

Interview with Christopher Kucinski by Laura Gray for the Boston Hemophilia Oral History Project, November 23, 2004.

GRAY: I am in Raynham, Massachusetts with Christopher Kucinski, who kindly agreed to participate in the oral history project. And today is November 23, 2004, two days before Thanksgiving, and we're sitting in Chris's home. Chris, thank you.

KUCINSKI: Yeah, you're welcome.

LG: Chris, let me start by asking you how old you are, when you were born.

CK: Born December 11, 1949. I'm 54, pushing 55.

LG: And where were you born?

CK: In Brockton.

LG: And what kind of hemophilia do you have?

CK: Hemophilia B, or Christmas Disease.

LG: And what severity, do you know?

CK: I'm not sure.

LG: Okay. And do you have any other chronic illnesses?

CK: Quite a few.

LG: Quite a few. All right. Well, then we'll get to that later.

CK: Yeah.

LG: So let's start, Chris, by telling me where did you grow up—whom did you grow up with?

CK: I grew up in Brockton with my family, my mother, father and they had a total of 10 children in the family. I was one of the 10.

LG: Ten kids.

CK: Right.

LG: Okay. And were you the only one with hemophilia?

CK: No, there was—my two sisters and one brother were the only ones that didn't have it.

LG: Your two sisters and one brother were the only ones that didn't have it.

CK: Yes.

LG: So that means there were six boys that had hemophilia?

CK: Yes. No, seven boys.

LG: That's right. There were seven boys in the family.

CK: Junior and Bobby and Georgie, which I—was—had died before I was born. And I lost my count.

LG: How about starting with the oldest to the youngest.

CK: All right, yeah.

LG: That would be helpful.

CK: All right, there's a—oldest of everyone?

LG: Yeah. Let me hear all the kids.

CK: All right. There's—my oldest brother was Junior, or Godfrey—Godfrey, Jr. Then there was Fabian and then my two sisters, Helen and Katherine. Yeah, and then Richie, and then Franny, and then me, and J.J. and Kevie. And Georgie was in there before I was born. He was born I think before Franny was born or after Franny was born.

LG: And so seven of the ten boys had hemophilia.

CK: Yes.

LG: I can't even imagine. You lived in Brockton. And did you live in a big house or did you live in the city?

CK: We lived in a big farmhouse on a farm in Brockton. Yeah, my father had a farm and he raised all kinds of animals plus garden supplies.

Garden—you know, tomatoes and corn and everything else. He had pigs for years and then he also had turkeys at one time or another. And we worked hard. We were—we, you know, worked in the fields weeding, planting, picking vegetables. Then we had a farm stand out front that—that one day they decided to start selling some of the vegetables, and it built up into a pretty good business. And we worked hard for my father, all the kids.

LG: When you say “we,” who was “we?”

CK: Me and my brothers and sisters.

LG: So the whole family worked on this farm.

CK: About the whole family, yes. Yes.

LG: How did this work? How did you fare working on the farm with hemophilia?

CK: Well, when we were lame and couldn’t work or be in the house in bed or something, putting ice on a joint or whatever was bothering us, and the other kids that were feeling okay or working okay could carry on with the work.

LG: Were you laid out much? Were you lame, as you say it, much?

CK: Yeah, different periods—go through periods of months that I’d be okay, and also go through periods of weeks and months to be lame, stiff and sore and not able to walk, and things like that.

LG: What do you remember, Chris? What do you really remember about when you were a kid with hemophilia?

CK: I remember not being able to run. I couldn’t run because my knee was stiff and sore.

LG: You could never run?

CK: I could when—I could when it wasn't stiff. I could run. I was—I could skip. I could do everything good. But then as—you know, as you got bleeds in joints that—swollen up and you couldn't straighten the leg or you couldn't put pressure on the leg, you couldn't run. You couldn't walk sometimes. Sometimes I would hop. In the house, I would hop on one foot to go to the bathroom or wherever just to get around. I got real good at hopping on one foot because the other leg would be sore and not straighten or whatever because of the bleeds in it. And it'd be like a knee or something, usually a knee or an ankle.

LG: Do you remember mostly bleeds in your knee or ankle?

CK: Yes.

LG: Not in your arms or—

CK: I did have them in my elbows, yes—in my shoulders once in a while—very painful, and once in awhile in a hip. My father used to—when I had to go to the bathroom when I was real, real sore, he'd put me on a chair, just a regular type chair and drag the chair, tip it back and drag on the two legs, you know, so you could go to the bathroom. We didn't have a wheelchair or anything. So he'd, you know, drag me on the chair. I'd be sitting on the chair and he'd just tip it backwards and drag it into the bathroom beside the toilet and I'd go—stuff like that.

LG: You remember your dad helping you out.

CK: He helped us all the time, yeah.

LG: What were your parents' attitudes towards all you boys having hemophilia?

CK: Oh, they were worried. They were always worried and concerned. Many times when I was at the hospital they always said stuff like they

don't know if I was going to make it through the night. And a priest had come in and given me my last rights many times.

LG: Really?

CK: Yes, I always had lots of problems. They couldn't stop the bleeding and they'd just keep transfusing me. And they'd give—they'd give you plasma. They did not have any clotting factors or anything like that. So they'd load you up with plasma and that would sometimes help.

LG: What was that like when you got last rites or your parents said, "Oh, my God! He may not make it through the night."

CK: Well, I was kind of young and I didn't really know the difference, like, yeah, I was sick at the time. But whatever they said, I didn't take very—worry about because I was just too young to take—to understand it, I think.

LG: I see. Did you worry about yourself a lot as a kid?

CK: No, not really.

LG: Not really?

CK: No, I just wanted to, I don't know, do things. And we—Father wouldn't let us do many things that—you know, he'd say, "Can't do this; you'll get hurt. You can't do that; you'll get hurt. You can't go"—you know, we couldn't, like, play and fight with other kids and do the stuff normal kids would do a lot of times, because they'd be afraid we'd get hurt. And we would come back hurt from different things. But we used to horse around amongst ourselves and get hurt anyways. So he said if we—if he kept us working and busy we'd stay out of trouble. We wouldn't be getting hurt so much. So that was his idea to try to help.

LG: So how did he keep you home? What did that mean? Just by keeping you busy working?

CK: Yeah.

LG: Yeah.

CK: I mean, we had friends, you know, that would come in and stuff. But we wouldn't usually go to anybody's, other friend's houses or anything like that because, I don't know, he just didn't want us to horse around and get hurt, get a bleed or get bruised up and stuff. And he'd always say when—you know, when other kids would say—would come to our house or something, he'd say, "Take it easy with him. Don't bruise him up. Don't—you know, they're bleeders. They bruise easy," and stuff.

LG: Is that what he'd call you, a bleeder?

CK: Yeah, he'd used to say we'd bruise easy. Yeah. Yeah.

LG: What about your mom? How did she handle having so many kids, and then, so many boys with hemophilia?

CK: I don't know. She used to worry and she used to say prayers all the time. And she used to do a lot of cooking though. She cooked a lot and that was—you know, she worked. She worked in a factory and different places and she also cooked a lot. And I don't know. She was just—she was a good mother. She always took good care of us.

LG: Were you diagnosed with hemophilia? Did you know what it was?

CK: No.

LG: You didn't?

CK: I didn't know at first, no.

LG: What do you remember about that? How—did your parents understand what was going on?

CK: Well, I think the doctors told them what it was. And I guess they did understand, yeah.

LG: But you didn't.

CK: No, I didn't understand it at first. Not when I was younger.

LG: Do you remember what you used to think?

CK: I just couldn't understand why, you know, my leg all of a sudden would get stiff and swollen and I couldn't move it. And I'd be outside trying to walk and I'd say, "I can't—what is the matter?" I just didn't understand why it wouldn't work, the leg wouldn't work, or a bleed or why all of a sudden I woke up in the morning I can't step on my foot. It hurts.

LG: And did anybody explain it?

CK: Yeah, they explained it but I still didn't—

LG: Didn't make sense.

CK: No, they said, you know, "You're a hemophiliac. It means you bleed in the joints." And I—yeah, well. Yeah, I'm not a doctor so how could I take that in and understand it?

LG: Right, right.

CK: I just knew other kids were walking around and didn't have any problems. And it was odd that—you know, you didn't understand why.

LG: What about your other brothers?

CK: We had the same experiences but I can't speak for them because I'm not sure what they thought about things.

LG: Did you guys ever talk about it together, what's going on, or wonder why do we have this?

- CK: No, we just used to say, “I’m lame. How’s your leg?” This, that. You know, we just—I don’t know. We used to put cold cloths on our legs when they got sore at night. I used to always wrap them up. I’d take a face cloth, get ice cold water and put it on and would relax you for the night, stuff like that. We didn’t, like I say, discuss it though. We just would say, you know, “How’s your leg today? Any better? Feeling any better?” And like that.
- LG: So all you remember for treatment when you were young was putting a cold cloth on.
- CK: Yeah, and ice packs. We—if we hurt ourself—like, if we knew we banged ourself right away, my father would say, “Get ice. Get ice.” And we’d automatically put ice on it and keep it cold and get off it. And that would usually, well, slow it down on occasions. Sometimes we wouldn’t get a bleed but most of the time we did.
- LG: And so what would happen if you got a bleed?
- CK: It would swell up and that would mean you couldn’t be on that joint for days, weeks even, sometimes.
- LG: Weeks even.
- CK: Yeah.
- LG: What about school? What happened with your education?
- CK: We had home teachers. I went to school. A couple of my brothers went to school and I went to school. But I couldn’t—I couldn’t walk. I couldn’t take it. So they put me at a—the teacher would come in five days a week, I think it was, for a couple hours a day. We had home schooling.
- LG: For how long did you have home school?
- CK: I graduated through high school with it.

LG: Really?

CK: Yeah.

LG: So you never really went to school.

CK: Not really.

LG: Was that true for the rest of your brothers?

CK: J.J. and Kevin and I think my brother Franny too. Yeah.

LG: Where were you in line?

CK: Well, I'm third from the bottom.

LG: Third from the bottom.

CK: Right. I mean, Kevin's the youngest; Jeffrey, then me.

LG: So all of you were home schooled and when you could you worked on the farm.

CK: Yeah.

LG: And when you couldn't you were laying in bed.

CK: Right, or sitting around or whatever. But we couldn't walk; we couldn't do much. Well, we—if we could get out to the stand where we sold the vegetables, we could get a chair and sit down and wash tomatoes or do something, even with a bad leg, when we could, just so we'd be busy and try to help. You know, even if we had a sore arm we'd use the other arm and do whatever we could one-handed. Just so that we kept busy and took our mind off our troubles of our pain.

LG: Uh-huh. So the attitude wasn't, 'Oh, poor thing.'

CK: No. No, I'd put a sling on and get my arm comfortable and if I wasn't almost crying that means I was [chuckles] okay. And I'd just go and do whatever I could, one arm or whatever. And the same way with the leg. If you could walk on it you would and if you couldn't, you wouldn't. Hop around or whatever.

LG: And you'd just wait until you could and that would be that.

CK: Wait until it improved, yes. Then after it—after the bleed went down you'd try to walk and keep walking so that the leg would get back to getting stronger. But we didn't have any physical therapy or anything in those days, so our joints never really got real good after they were injured. They would keep getting injured and never really had any physical therapy.

LG: What about doctors and nurses—were they around when you were young?

CK: Well, we only saw them really when we went to the hospital.

LG: Okay. And when would you go to the hospital?

CK: When it was something more serious, like bleeding or like actual wounds. Like, I got cut in the head one time and I was bleeding. And another time I fell back in a chair and cut my mouth and it was bleeding and stuff. And we went in for those reasons. I had internal bleeding once or twice inside me, a bleeding ulcer and something else when I was young. And I was in there for that and they were flushing me. They had to put a tube in my side and flushing cold water inside to heal me up and drain me and stuff. They did all kinds of stuff.

LG: Where did you go when you went to the hospital?

CK: Brockton Hospital, the Brockton.

LG: And what was it like in the hospital when you were a kid?

CK: I hated the place.

LG: Why?

CK: Because I wanted to get home and run away from the hospital. All I was doing was making plans to run home. And I said, "If I run home my parents will bring me back." That was my biggest problem. I

said, “They’ll bring me right back here.” So I never ran home.

[chuckles] And I always planned it.

LG: Why did you think of running home?

CK: Because I didn’t like the place. I wanted to be home.

LG: Why?

CK: I just wanted to be home with the family and everybody. I was lonesome; I didn’t like being there.

LG: Because you were there by yourself usually?

CK: Yeah. I stayed there for 30 days at a time, a minimum—

LG: For 30 days?

CK: Thirty days at a time was minimum, yes.

LG: Was the minimum?

CK: Yeah.

LG: Did that often happen that you were there for a month at a time?

CK: Yeah, it was a minimum of a month; a lot of times it was longer.

LG: And you were—were you alone in a room or—

CK: Yeah, usually had one room—one person to a room. I was usually by myself.

LG: What were the doctors and nurses like?

CK: They were good to me. They were real nice. Oh, they were sweet. They always liked me; they all liked me. I got along good with all of them.

LG: Yeah, but you just felt so left out.

CK: Right.

LG: Because you were separated from your family.

CK: Right.

LG: Were all your other brothers in and out of the hospital like you were?

CK: Some were. Not—I don't think I was in there a lot more than some of them. I don't recall though. I'm not sure. It was, like, different times so it's hard to know which ones—yeah, they were in there too.

LG: What do you remember? Were you a sad kid? How'd you handle this emotionally?

CK: I was always smiling and happy. I always had a smile on my face and sort of, I don't know—I was always, like, joking around and always, you know—I wasn't serious about things. I don't know—not that serious.

LG: So even though all this stuff was happening, you were able to somehow keep a smile on your face?

CK: Right. Yeah, because [unclear]—

LG: What do you make of that, Chris? Did that have anything to do with the family attitude or do you think it was just how you were born? What do you think?

CK: I don't know. I think family has a lot to do with it, you know.

LG: Tell me about that.

CK: Well, we had a lot of fun, me and my younger brothers. We always horsed around, did everything together, the three of us, me, Jeffrey and Kevin. And, you know, we hung out together and—

LG: Mostly you younger guys.

CK: Yes.

LG: Why? Were the older guys too much older?

CK: They—yeah, would be—well, they were just with themselves. They were too mature for us or whatever you want to call it. They didn't hang out with us. I mean, we used to go down the woods and go hunting—we called it hunting—with homemade bows and arrows and

things. And, you know, we never shot anything because we had strings and sticks and things to—but we walked around the woods, walked along the rivers and stuff, see what was going on. We'd take hikes and stuff.

LG: So you still had a sense of adventure.

CK: Oh, yeah.

LG: Even though your mother and father were always saying, "Be careful. Don't do this; don't do that."

CK: Yeah. We used to go in the winter on the snow and the ice and on the pond and slide and go down the hill on sleds. And we used to get hubcaps, two hubcaps. And we'd sit in one, put our feet in the other. We'd put—[unclear] our bags underneath us. And we'd slide down the hills and stuff.

LG: And your parents didn't forbid you to do that?

CK: No.

LG: Yeah, even though they knew you might get hurt?

CK: Yeah. [chuckles] We did sometimes, yeah. But it was hard to keep us from not doing stuff, I guess.

LG: You wanted to do stuff.

CK: Yeah, right. Right.

LG: Even though you knew you could have a bleed.

CK: Oh, yeah. The risk wasn't there. You didn't worry about it. You just tried not to happen, tried not to bang your leg into something or fall or do things that would hurt you. So you would try to avoid it but wasn't always avoidable.

LG: But it didn't stop you from sledding or—

CK: No.

LG: —doing things that it would be so easy—

CK: Right.

LG: —to get hurt with.

CK: No, we used to try to slide and ski and all that stuff but, you know, it was—

LG: So in a funny way, even though your parents said, “Be careful”—

CK: Yeah.

LG: —they gave you the freedom to—

CK: Yeah. When we were out of sight [chuckles] we did what we wanted. They couldn’t watch us all the time either. I mean, if they caught us doing something—they saw us doing something bad, yeah, they probably would have stopped us. They did stop us and say, “Hey, that’s enough of that. Come on. Knock it off. Get home.” And stuff like that.

LG: Did they ever get mad at you when you got a bleed?

CK: No.

LG: Never did?

CK: No, they always—they always were good to me and always said, “Take it easy. Don’t do this again. You know, you’ve got to be more careful.” That’s all. But they never picked on me or blamed me for—

LG: Never did?

CK: No. They understood it pretty good.

LG: You had said to me that your mom prayed. Tell me about that.

CK: Well, every week she’d say—she’d kneel on the bed and say her prayers with the Rosary for us.

LG: Did faith and religion play a big part in their lives or in your life?

CK: Yeah, yeah.

LG: Tell me about that.

CK: Well, we—they made us go to Sunday school and we had even home teachers come out for Sunday school to make us get—make our First Communion and all that stuff.

LG: So you were Catholic?

CK: Yes.

LG: And what about today, Chris? Is this an important part of your life?

CK: Oh, yeah.

LG: Tell me.

CK: Well, I make sure I try to pound into the head of the kids here—everybody—we took all our children and made them, you know, go through the First Communion and make Confirmation and all that. And we'd just hope they'd continue with the religious—and whenever we can—they go to church and I used to go when I could. I haven't gone that many times. But I always had trouble sitting down and getting up in the pews because of my legs. I'd sit down; then I got to stand up and you got to sit down. And I—it was hard to do. Then the priest said, "You don't have to do that." But I still—it was hard for me to get into church and stuff—a lot of times with bad legs and stuff.

LG: Was church a strength for you as far as coping?

CK: Well, yeah. I've always believed—I always believed that when—you know, when things got better I prayed harder and said more prayers.

LG: You always believed what?

CK: I always believed God's going to help me because I believe in God. I—you know, I'm religious—the fact that I was taught that way to believe. And my grandmother told my mother, says, "Better to believe than not believe." Says, you know, "What do you think? Is

it—you know, is there anything to it?” She says, “It’s better to believe than not believe.” And I’ve always believed. That was the right answer.

LG: So your memory of your childhood was oftentimes being in bed or in the hospital with a bleed—

CK: Well, yeah.

LG: —cold compresses or out helping or running around when you could.

CK: Well, we had—me and my brothers horsed around a lot. We took the tractors. When my father wasn’t home we drove around, raced around. We had BB guns we had gotten, and we had fun shooting BB guns and things. We had fireworks and we had a lot of fun blowing off fireworks and doing things that my father would have, you know, not approved of. But he’d go to pick up my mother or something like that, wouldn’t be home and we knew the time and how much time we had to horse around, and we’d take advantage of that. So, I mean, it wasn’t just a sad—a sad thing all the time. We had a regular life except when we were lame.

LG: So you had a regular life except when you were lame.

CK: Right.

LG: So you didn’t feel that different then?

CK: No.

LG: You didn’t?

CK: No. Even today I don’t feel that different, that I do anything that I could. The only thing that—holding me back is the physical part of things.

LG: Mm-hmm, but mentally you didn’t feel any different.

CK: Mentally, no. Right.

LG: Interesting. I'm fascinated by that because I always wonder, "How come?" You know, what do you make of it, that you didn't feel different with being in the hospital for a month at a time?

CK: Right.

LG: Why not, do you think?

CK: I don't know. Just the fact that you're born with whatever you're born with and that's—that's part of it, I guess.

LG: Uh-huh. So it was more that you were just born with it and it's who I am and—

CK: Right, and I've got to deal with it and am I going to sit and cry in my beer all day, or am I going to just carry on and do everything? I—I got married; I had kids. I did everything I could. I raised plants and did some landscaping when I was younger, and I worked with my other brother driving a truck and doing a few other things. And I always, you know, tried to do as much physical stuff as possible. Even though my legs and joints were weak, I still kept going and trying to do, you know, whatever I could and—just like anybody else. I mean, I know I was limited but I still tried to get around the limitations whenever I could.

LG: So you didn't really focus on what you couldn't do.

CK: No.

LG: You focused more on what you could do.

CK: I tried to do everything. I just would try to accommodate myself differently. Like, if I—if I got down—I'd work on my car or something. I'd have a box or something so I could sit on the box and lower myself down to get under the car, because I couldn't get up and down like somebody else on the knees, bend the knees and do this.

But I always tried to do it because as long as my hands were working, which they always worked better than my legs, I always tried doing things—fix things, build things, did a little carpentry work when I could. I used chainsaws and cut firewood and stuff. And it was dangerous but I'm very careful and try to get in a good position before I did anything, so that—you know, wouldn't take a chance on getting hurt, if I could.

LG: What do you remember about treatment and the changes of treatment?

CK: Well, there was no treatment really for years, except, like I said, the plasma—the plasma and the blood.

LG: What do you remember about the plasma and the blood?

CK: They'd give you a lot of it. When I—when I was—emergency, which I usually went in, my father would come in and give a pint of blood because he was the same type as me. And he'd—

LG: So he'd give blood for you.

CK: Yes, when I went in on an emergency, usually he was there to give a pint of blood to get me started. And I usually would have 30 pints of blood at a stay. That wasn't common—I mean, uncommon. That was—then they would give me plasma and then finally I'd improve and go home.

LG: And were you strapped down with IVs a lot?

CK: Well, they'd put a board—

LG: What was that like?

CK: Yeah, it was very uncomfortable. I hated needles, couldn't wait for them to come out. They'd—they'd put a board down, then tape you to the board, the arms and put in the needles and stuff. And you're stuck there for quite awhile.

LG: How long?

CK: Well, for duration of the hospital stay usually.

LG: You mean you'd have needles in you the whole 30 days?

CK: Yeah.

LG: And how often would blood or plasma be dripping into you?

CK: Almost every day some days—sometimes. Most of the time I was there being treated. Once I wasn't treated, I was usually well enough to go home.

LG: I see. I see. So you remember just lots of blood going in or—

CK: Right.

LG: —plasma going in.

CK: Right.

LG: That's what you remember.

CK: Right.

LG: Anything else that you remember as far as treatment?

CK: No. I remember them doing quick cut-downs where they couldn't get a vein so they'd cut across it—off—cut across your vein and then they could put a needle in it, because otherwise they couldn't find my veins. I had such tiny veins; they had a problem with them all the time. Then I have scars on my legs where they had to cut them open to do the same thing. And I've still got the scars.

LG: Did that hurt?

CK: At the time it didn't. I don't remember. I was a little kid; I was young. I don't even remember the age.

LG: Tell me about pain. Did you have much pain?

CK: Oh, yeah. I had pain that, oh, I'd moan and cry all night with a shoulder or a—or a big knee, or an ankle that would swell up. You'd

put it down, like you'd get comfortable by putting it on the floor or something as you're sitting. Instead of putting in the bed, you'd be sitting on the edge of the bed and the foot would swell up because of circulation. Oh, then it would be sore and it would take days to go away.

LG: How did you handle the pain?

CK: Well, once in awhile my mother would call the doctor and we'd get some codeine and that would help. It would knock you right out though. It was real strong. And that was, like, a very hard drug to deal with. And you wouldn't get it very often, or wouldn't use it that often either, because only if you really were in enough pain that would make you practically cry. It was hard when we were in pain like that. I used to watch my brothers. A couple of my brothers used to get shoulders that were really sore. And they—they had the same trouble with their shoulders, really moaning and groaning and suffering, holding—holding their hand, holding the sore shoulder—the hand of the sore shoulder with their other arm because if you let it hang it'll hurt the shoulder. So you sort of do this. You've got to put a sling; you can't got the sling long enough or short enough to be in the right position to be comfortable. So you end up holding it with your hand so that it'll relieve some of the pain. But it was hard.

LG: It was hard.

CK: Yeah. When you were in pain and injured it was hard. But you didn't dwell on that. You tried to dwell on the better stuff, the good things, the things that you liked to do. We used to eat. We used to like eating. My father and mother would both cook food and we'd have, you know, all homemade food and it was real good. We'd have

potato pancakes, French fries, American chop suey. Everything, just you name it. Polish food, golonkies and all that stuff—perogies and stuff. It was good.

LG: Do you remember your parents' reaction when you guys were in pain? What would they do?

CK: They would, like—you could see it in their—in their eyes and in their face that they were distressed. But they wouldn't let on that—you know, they said, "Well, what can I get you?" Or, "What do you want? Do you want some orange juice?" Want this? Want that? Anything to try to help you. "Want a wet face cloth? Want an ice pack?" You know, they tried to do anything they could for you. But it was in their face that they—they were suffering too.

LG: Mm-hmm. But they didn't talk about it.

CK: No.

LG: They just were active in trying to figure out how to help.

CK: Right. They didn't let on like it was bothering them.

LG: Are you glad for that or do you wish they had?

CK: No, I think they handled it the way it had to be handled, I guess. I think if they would have—if they—if they were, you know, saying more, then maybe we would feel it worse. It wouldn't make us feel any better. Put it that way. It was probably better that they didn't do it that way.

LG: Do you think you have a different relationship with pain than people who didn't grow up with hemophilia?

CK: Yeah.

LG: What is it, do you think? What is your relationship with pain?

CK: That I can take more pain than anybody that I know of.

LG: Really?

CK: Yeah.

LG: So you think your tolerance is enormous.

CK: Very, yeah. I can take a lot of pain before I—before it makes me cry or makes me sad enough to break. But I know I’ve dealt with it many times without—no pills, no Tylenols, no nothing for years and got through lots of bleeds, and lameness, and injuries and, you know, took nothing for pain. And I still don’t take much for pain.

LG: How come?

CK: Just—I just don’t want it. I—if I think I really need it, I would take it. But it has to be excruciating before I would take any.

LG: Because...

CK: Well, because I think that when—everyday you’re walking and your knee is a little sore. And this elbow has never been right and the shoulder still hurts—that you’ve been living with this pain anyways everyday—some pain. So you’re already tolerant of pain, like you can—you can handle pain more, because now this new pain isn’t much more than you’ve already been dealing with everyday. That’s the way I feel, that, you know, like they said, “I’m stiff. I’m stiff.” Everyday I get up and I say, “I’m stiff. I’m stiff.” And I start walking; I loosen up. Okay, my legs are still the same sore legs and everything but I’m moving. I’m getting them going and I’m doing better.

LG: Did the pain ever scare you?

CK: No.

LG: Never did?

CK: No.

LG: You were just, “This is it. Okay.”

CK: Yeah, just—yeah, it would—it would make you hurt. It would make you sad and stuff. You’d wish you would get better. I mean, I cried. I had times when I was sore enough with joints that I did cry when I was a kid. But eventually I avoided all that. I don’t know. Just—I can have the pain now and it wouldn’t—the same amount of pain won’t do that to me anymore. But it’d still be tough to deal with.

LG: So anyway, you were telling me about the treatment. What do you remember about it? So you remember sort of getting these cuts in your vein and—

CK: Yeah.

LG: —treated with blood or plasma.

CK: Right.

LG: And being in the hospital forever.

CK: Right.

LG: Then what do you remember?

CK: Then all I remember is I start—we start going to—me and my brother decided—we were told to go to Children’s Hospital around 1969. And they said they had factor. There was a Dr. Kevvie there, Sherwin Kevvie. And we met him and he said, “Yeah.” He says, “We can help you. You’ve got to—you’ve got to give us a chance and everything.” And we said, “What about the coverage?” We weren’t sure we would be covered because it was an expensive product and all this. And he says, “Don’t worry about it.” Somehow, we were covered. And they started giving us the factor and we would come into the Children’s Hospital once a week or more if we had a bleed and get a factor IX infusion and then go home. And then—

LG: You mean you'd come in once a week whether you needed it or not?

CK: Right.

LG: You'd just come in once a week.

CK: Right.

LG: So this was in '69.

CK: Right, [unclear].

LG: And you were born in '54?

CK: '49.

LG: '49. So you were 20 years old by this time.

CK: Yes, right. Then—and then we started getting it at the Cardinal. They sent it—they gave it to us to bring to the Cardinal and we started going to the Cardinal for infusions.

LG: Is that a local hospital?

CK: Yeah, the—it's—it's the Good Samaritan now but it was the Cardinal Cushing in those days. And then finally the next step was to have home treatment, to take it home and, you know, infuse ourselves. We were taught at the Children's how to do it and stuff. And we did well that way.

LG: Was it a big difference to be getting factor?

CK: Yes.

LG: Tell me what it was like.

CK: Well, we didn't get as lame as often. And we could—if we could get to a start of a bleed before it went into a full bleed we could stop it. And that was—you know, and it would—I'd go, oh, months at a time without a bleed or anything with the factor. Months.

LG: What was that like for you?

CK: A lot better. Very much better.

LG: Could you believe it?

CK: No. No, and I was able to move a lot easier, do a lot more things with a lot more, you know, ease.

LG: Yeah. So this didn't really come to you 'til your 20s.

CK: Right.

LG: You know, and for your younger brothers when they were in their teens.

CK: Right.

LG: And what about your older brothers?

CK: Well, they never had it. They never—well, my oldest brother, Godfrey, did get it, yeah. And Franny—Franny was the next one who had hemophilia. He got it also.

LG: What about the other ones?

CK: Which ones?

LG: Well, there was seven of you, right?

CK: Yeah, but Georgie and Bobby had passed away.

LG: How did Georgie and Bobby pass away?

CK: Georgie had hit his head. He was, like, four years old. This was before I was born and he banged his head and he got a big bruise on his head. And they said they touched it and it was—blood came out and they took him to the hospital and it was too late. And then my brother, Bobby was like 20—23 years old. This was in 1962 and he was driving a tractor or something. I don't know. Somehow, one of his kidneys started bleeding. He went to the hospital and the same thing. They couldn't stop the bleeding internally and he had died.

LG: So what was that like for you as a kid to have two of your brothers die from hemophilia?

CK: Well, my youngest brother—I mean, the young—Georgie—I wasn't around.

LG: So they didn't talk about—your parents didn't talk about Georgie.

CK: No. Well, they talked—him and they were sad every time they told me, you know, how—how it happened and everything. They had, I don't know, said he banged his head on a solid door or something. And they put ice on it and stuff, and then they said a day or so later it was bleeding and took him to the hospital and that was it. But my brother, Bobby, you know, used to work around the farm, do everything. I missed him when that happened. I was sad. Yeah, I was—I never—that was the first time I actually saw a death in the family, a death of anybody actually close enough to even know what even death meant. I didn't even know. I was like—

LG: How old were you when he—

CK: Thirteen.

LG: Thirteen.

CK: I was about 13.

LG: Did it make you afraid for yourself?

CK: Yeah, then I started thinking—then I started thinking that, you know, 'How much time have I got left? What would happen to me if something like that happened?' I always had that in my head that, you know, 'Will I live to be 20 or 30 or 40?' I kept saying, "I hope I live to this age." And then when I reached that age I'd say, "I hope I live to this age," and like that. I did. I was concerned because, I don't know, that—that death, you know, put a thought in my head that, you know—that I'm in a dangerous position [unclear].

LG: So you realized that this could be—

CK: Yeah.

LG: That this could kill you, really.

CK: Yeah. But I didn't know that until—like I say, until after he had died.

LG: Right.

CK: And I realized what death was.

LG: Did that change your behavior at all as a kid?

CK: Not really.

LG: Did it make you more frightened or more cautious or—

CK: No, but it—but it made may always have that in my head that I—that I hope—you know, that I lived more. And I'd say, "Well, I hope I make it to the 20s." Then I'd say, "Well"—then I'd say—when I got to my 20s I'd say, "I hope I make it 'til I'm 35." Then I'd say, "I made it to 35. Gee, I'm still going." [chuckles] "I hope I keep making it."

LG: Are all your other brothers still alive?

CK: Yeah, well—yeah.

LG: They are?

CK: Well, J.J. and Kevin and my brother, Richie, who doesn't have it—he's alive, and my two sisters. But Franny had—Franny died and Junior—Godfrey died—'90 and '91.

LG: Okay. What about work, Chris? Were you able to work in your life—

CK: Yes.

LG: —with all these bleeds? I know you worked on the farm as a kid.

CK: Right.

LG: But when you became a young adult, what happened?

CK: Yeah. In 19—I think it was 1971 or so. I turned about 21, I think, and I went to work for a bakery. And I—I made dough. I was a dough maker. I loaded flour into a mixer all night long and worked. I did that—

LG: That must have been heavy, physical work though.

CK: It was very heavy. I was unloading pallets, hundred-pound bags of flour all night, like, 80 bags. And I was in good shape though in those days. And I was young and strong and it wasn't too bad.

LG: Uh-huh, and there was factor at that point.

CK: Right, yeah. And then I went from there to another bakery to deliver bread. And I delivered bread for two years, drove all over Quincy and Boston and everywhere. All the surrounding towns—delivered Italian bread for two years so I stayed pretty busy.

LG: Were you ever worried about telling people that you had hemophilia and how they'd react to you or treat you?

CK: I never told them it because most people wouldn't understand it. I would just tell them—you know, they'd say, "How come you limp? What's the matter with your leg?" I'd say I hurt it this way or I hurt it that way, or something. I never really told them. When I went to the—work at the bakeries I did tell them I had hemophilia and that I could get bleeds and stuff so they would know. But I never told most people.

LG: If you did disclose it, do you remember ever having any particular reaction to it? Either by kids or—

CK: Yeah, when we were kids they would tease us and stuff, you know. Say, "Oh, bleeder. You're a bleeder," or something like that they'd say to us. You know, because they would say, "You're a bleeder;

you're a hemophilia. Oh, that's a bleeder." And they would say, "Oh, Bleeder, Bleeder." Stuff like that to you and, you know, it wasn't—wasn't nice. We didn't like it. I didn't like it. They did it to me. So we didn't never tell anybody that I was a hemophiliac. Most people I didn't tell. They'd say, "How come you're limping?" And I'd tell them something else.

LG: Did it affect your dating or your love life to have all these bleeds or issues?

CK: Yes, it slowed me down. I couldn't get around as quick as I would like to and stuff. And, I don't know, I was just slow. Shy—I was very shy too. So it took time.

LG: Did you date much or—

CK: No, not too much.

LG: So what happened? How did you meet your wife?

CK: Well, I went into Children's Hospital and I had my teeth done because I had bad teeth. And I had most of them removed and I met Janet.

LG: At Children's?

CK: Yeah, and she was a nurse's aid there and that's how we met. We've been together for 33 years.

LG: Oh, my goodness! So you didn't have to tell her you had hemophilia; she knew.

CK: No, she knew. But she understood. And I went over it with her even before we were married and told her, "You're sure you want to go through life with me? Because the problem is I can't take you out dancing. I can't do this. I can't do that." I says, "I'm going to tell you right up front. Don't expect too much of me. There's a good

chance, you know, that I'll have problems further down the road too."

But she—she didn't mind. She didn't care. She understood. So—

LG: So you were very honest with her about—

CK: Right.

LG: —your own concerns—

CK: Right.

LG: —about what it might be like to marry you.

CK: Right.

LG: Uh-huh.

CK: Yeah, I couldn't get rid of her.

LG: [chuckles] So how old were you when you got married?

CK: Twenty-one.

LG: Twenty-one?

CK: Right.

LG: Wow! Was she the first person you really dated?

CK: Yes.

LG: She was?

CK: Right.

LG: Okay. Did you worry about children?

CK: No, we didn't. The doctor said—said that the female would be the carrier and there's a good chance, you know, your kids will be fine.

But the girls could be carriers again.

LG: Mm-hmm. So how many kids did you end up having?

CK: Five.

LG: You have five kids.

CK: Yeah.

LG: And how—what—boys? Girls?

CK: Two boys, three girls.

LG: Two boys, three girls.

CK: Yeah.

LG: Okay. And did they know about hemophilia?

CK: Well, not at first but now they do. Yeah.

LG: They do now. How old are they now?

CK: Well, they're from 33 down to 20, 21.

LG: And do any of them have kids with hemophilia?

CK: No.

LG: None of them do?

CK: Well, there's only two children so far. Two grandchildren and the two girls but not as—they're not—they don't have hemophilia.

LG: Were they tested?

CK: Not yet. But they seem to be healthy.

LG: Were—were they worried about it? Did they talk about it with you?

CK: No, not really. They're not—they understand it but they're not, like, worried about it.

LG: Do you have concerns about having a grandchild with hemophilia?

CK: Well, no. I'm [unclear]—we're into the age where we keep going forward and forward and forward that what—when I was born they didn't have much. Now, here it is quite a few years later. They get a lot more now than they ever had and there's all kinds of options. And they say they can even do it before a kid is born to find out if they do have hemophilia.

LG: Right, sure.

CK: So they've got all those options that can be considered.

LG: So you don't think it should be something to prevent someone from going ahead and having kids, even if that child might have hemophilia?

CK: Right.

LG: How come?

CK: Because a life is still a life. A family wants to have children and it makes your life when you have kids—children. They're a good part of your life. Without them, my life would be real dull. No, really. As you get older, you know, you like to have [chuckles] somebody around. And they're good kids and, you know, good family.

LG: But given what you've been through with hemophilia, did you ever worry, "Oh, I don't want anybody to have this disease."

CK: Oh, I don't want—I would not like to see anybody ever have this disease. But like I said, there's a good chance that if someone had a child now, they'd have a better chance at having a much better life than I did. With the treatment and things they've got. And maybe, who knows, in a few years it could even be even better. So that's why it's a—no, I wouldn't advise them to have one if they knew. But at the same time, they'd have to make that decision and work it out. I wouldn't be a hundred percent against it. I'd just say that you'd have to go the way you think. But they would have a better chance at having a better life than I did.

LG: Mm-hmm. Did you experience that a little bit yourself with the factor? I mean, did you—

CK: Oh, yeah.

LG: You did?

CK: If I had factor probably when I was born—you know, when I was young, I wouldn't have went through half the things I went through. I'd been treated quicker and healed up quicker and had a much easier life.

LG: Yeah, yeah.

CK: In fact, it would have made a big difference early in my years.

LG: Let's talk about the '80s.

CK: Yeah.

LG: When that all came around.

CK: Right.

LG: You know, and the HIV and then ultimately the hep C. What do you remember about that whole period?

CK: Nothing much. That they said there was a big problem coming up.

LG: Who said?

CK: The doctors and the Hemophilia Association said, "Oh, we're starting to—we're starting to hear these people are getting sick." And we didn't understand what it was. Then they said, "There's something wrong with the factor." And we called the Hemophilia Association and I don't know what doctors I talked to. And they said the same thing. They said, "If you came in with a bleed or an injury we would give you the—"

[end of side 1, tape 1]

LG: They were saying, "If you get a bleed we're going to give you factor."

CK: Right, they would say—well, they still would give you the factor, knowing the chances of something that they weren't even sure what it

was, what illness it was or—they didn't even have a name for the HIV yet. They didn't really—I don't think they called it HIV at first. They didn't have a name for it. And there was a lot of—I guess it started out with the gay people getting it and getting real sick and dying. And then they realized that some of the blood had come from some of the people that were gay and had this disease. But they didn't know all this. They didn't know very much about it. But they said to keep taking the factor. They said if you came in we would give you the factor and not worry about the risk of getting this disease, because they didn't even know what the disease was or if they could treat it or not. But they weren't concerned with it.

LG: Who's they?

CK: Well, it was—

LG: Were you at Children's at that point? You were about 30 by this time.

CK: No, I was over at the Brigham.

LG: You were at the Brigham by this time.

CK: Yes. But it was—it was the New England Hemophilia Association that I used to get a newsletter from. And I had called them and I had called a couple of doctors that were listed on there too. And they said the same thing. They says, "We don't know a lot about everything but we would say keep taking the factor. Don't stop taking it," because the risk was, I don't know, minimal.

LG: So then what happened?

CK: Well, then, I don't know. Around '80—I guess it was—they said '86 but it was like—I said '86. It was '83, they said, and that I got up with night sweats and stuff. And I was—I went into the—Brigham and they took the test and said I was HIV positive around the fall of

'86. And then I—and then around 1990 started on AZT and other things. And then a few years later it changed and I was taking all the cocktail—a few—a few years ago. And now I'm not on any of it. My numbers went down; they took me off it. So I'm not on any of the viral meds right now.

LG: You're not on any of them?

CK: No, not one on them.

LG: Yeah, yeah. And what about the hep C? When did that come in?

CK: Well, see, I don't even know. They said I had it. Then they said my body had cleared it. So I don't even know but they say I was exposed to it and it's still in me a little bit. But I don't know much about it and I don't know when I got it or, you know—really not sure.

LG: How did you handle it when you heard that you had these infections? What did you think?

CK: Well, I started saying a lot more prayers as soon as I found out I was HIV positive. And I figured I only had a few years to live based on all the stories going on and how people were dying. And I just kept saying prayers. Then, like I said, I had started taking AZT around 1990. And they kept checking my numbers and they kept staying in decent shape. And so I started believing, you know, things are doing better. And that was it. And like I said, been saying lots more prayers since then than I ever did before.

LG: Prayers for what? What would you pray for?

CK: Prayers to live, prayers to be healthy, prayers to stay with my family.

LG: Mm-hmm. Did your kids know about all this?

CK: I didn't tell them right away.

LG: You didn't?

CK: No, slowly they learned. I didn't want to scare them. We were afraid to tell people I had it because at first everybody seemed to be prejudiced against anybody with HIV. If you told them they would, like, blackball you, you know what I mean. They'd talk about—I had my neighbors I never even told when I lived in West Bridgewater, because, same thing. They—I would hear them talking and saying, “All these people with HIV” this and that. And they weren't—they weren't nice about it. And I says, “The minute they found out I had it they'd have nothing to do with me,” because that's what I figured. So I never told them. That's why I never bragged—you know, not bragged but spread the news about it to anybody.

LG: Did you ever want to meet other people with hemophilia and HIV?

CK: I don't know. I just—I'm not—I'm not—like, I'm not a—one of those pushy persons or a person that looks around for friends all the time. I'm just, like, shy. I like being by myself. I like my lifestyle. I don't—I don't interact with a lot of people, just a few people I know here and there. I meet; we talk. We do this and that. But not many.

LG: Did you ever feel it would be helpful or something you'd want, to meet another person with hemophilia? Not that you didn't have enough in your own family.

CK: [chuckles] I got my own family with it.

LG: [laughs] Right.

CK: So, yeah.

LG: Right.

CK: Well, I knew a kid lived down the street that had hemophilia, the A, the factor VIII. And, well, he's passed away since then but I mean, we knew his father and stuff. And we used to go over to his house

and play cards and stuff. And they knew we had hemophilia and he knew it, and he had it and so it was no big deal. But that was about the only friend I knew that had it.

LG: Are you close to your brothers today?

CK: Yeah.

LG: You are?

CK: Yeah.

LG: Is it something you guys ever sat around and talked about or—

CK: Not really. We complained about it. We might have—well, we all—we said one time, “Yeah, we’re all probably going to die from this.” You know, just mad and just talking in general, one time we said that to each other. “Yeah, we’ve all got it. We’re all going to die from it so what’s the difference? And keep going.” You know, that’s about all we said about it.

LG: Do you think it made you closer because you all had hemophilia or not?

CK: Not really. I think we’re just close because the family.

LG: Yeah.

CK: We did stuff together. We didn’t have outside friends as much as other kids so we were our own friends.

LG: So it sounds like as much as you had to deal with it physically, with pain or laid up or the hospital, it didn’t spend a lot of time being part of your—

CK: No.

LG: —psychological self.

CK: No, it didn’t block off things. The whole world went around and I was involved in anything else that I felt like. I’d read books. I’d

build things. I played with the garden—always had a garden in my yard and stuff. Did the things I wanted to do whenever I could. And that wasn't a top priority. My health was up to a point but I didn't dwell on it. And, like, my kids all know that, yeah, I can't walk too far. I can't do this. But I never could do a hundred percent of everything that other people do, but we still always went to places. I always took the kids to the parks, to Riverside and Rocky Point Park in Rhode Island and stuff every summer. And I'd walk as far as I could, sometimes walk with a cane. And I always went there. We went—we ate and we did stuff and they—you know, and all the rides and different things. And we did that every summer for quite a few years when they were young.

LG: This might sound like an odd question, but do you think having hemophilia or going through all these physical challenges—do you think there's anything positive about it?

CK: It's a—it's hard to say. Positive—

LG: I don't know. Just anything good come out of it?

CK: I can't say that anything good came [chuckles] out of it. But I don't know.

LG: Did it make you stronger, more—do you feel like you were more sensitive—in that way?

CK: Yeah, it made me—

LG: It certainly didn't make you any healthier.

CK: No, but it made me stronger in the fact of how to face things and how to do things, that it sort of taught you that you're going to have to overcome this and that. And don't be afraid to do these things because, you know, this is like a setback. Don't let it set you back.

LG: So in that way you think—

CK: It encourages you to be stronger, yeah.

LG: A certain strength of character that you might not have had—

CK: Right, right.

LG: —without these challenges.

CK: Sure.

LG: They've made you—

CK: No.

LG: —in some ways more strong.

CK: Yeah, yeah. I think so because I feel—you know, I don't feel like I was cheated or anything. Yeah, I wished I was born healthy. But in the same time, my life—I've gotten through this much of it and I've did fair. I won't say good but I'll say fair.

LG: Why do you say fair and not good?

CK: Well, good, I'd be happy a hundred percent. [chuckles] I'm not happy a hundred percent. I'm, you know—some—I have good days and bad days.

LG: And the happiness, the hundred percent—what is that due to, do you think?

CK: I don't know. Just make you happy, I guess. I just think it would make you feel better. I mean, I've done lots of stuff so what can I say?

LG: Could you work most of your adult life?

CK: I tried to but I couldn't.

LG: What happened?

CK: My hip went. My left hip went and I was really having trouble with it for years. I just got it replaced just a couple years ago. But I was

having so much trouble with that. That kept me off doing a lot of work. I wouldn't get around so good and I'd—getting in and out of the vehicle would be a hassle, getting in, getting out, and walking distances and things like that.

LG: So you were really disabled.

CK: Yes.

LG: So what did you do with yourself? How did you fill your time?

CK: Well, I read books and stuff. And I had greenhouses. I raised plants. And I got the kids and my wife and stuff and we took them to the flea markets and we had, like, two or three trucks. And we sold plants for a few years, raised our own flowers, herbs, plants. Did all that kind of stuff and I enjoyed it. No money profit-wise in it. It was like you'd make a little bit but wasn't worth doing, but kept us busy and stuff. And I thought we could make money doing it but it didn't happen. But it was seven days a week. It was a lot of work. But it was a lot of fun. I enjoyed the plants. I enjoy growing things, and flowers that bloom beautiful and stuff. I learned all that. I read books and studied, and figured out how to make things work and it worked.

LG: Do you think it's affected your value of life in some ways? You know, of appreciating what you have?

CK: Oh, yeah.

LG: You do? In what way?

CK: Well, you know that everything you got and you earned it, you feel good about it. And you know that you didn't start with a silver spoon in your mouth, like some people. So you know that you've done all the things that—that they've done but you've done it the hard way. Or you know what I mean. Nobody just handed it to you so you

appreciate it much better. And it's just like the kids. I tell them, "Work for it. Work hard. You'll get there some day. Whether they do or not, you've still got to try.

LG: Are your kids nearby?

CK: Yeah.

LG: Do you think it's affected how you are as a parent, having had all these physical challenges in life?

CK: Yeah.

LG: In what way?

CK: Well, I think it made me learn that—to appreciate the kids and stuff, to appreciate they're healthy and that they—you know, try to help them by realizing I didn't have the same physical abilities they have. That's the only thing.

LG: And so how did that affect you as a parent?

CK: Well, it didn't really. It just makes me feel better—just makes me feel better that they're all healthy and strong and I—I did something whenever I can to help them. And I can even help them even though I'm not healthy all the time. Yeah.

LG: And what about in your marriage? Do you think having these physical challenges has affected your marriage?

CK: Not—not to me. My wife doesn't seem to mind. She's been real good. She's been real good; every time I'm sick or every time there's a problem she's been right there. And I tell her, you know, "Go home. Don't spend the night," when I was at the hospital and at the rehab center. She was there every night sleeping every night there. And I told her many nights to go home because, "You don't have to come. You don't have to visit me. Take a couple days off." She

wouldn't do it. She wouldn't do it. You know what I mean? She's really been good.

LG: If you had a grandchild with hemophilia—if one of your daughters said, “Dad, he's got hemophilia,” how do you think you'd feel? Or do you think you'd have any thoughts for your daughter?

CK: I'd just say, “Take him into the Boston hospitals and have him checked out and follow what they tell you for advice to keep him healthy and strong.” That's what I'd tell them. I'd tell them what I did but I'd also tell them, “Go with the modern ways because that's your best options.”

LG: Mm-hmm. Would you have any advice for how they should bring up their kids, given that the kids have hemophilia?

CK: That I don't know because I—I don't—I don't really know.

LG: I mean, anything that your parents did for you that you felt was helpful, or wasn't helpful, let's say.

CK: Well, they didn't let me deliberately get hurt on things that I probably would have. Put it that way, things like that. Physical things that—“Don't climb ladders and things you shouldn't be climbing because if you fall you're going to really be in trouble,” and other things like that. You know, anything that would be dangerous to hemophilia. That's about the only thing, the physical stuff, I think.

LG: So you think that parents really should watch out for their kids in that way.

CK: Right.

LG: You know, because the other side of a parents' worries, “I don't want to make my child afraid of himself.”

CK: No, but they say that hemophiliacs have what they call the “daredevil syndrome” in them. That means they try to do everything because they’re told not to do it—

LG: Right.

CK: —and because other kids do it. And that’s always going to be a challenge. So you’re going to have to watch any little kid that has hemophilia, because he’s probably going to do the same thing we all tried to do, take risk. But sometimes when you’re young you don’t know what a risk is and what a risk isn’t. Everybody else is doing it. Climb up the ladder. Go up there. Go do this. Jump off that thing. Then you hurt your leg and you don’t know why you hurt your leg and all the other kids didn’t. But that’s—that’s part of the hemophilia and understanding it.

LG: But as you were a kid, whether you hurt your leg or not, you were up doing that stuff the next minute anyway.

CK: Right, right. First change you’d get you’d try to do it again. I don’t know why. It just was in you to do it.

LG: Mm-hmm, mm-hmm. Chris, is there anything that I haven’t asked you that would—you think would be useful to just get down on this tape?

CK: No, I don’t really know offhand. I mean, my—it’s hard to take everything in at once and to remember everything.

LG: You’ve had a lot of health struggles lately in the last few years.

CK: Right.

LG: I mean, my goodness! You were in the hospital rehab for how long recently?

CK: Right, eight months.

LG: Eight months. And that was mostly with your liver disease.

CK: Yeah.

LG: Is that the main problem now?

CK: Well it started out as a heart infection and they said then I had a liver disease, and then I don't know what else—two or three different things. I was—had some internal bleeding. The esophagus was slowly—they said it was destroyed. Then there was something else—I was bleeding internally—they couldn't find. So I don't really know. There have been a lot of things, yeah.

LG: But you're sitting here in your house today.

CK: Right.

LG: Do you have any thoughts for doctors and nurses or social workers, just about what's helpful for someone, or not, in dealing with so many health challenges?

CK: Well, I think it's good that people get involved and talk to the patients, the people that are sick, and try to help them. You know, what I mean, just as they do though. But to talk to them and I think it's helpful.

LG: To talk.

CK: Sure.

LG: Not just to say, "How's your liver?" or "How's this?"

CK: Right.

LG: But more, "How are" —

CK: Right, in general find out about their life and a little deeper than just the surface.

LG: Yeah.

CK: I think that helps people understand, feel better about themselves.

LG: How have health practitioners been with you? Has it been—

CK: They've been very good.

LG: Very good?

CK: Yeah.

LG: Did that change your relationships with doctors and nurses when you discovered you had HIV and Hep-C?

CK: No, I had thought—I had thought they were going to be afraid to touch me or to, you know, shake hands with me or anything. And they didn't. They shook hands and they intermingled just like anybody would, any doctor would. But I had thought they would be, you know, put rubber gloves on and put their hands out and say, "Yeah, you stand over there while I talk to you, because I was afraid because of all the stuff they had said that everything was so contagious and everything was so deadly that they didn't—at first, the health care workers didn't know what to do and, wear gloves. And then they were worried about the needles and things and everything else. And I was afraid the doctors and other people would, you know, shun me somewhat.

LG: But it sounds like that wasn't your experience.

CK: No. No, I thought they would, you know, hold it against you, saying, "Oh, this guy's probably gay," or, "This guy probably got it because of this or that." And I thought, you know—I thought, you know, maybe they would think that. You know what I mean and, like, stay away from me or, like—but no, they weren't like that. The people were nice. They always were. They were always friendly and real professionals.

LG: Did those infections change your attitude politically to the government, to the pharmaceutical companies, to your doctors?

CK: No. No, I was disappointed that, like everybody was—to hear that they—they knew the factor was bad and, yet, they kept pushing it and selling it and letting people use it. And that should have stopped way back at the beginning. And the government didn't do its part either but I didn't hold that against them either. I said, "This is the way of the world because big business always thinks of themselves." People—they sell these cars and people get killed in them. And they'd rather hire their lawyers to fight the suit than to stop making the cars, because they're making so much money. And that's the way it is.

LG: So you're not someone who's blamed the world or blamed—

CK: No.

LG: —the government or—

CK: No.

LG: That hasn't been your experience?

CK: No, I don't think you can blame them. You—you break the government down; they're only people. They can only do what they can only do. And, yeah, there's a few that don't do their job right. You can't blame them all for the one or two guys that didn't do right or people that didn't do something. The big companies are more to blame than the government, I would think, you know. Where they—where they had to start and they knew what they were doing and then—

LG: Did it change your attitude toward medicine at all?

CK: No.

LG: No?

CK: No, I still—I still take whatever medicines I need and I don't—I don't worry about the side effects. I—we always think about it, saying, “Well, what about this? What if—what if another thing?” Like now, they have the mad cow disease, you know. And if that gets in the blood, that could be a problem. If—you know, if ever. But who knows? Right now, chances look very minimal—if any. But there's always something that could loom up. Whatever—whatever you think won't happen, there's always a chance it could happen.

LG: Chris, did you ever pray that you didn't have hemophilia or wish you didn't have hemophilia?

CK: Oh, yeah. Sure.

LG: You did?

CK: Yeah.

LG: What do you remember about that?

CK: Well, I always prayed that I'd be cured of it or that I wouldn't have it. I don't know, just, you know, always wanted to be healthy. But then after awhile, you know, you just have to deal with—live with it, you know. But—because everybody must have prayed that they, you know, wouldn't have it or didn't be born with it.

LG: But then at some point you stopped praying for that because—

CK: Yeah, because you know that you're stuck with it most likely and you're going to have to realize to deal with it instead of hoping for something that might not be possible.

LG: Uh-huh. I don't think I have any more questions.

CK: No more questions? Oh, gee.

LG: [laughs] Because I think we really covered most everything that I hoped to cover.

CK: Right.

LG: And my biggest question is, is there anything that you think I should have asked, or that you wanted to speak to in this?

CK: Not really. I think in general my life is similar to a lot of hemophiliacs in my time zone—you know, my age and everything that had to deal with very similar things. I mean, I can't speak for them because I don't know, but I can imagine by what I've done what other people would have to go through.

LG: Well, I want to thank you, Chris—

CK: Right.

LG: —for sharing your story with other people.

CK: Right. It isn't a curse; it's a—it's something we have to deal with like anybody else.

LG: It isn't a curse.

CK: No.

LG: And as much as you might pray that you wish you didn't have it you don't feel it's a curse.

CK: No.

LG: What is it?

CK: It's—it's like just a draw. Like you say, 10,000 people are born. One has this; one has that and one has this. Just there are going to be so many people in the world and that's what makes the world go round—different people. Why we're born white, why we're born black, why we're born blind, why we're born, you know, with different infirmities and illnesses. It's just that, I guess, the percentages and you happen to be one of the ones in that percent group that was unlucky or whatever.

LG: It's just part of life.

CK: Part of life, yeah. Yeah. I mean, I'm sure we'd all wish we could take back to the beginning of our life and set it the way we would want it. But that's not been done.

LG: Not yet, anyway. [chuckles]

CK: No. So I think we've just got to deal with the way it is. Some people, you know, deal with it better than others. That's the only difference.

LG: So if you had a mom come to you and say, "Oh, my God! I just found out my son has hemophilia," what would you say to her?

CK: I'd just say—

LG: Or a dad.

CK: Right. I'd just say, you know, the same thing I said before that, just it's still your child and it's still going to make your life happy. And just deal with the times when the illnesses come up and, you know, do the best you can. Seek professional help whenever you can to make it easier. Yeah. [tape turned off/on]

LG: Chris, I was saying that you only had two brothers who died. And you were saying, no, four.

CK: Yes.

LG: So I knew about Georgie and Bobby, who had the kidney problem on—

CK: Yes.

LG: —the tractor. What about—what happened with the other two?

CK: Junior, my oldest brother—he died of internal bleeding; I think it was 1990. And Francis died a week later in '91 or it was vice versa; I'm not sure of the dates. And he had meningitis and he had passed away.

But they had bleeding involved with the hemophilia and that's when they died. They were—

LG: How old were they?

CK: Franny was, like, 44 and Junior was, like, 55.

LG: They weren't using the factor at that point in their lives?

CK: They were, yes.

LG: They were.

CK: Yes. They—my oldest brother was very weak. He only had one kidney and stuff. So, you know, through his life he was always on crutches and stuff, and he had a hard life. And my other brother, Francis, well, he used to, like, drink a little bit and stuff. And I don't know, he was—he was kind of reckless. He had a wife and a couple of kids and stuff. And we used to say to him, "Take it easy." Don't do this; don't do that. But he worked hard and he raised animals and stuff. And he got sick one day and they told him it was sciatica or something in his back, and he kept having trouble with it and stuff. And then finally they said it was meningitis. And then by the time they diagnosed that it was just too late; he just couldn't pull through. So, I don't know.

LG: It's so unclear if that was actually hemophilia related.

CK: Yeah, I don't know for sure.

LG: Yeah, yeah. Okay. So the real losses that you remember from the hemophilia—

CK: Right.

LG: —are the two—

CK: Right.

LG: —that when you were young, yeah.

CK: Right.

LG: Okay. I just wanted to get that. Thanks.

CK: Yeah, you're welcome. [tape turned off/on]

LG: One more thing to ask Chris.

CK: Yeah.

LG: And that is, Chris, what about death? God, I'm—I've asked you—four of your brothers have died, as young men or babies or teen—
young boys. Has this affected your view of death? And you've dealt
with life-threatening situations. What do you think about death?

CK: Well, what I think about death is it'll come to you eventually.

LG: Comes to all of us, I hear.

CK: Right.

LG: Yeah.

CK: But I'm not worried about it. I'm not afraid. The worst thing I'm
afraid of is, like I had said before—is that my family to miss me or me
to miss them. That's the only thing that kept me going when I was
facing death awhile ago. That's when all I kept saying is, "I don't
want to go anyplace. I want to be with my family and I know they
want to be with me. And that's what I don't want to leave.

LG: But you said death doesn't frighten you. What do you mean by that?

CK: I mean I don't think it's anything more than going to sleep and
napping out, just like, you know, you won't know. When that final
time comes you'll just close your eyes and be tired and go to sleep,
something similar to that. I don't know what you'll see after or
what'll exist after, you know, in your body and your mind and your
soul. But I believe in God and everything so, hopefully, there'll be a
heaven for us.

End of Interview