something on TV, well, I'll take a look at that.

CH: It might be worth ten minutes a day.

AF: Yeah, I don't know. [laughs]

CH: Would your wife agree to that? Would that be something she would relate to?

AF: I think more now. I think maybe when I first got interested in this I thought it might be one more difference between me and

everyone else that I knew. There's certainly nothing unusual about it here in [name of town] but in [name of town] and—

CH: You mean just the thought of meditation.

AF: The concept, meditation and—

CH: The concept of philosophies.

AF: —sort of Eastern philosophies and all that—

CH: Yes.

AF: —is sort of ingrained around here but not anyone else in my family. [chuckles]

CH: No.

AF: Now, it's—it's more—it's more everywhere that you hear about people at least thinking about it or at least the westernized versions thereof. But I did actually meditate for awhile when—you know, with the kids around. And I would just tell them I was going to be in the other room. They thought it was weird. I'm now swinging around to thinking of it—it's just something that you do.

CH: I just spent 10 days with a woman suffering cancer. And I watched her deal with both the discomfort of her chemo—it was more than discomfort—and the truth of her situation, which was tragic. And she really achieved a lot through quietness. So she really has achieved some level of peace that I think has been very good for her. It has allowed her to have a whole new outlook on life. She went quiet when she felt nauseous, for example—and I find this when I'm sailing—if you can let your muscles go—if you can truly let those muscles go, a lot of things change in your body. And it relieved a lot of that for her. I'm not equating it but it was interesting watching her.

AF: I do think the phrase, "Let it go," that people use, or you see in many, many contexts, that—I'm borderline obsessed with that,

because I'd like to know what it is [chuckles] and how I let it go, because I'm pretty sure I should, if you know what I mean. I know I'm being kind of vague. But you just hear snippets of that—that I—when I let go of this I realize this and that. But I'm not sure what that means other than it was pretty obvious from the pain context. But I'm sure it has broader meaning.

CH: Well, I know when I felt seasick, I could learn to consciously let my muscles go, starting up here all the way down my body, and I would feel fine. And a lot of what was happening to me was the tension around beginning to feel ill.

AF: Right.

CH: The minute that I let that go I was better. And you start with these muscles here and you can really feel it just going down your face. And it is a very peaceful feeling.

AF: Well, yeah, that's what we're wired to do, unfortunately.

CH: All around pain too, anything that hurts.

AF: Right.

CH: We tense up around that.

AF: Yeah.

CH: I think there's a lot of value in it.

Your parents seem to me to have been really quite extraordinary in their attitudes. I don't know whether you've experienced much in terms of how other families have handled the issues around hemophilia, but your family seems to have been very positive.

AF: They're just very—they were—my dad died about five years ago from complications of lung cancer. But I think of this all the time, aside from putting things in context. He had decided he wasn't

going to have any more—any more procedures to try and figure out what was going on. And then they said, “But if we do this, maybe we can figure this out.” And he said, “Wouldn’t that be joyous?” And that was the last procedure he ever had. But even at that point after all he had been through, he was still hopeful that this procedure would tell him something, even though he was tired of going through it. And of course it didn’t. [chuckles] You know, it’s not a—it’s not a fairy tale. But just that attitude, that, plus—coupled with—he would always say, “Well, we’ll find a way.” And my mother was the same way and that—you know, the perspective comes from how they—where they grew up and other factors. But just that sort of, “We’ll figure it out,” I think has translated to me in that extent. And then, honestly, having kids around, you sort of get through that first—you have to watch your first reaction, or at least I do, and you say, “All right, let’s figure what’s going on here.”

CH: Yes.

AF: And so that’s—that’s is a big deal, I think, once you get through that, especially if you feel like they’re probably just making stuff up to set you off, [laughs] that you should really just kind of figure out what’s going on before you get too concerned about it. But they were very positive folks.

CH: They seemed very perceptive and creative in the way they handled things.

AF: Yeah, I—my dad, not as much because he worked nights and we didn’t see him that much and all that. I did learn to infuse by myself because he was not good at it because he was afraid of hurting me. He was just concerned about it. So, like, Dad just—you know, just stick it in there—be doing more good than harm but—

CH: Yes.

AF: Yeah.

CH: You said that their attitude came from their backgrounds. And what was that? What was it in their backgrounds that gave them that perspective?

AF: Well, I think my dad grew up with nothing, really—essentially nothing, not even a very great family life. And I don't know what—what made him be the way that he was. He ended up—he was an alcoholic later on so there were a lot of years that weren't good. But just when I think back on what he didn't have and what he was able to do, that just impresses me and I just—I think he was happy with everything that he got. He was grateful for it. And my mom just—it's just the large family kind of shared experience and her—you know, no real traumas to speak of when she was growing up that—that I know about anyway. So I think she had, like—for the time, anyway, a pretty good childhood, and that just informed the way they were. And, you know, he went off to Korea, came back and they got married and were going to have kids. And, you know, that's sort of the—they were sort of on track with everything. My wife's parents almost exactly parallel, almost to the—like, one year off—the dad off to Korea, the mother—you know. So it's just kind of funny that that's—and probably this kind of socio-economic values that make my wife and I work pretty well.

CH: Yes.

AF: So I actually think that's probably more important than almost anything else. [chuckles] Figuring out what your expectations are.

CH: Yes. Figuring out your intellectual properties.

AF: Mm-hmm.

CH: But you're right. It's very difficult to meld very unbalanced perceptions and expectations.

AF: Or people that—just whose expectations from the way—what they've been through are wildly different than your own.

CH: Is there anything you'd like to add? And I'm looking for any—anything at all that you'd like to add about the experience of hemophilia and getting to this point.

AF: Let's see. I guess I'm hopeful, as I—from purely selfish aspect, that gene therapy or other kinds of therapies emerge that can actually—if not cure, come closer to providing management of this disease, because having to infuse—having to do an IV infusion in 2005 [chuckles] still seems kind of antiquated. A long time ago I told my wife I'd be in better shape when I was 40 than I was at that current age. But I've since learned about the delayed promise of biotechnology, [chuckles] so I've had to rescind that. Now it's 50. But it's basically just I hope, again, from a selfish point of view, that advances help get rid of this because I would really enjoy not having to think about it for a little while. It really is every day and there are the underlying concerns that I mentioned about, “Will I get sick from this or that or something we don't know about yet?” But I guess that's really it.

CH: You mentioned those flashes of moments when you don't feel pain. Just the converse of what most people feel, which is flashes of moments when they have pain.

AF: I guess, although I'm not sure anyone's—most people are aware of that either, right?

CH: Oh, I don't think so.

AF: Yeah.

CH: No.

AF: I think I'm only aware of it because it's unusual. So that
[laughs]—

CH: Yeah, that's an unusual perspective.

AF: So that's actually pretty cool but it just doesn't last that long.

CH: No, time without pain is sort of a little nirvana.

AF: Yeah.

CH: It should be the norm.

AF: That's what I think too when you ask about, do I get depressed?

And I think my natural level is actually pretty calm or it used to be.

[laughs] And just enjoying it now but, you know, as soon as some
interference comes along it goes away pretty quickly.

CH: I really appreciate you're coming. Does your leg hurt you, for
example, from sitting?

AF: Yeah, I mean, it just—it hurts most of the time and then this
block of weather's nice, but the last few weeks have just been
ridiculous in terms of trying to deal with any kind of pain.

CH: I can imagine.

AF: Yeah.

CH: I really appreciate you making the trip up here.

AF: Oh, my pleasure.

CH: And if you think of anything else you'd like to add—

AF: Okay.

CH: It was very, very interesting. Very informative for me.

AF: Thanks.

CH: I've learned a lot.

AF: Thanks.

CH: Do you think your experience of physical pain has made you

more sensitive to, say, people who are crippled with emotional pain?

AF: I think so, yeah, because my—my limitations are largely physical. I'm sure I have some emotional ones but I think my parents did a great job of starting me off with a good chunk of self-esteem, possibly more than justified. But when I see that lack in others, that really makes me sad.

CH: Yes.

AF: Because that's not something you can do much about. In fact, to the point where I—you know, like movies like "Shine" or movies—I don't really enjoy them the way that a lot of people—"Oh, that was a really good movie." And I almost never find humor in them, even if they're funny because I know that that person is really quite anxious. And I really, really feel for people that are anxious. And if I could study one thing, I would like to go over, get back into neuroscience.

CH: Yes.

AF: Because I'm not—I'm interested in people that have diseases, right. But I'm also interested in what limits an otherwise normal person from reaching more of their potential. And a lot of that, I think, has to do with just emotional, if not pain, then just perception of—that they're more limited than they are.

CH: Limited by lack of self-esteem.

AF: Yeah, and I think that's so huge.

CH: It is huge.

AF: But—so I'd—you know, I'd much rather deal with a sore knee but feel that I'm probably okay. [laughs]

CH: Oh, absolutely.

AF: You know?

CH: Oh, I think—absolutely.

AF: Yeah.

CH: Even if you can't see a finite cure to the physical pain, it's at least tangible, isn't it?

AF: Yeah.

CH: And you can feel joy.

AF: Right, as opposed to anxiety of—

CH: Right.

AF: That's pervasive, that it's going to color everything, you know, as opposed to, "Well, it's a sore knee. I can't go skiing; it's not that big a deal."

CH: So I think the participation goes way past being a hemophiliac.

AF: Mm-hmm.

CH: It goes way into looking at what people experience with a chronic, lifelong issue.

AF: And it has made me think of it just sort of what actually limits people, myself included. The physical ones are easy to see. But what is actually preventing me from walking around feeling more calm or happy in a given moment than otherwise? And it's probably looking ahead at something I'm not looking forward to, [chuckles] if you know what I mean.

CH: Yeah.

AF: So it's like [unclear].

CH: Do you think things have turned out differently than you thought they would? Has it been more difficult or did you really think about the long term prospect when you were a young person?

AF: Oh, it's definitely easier than I thought it might have been.

CH: Really?

AF: Yeah, definitely easier, with the exception of HIV. [chuckles] That's just—I mean, that is the exception and, hopefully, will remain the singular one, as opposed to hepatitis C or—because that—that's what people were concerned about before HIV, right. They were very, very worried that we'd all develop these terrible liver problems. But I think it's just easier from the management point of view. It's a nuisance. And I am—it would be great—even if—it would be great to be able to infuse twice a week and know that I always had enough factor level. That would be good; that's not the case now. So you always have this sort of underlying concern that I have to watch my activity so I don't start a bleed, based on whether or not I happen to have factor, or, more likely, that I tailor my activities to when I've infused. So, you know, there's—

CH: You have periods of higher activity when you've just infused.

AF: Yeah. Yeah, I even jokingly call them—you know, tell my wife, “Well, I don't have too many activity units today, so I don't think I'll be doing that.” [laughs] Or, “I won't be hanging up that shelf or something today.” But it's just an awful lot of management, as opposed to just doing. And that's—aside from—on the less serious issues, that's the biggest drag.

CH: The spontaneity.

AF: The concern about life-threatening issues down the road, the physical limitation, but just—right, the almost complete lack of spontaneity, and just really, with the pros aside, always having to be aware of the consequence of, if you're kind of not paying attention for a minute or two, or—that weighs pretty heavily. But I think the advances in the treatment have just made it huge—

CH: Yes.

AF: —compared to having to go to a hospital and wait for them to show up with these enormous syringes and all of that. So it's definitely easier than I thought it would be.

CH: Did you find the process of infusions in those days very difficult and painful?

AF: The—before the lyophilized stuff, definitely. I do remember being in a lot of pain as a little kid, being brought into the hospital and the nurse coming in with five—either 30, or probably 50 cc syringes of the old, almost yellowish. Could have been a problem. [chuckles] Could have been a signal with what we now know. But—so about—I think it was five 50-ml syringes. And I remember saying to my mom, “I'm feeling better now,” because just the thought—and they weren't going to use any big needles, but just the thought of all of that stuff and what it meant.

CH: Some people told me that when the factor was cold it was very painful.

AF: Yeah.

CH: Some places were much better at preparing the infusion.

AF: Right. And then actually I remember that very first time I had, I think, cryoprecipitate—it must have been cryo—I had an infusion reaction on the way home from the hospital.

CH: What was that like?

AF: Chills, fever, shaking and more to the point, being concerned that I couldn't have that. And it never happened again; it was just the first exposure—but a real concern that—and obviously, the physicians know that that's likely, and may not be a concern, but until you see it in your head, you know, so to this day I still have Benadryl somewhere in the house. [chuckles] God forbid, I should need it

but—

CH: That must have been very difficult for your mother.

AF: Yeah.

CH: It must have been difficult for her to watch you as a child, fearful, having to go through all that.

AF: Yeah.

CH: It must have been very draining for her.

AF: Yeah. I think—I'm sure it was.

CH: And then to put her best foot forward to keep your spirits up.

AF: I guess—I don't know how related it is but I did sort of enjoy things like drawing and things that were more sedentary anyway, although I'm sure I'd loved to have run around more. So I think that helped compensate, that I could spend hours and was pretty happy doing this or that. But it's—yeah, I know that was difficult for her. I'm sure she has some huge guilt issues that don't deserve to be there.
[chuckles]

CH: And, of course, she worked. Was your father home with you the days you had to stay home? Was your father the one at home?

AF: My mother didn't work all the time.

CH: Oh, she didn't?

AF: I think she was at home part of the time until we were in school.

CH: Yes.

AF: But, yeah.

CH: Well, I really—I'm pleased to meet you. And—

AF: Nice to meet you.

CH: And I certainly wish you well.

AF: Thank you.

End of Interview