Interview with Shirley Wilson

Interviewed by Fraser Nelson

Interviewed on March 21, 1995, at the Hemophilia Foundation of Minnesota/Dakotas, St. Paul

FN: Shirley, these interviews are about where we're at as an AIDS movement. They're not a typical history, in that I don't ask you what happened when, but it's more to kind of get a feel for where we're at as a community. But I want to start by giving people a sense of who you are, so can you tell me where you were born and how long you've lived in Minnesota?

SW: I was born in St. Paul, Minnesota, in 1953. I've lived in Minnesota almost my entire life. In the spring of 1983, we moved to Wisconsin and lived there for five years. That's when we found out that Andy was [HIV] infected--in fact, it was in 1983--I know that there's some question because there wasn't the ELISA, the Western blot test,¹ in 1983, but the Centers for Disease Control was investigating the incidence of men in the hemophilia community dying of AIDS-related diseases. They had a recall of a lot of Factor VIII, which is the blood components that Andy transfuses, and they had a recall of this lot, so they were investigating all the members of the community that received this blood product. So a woman from the CDC came and drew his blood, they tested it and they said--in fact, I think back then they called it HTLV²--that he had this whatever it was that causes AIDS and that he would die in two years.

FN: And how long ago was that?

SW: That was in 1983. This is 1995 and he's doing well. He's doing very well.

FN: Shirley, how do you think people describe you?

¹The two tests first developed to detect HIV infection.

²HTLV was Human T-Cell Leukemia Virus. Before 1985, when HIV was identified, the virus was referred to as HTLV.
SW: I think people would describe me as assertive, genuine, compassionate, and committed.

FN: Very true. So you first became aware of AIDS when Andy and you were visited by this person from the CDC?

SW: Yes.

FN: What did it mean to you then?

SW: What it meant to me was I was very scared, because what we had been hearing is what was on TV, that there was this disease that was affecting gay men, that they were going into the hospital in Minneapolis and they had a red rash on their body and they were dying, and we were very scared. We didn't know what this meant. In fact, at some point later, and I think it was probably a year or so later, they told Andy at the University of Minnesota they didn't know if being positive was a good thing or if it was a bad thing. They didn't know because there was so much unknown about HIV/AIDS at that time. We had no idea that it was sexually transmitted until 1988. Now, I'm sure that we might have heard the information, but we didn't make the connection to us personally.

FN: Why do you think that is?

SW: I think because the way it was presented, that when I first heard it, "Well, of course you know you should be practicing safer sex," I didn't even know what was meant, what they meant by safer sex, so I had to do a lot of learning. The medical profession, or the physicians at the Hemophilia Treatment Center, were unprepared to deal with sexuality issues in the community, and so were the nurses. So I just did a lot of digging and found out what basically that meant, what they were trying to tell us, is either use a condom or abstinence. And I think that there's a lot more involved than just using a condom or abstinence.

FN: How did it feel to have to go after that information? Were you very comfortable talking about sex in those days?

SW: No. I remember when I was talking to Andy's physician. Andy had had a knee replacement in 1988 and I had said to him, "You know, Andy's been having a lot of night sweats.
This doesn't have anything to do with his AIDS business, does it? Andy and I had went through a very strange period of denial together where we received the information in 1983, but almost as though we went through a conscious denial of that information.

**FN:** What do you mean by that? How did that play out?

**SW:** We never talked about it. We never talked about it in 1983, and in 1984 we didn't talk about it. In 1985 we did start talking about it, but as though it was removed from us, that it wasn't affecting us personally, and then around 1987, 1988, we had to. I mean, we did have to take it personally, and we didn't know what to do with the information. We were both very afraid. Before we knew that it was sexually transmitted or the incidents of sexual transmission, Andy felt hurt and rejected when I would say, "No, you have to use a condom," because that wasn't a part of our normal practice, so there was the emotional part that I would feel guilty, like oh, maybe I shouldn't be pushing him to use a condom. So we went through a real period of having sex, not having sex, wanting to have sex, being angry because I wanted him to use a condom.

Then Andy went through a period of time where--and he is at this point now--he is so terrified of transmitting HIV to me that he will not in any way touch me in an intimate way, because we've met too many men [whose] wives became infected and the wives became sick soon and died, and the guilt that these men carry, I mean, I think that's part of it. Part of it is medically, and with all the medication Andy's on, he just cannot. That's just not--he can't perform sexually.

**FN:** So he's been infected, that you know of, since 1983.

**SW:** Yes.

**FN:** That's a long time.

**SW:** Yes.

**FN:** So thinking back to what AIDS meant to you then, what does it mean to you now when you think of AIDS, working in this field and having lived in it for so long?

**SW:** I think I am not going to let AIDS have that power over
me it did at one time when we were in isolation. Even though we weren't talking about it, it totally dominated and controlled my life. At that point in my life, I was really accelerating in my chemical dependency, my alcoholism, and I was drinking every day--every day--and passing out every day. I will not allow AIDS to have the control over me like that.

I was so afraid that I just gave it all the power I had, and I'm not going to do that again. AIDS doesn't have that much power in my life anymore. I think information is power, and the more informed I can be about HIV, about transmission, I need to seek it out. I'm not satisfied with all the information that I have found about sexuality and HIV. I think that there's many more options that we have out there.

There is a pamphlet that we have here, "101 Ways to Make Love," that I hated. It's like, go to the library, read a book, take a bath. I think there should be a book, a pamphlet, that says, "101 Ways to Sexual Gratification," because we are all sexual beings, and to deny that part is very tragic, I think.

FN: To talk like this so openly, is that different from the way you were raised?

SW: Oh, absolutely! I remember when I talked to the physician when I was referring to Andy's knee replacement and I was trying to think, because I wanted to know, basically what I wanted to know is can this virus be transmitted if Andy fingers me, but I didn't want to say it like that and it sound so crude, and I was just struggling--How do I say this?

How do I say this? I was trying to articulate it and I just couldn't figure out how to do it and not be totally embarrassed, and the physician goes, "Well, you know, you could do digital insertion," and I'm like... But, yes, I feel very open. Information is power, and I think that we are all sexual beings and it doesn't bother me at all.

I was raised an Irish Catholic girl. You know, you don't talk about sex. Period. First of all, women should never enjoy sex, and then you should never talk about it. You just put up with it.

FN: And here you are.

SW: Here I am talking about it, and I think that I very much enjoy it. [Laughter]
FN: Talk to me a little bit about your chemical dependency. Now, were you drinking before AIDS, or did AIDS really help accelerate that?

SW: I was drinking before AIDS. It's hard for me to tell because I never went through treatment or an assessment, but I was probably, in my opinion, borderline chemically dependent. I'm not sure. But when the information about AIDS came along to us, my drinking really accelerated. I drank every day. I drank until I passed out. I continued to work full time, and I didn't drink when I was working, but the minute I got home I started drinking, alone. I hid it. I didn't go to bars. I would buy my alcohol in cash from different liquor stores so nobody knew how much I was drinking. I mean, it was totally a horrible time in my life, very isolated, very fearful.

I was real interested, also, probably in the middle eighties, late eighties, about chemical dependency, pain management and HIV, because for Andy, he's had problems with addiction to pain medication, prescription pain medication. And how do we find that balance, you know? He had worked through all those issues and come out on the other end, but here we are finding ourselves in a position where he was taking pain medication for his knee replacement, and here were are today. How do we balance that? I think there's a lot of work that could be done in that area.

Basically I think how we have tried to balance it, and how Andy's tried to balance it, is [by asking this question:] Is he aware and living in the moment, or is he like just totally spaced out on the morphine? I think there are time where he's in a lot of pain, where he takes more morphine, where he is spaced out, but he needs the morphine. Generally I think he's found that balance so that he can function, because it's very important for Andy, and for me, for Andy to have quality of life where he can participate in our life and be active in our life together.

Some of the HIV medication affects his quality of life, so we make informed decisions on whether or not he's going to take that medication, on how it affects him physically. For instance, AZT--he's never been able to tolerate it. He gets very ill, very nauseated, and very lethargic on the AZT. We've tried it three different times, and each time it's the
same, so we just choose not to take AZT.

FN: It sounds like you’re saying there was a time when you found out about HIV but you didn't have a sense of its impact on your life, and maybe that was a period of that isolation and drinking. You said you had to start talking about it. Why did you have to start talking about it? What broke through that denial?

SW: I started talking about it probably in 1988, 1989. I started attending a woman’s support group through the Hemophilia Center at the university, funded by Ryan White, I believe. I went to the support groups and I met other women who were dealing with the same issues. We were all in different places on how we were handling it in our life. It felt to me like being in a very safe environment where I could talk about my fears, where I could just listen to other women articulate portions of how I felt, that I maybe couldn't find the words for at the time. It was very compelling to me to keep that up, to keep that momentum, because I found strength in doing that, and being with other people in the same situation.

FN: So would you say that was a defining part of HIV, being able to talk with other people?

SW: Absolutely. That was the beginning of me taking my power back, and it was a slow process. I think I would have, in retrospect, probably been further ahead had I made contact with MAP or other AIDS organizations. My one contact was once a month at a support group, and that was facilitated by nurses. As women in the support group, we started talking about how it would be even freer expression if we didn't have the nurse or nurses from the treatment center there, so I started a peer support group. I was really quite shy and hesitant to do that because I never viewed myself as like a

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3The Ryan White CARE (Comprehensive AIDS Resources Emergency) Act of 1990 provided emergency funding for AIDS health care and supportive services. The act is named after an Indiana teenager with hemophilia who went public about his HIV infection after being denied entrance to school.

4The Minnesota AIDS Project, the state's first and largest AIDS prevention and service organization.
facilitator or a leader of any kind, but I'd definitely seen that there was a need, and it was a need that I had, too. So I called women and we started getting together, and we started doubling and tripling the women attending the peer support groups, and really became a bonded group of women facing issues, and it really became like a good way of being addicted to getting better. It's like I wanted more and more of that.

I think it was in 1989 that the hemophilia chapter hired its first executive director, and that really was the catalyst. That's what just got me propelled into action and moving, and a sense of direction and how to do it, and that was phenomenal for me. The first executive director was Elizabeth Klein, highly respected. I had never in my life met a woman who was as assertive as she was, and in her interpersonal relationships with men didn't back down and was assertive.

My experience with women in the business setting prior to that was that women were always submissive to men, and it really opened my eyes that as a woman we are equal. There was a period in my life, and it was during the middle eighties, late eighties, where I did not feel equal. I did not feel that I was on the same playing ground with other people. I was very insecure, had low self-esteem. Today I feel equal with everybody. I feel that if I were to credit my heightened self-esteem to anything, I think it is being connected with other people and information. Information is so powerful, and not that you can go to one place and find out everything you need. I have found that I needed to be diligent in seeking out information so that I could make informed decisions, so that I could feel good about myself. It increased my self-esteem, it increased my ability to try new things, to reach out to other people or to stand up in front of more than one or two people and talk. It just increased all of that, and it's been very motivating for me.

**FN:** It's been motivating to see you grow in that role. What other kind of commitments do you have in your life? What do you do outside of AIDS? Like your family, church. Are you involved in other things?

**SW:** Actually, my life is pretty much consumed with hemophilia and AIDS, but outside of hemophilia and AIDS, we have three grandchildren that I love very much, and we see
them quite often. At one point, we had physical custody of them—we don’t now—and may some day again. So every opportunity that we get, we see our grandchildren and we’re involved in their lives.

Just very involved in AIDS. On a national level, I co-chair the Women’s Outreach Network for the National Hemophilic Foundation. I’m committed on a local level, although I’m not doing the actual work, but I’m very committed to outreach to women on a local level, and I’m very committed to my position here. I can’t imagine AIDS not being a part of my life. This may sound strange, but we have lived over a quarter of our life now with AIDS, Andy and I personally, and even though—and I don’t mean to diminish the fact that Andy has AIDS—but the only difference, it seems to me, other than Andy having all the physical effects, is that I test negative. AIDS seems so much a part of my life. It impacts me—I’m Andy’s primary care-giver—I administer all of his medication, do all of his TPN [total parenteral nutrition] and his dressing changes. It’s just so much a part of who I am, there isn’t a day that doesn’t go by that I am not talking about AIDS.

FN: Do you think that’ll always be the case?

SW: I don’t know. I hope some day definitely that there’s a cure for AIDS. I hope that some day I can talk about it: “Well, back when AIDS was an issue.” So I hope that that comes about very soon. I don’t know that that’s realistic. Just like I hope that Andy lives another twenty years; that’s my hope, but reality tells me that’s probably not going to be the case. So just face each moment as it comes, and not let AIDS have power over me like it did in the eighties.

FN: You said you were raised a good Irish Catholic girl. How would you describe your faith now?

SW: I do believe in a higher-power God, if you want to say, that God transcends all religions. I don’t believe that there is like one denomination or organized religion that has all the answers. I think God is intermixed in all of them spiritually. It’s love and compassion.

FN: How does that interplay with your work in HIV?

SW: It’s very much been a spiritual experience for me
working in HIV/AIDS. It's challenged me to face my own stock internally, my own prejudices, my own sexuality issues, my own levels of homophobia, although I don't believe I'm homophobic. It has challenged me to go deeper into my fundamental beliefs, and it's altered my fundamental beliefs.

FN: In what way?

SW: I believe that absolutely everybody is deserving of love and compassion, absolutely everybody, no exclusions. When I hear people describe the hemophilia community as "the innocent victims," it just turns my stomach, because it implies that other people are guilty. I think everybody that is HIV infected or has AIDS is guiltless. There are no guilty parties.

I guess it has just deepened me to seize the opportunity, because you don't know if there'll be a second chance. If there's someone that has touched me, that I respect, to say it then, say it now. Don't wait, don't just keep it inside; share that with somebody. I may come across as just gushing with emotion at times, but that's okay. It's worth the chance of appearing that way. I'd much rather tell people, "You know, that was really good, what you did." I've seen many, many courageous people sit on panels talking about their experience working with HIV/AIDS, and I always try to take the opportunity to tell them how they've affected me, because I think there are very courageous people in this community.

FN: How do you define your community?

SW: The hemophilia community?

FN: Your community. How would you describe it, and how do you find it? How do you participate in it?

SW: I like to think of myself as being a part of the broader AIDS community, everybody affected, although I'm not as involved as I'd like to be on a broader level, but I do see myself as part of the broader community. I don't feel that I have any less credibility based on the fact that I'm HIV negative. I think that AIDS has affected me so profoundly that I can speak genuinely about the effects.

I see myself definitely as a part of the hemophilia
community. HIV/AIDS is, in my strong opinion, the greatest medically induced disaster, and it will be genocide to generations of people with bleeding disorders. Typically in the hemophilia community we talk about men with hemophilia. There are women with bleeding disorders that are also infected, and that is like the forgotten group, even within the hemophilia community, so I see myself as being an advocate for women with bleeding disorders, in addition.

But because of all the issues and the fact that we are depending on blood-clotting products, we are dependent on the very manufacturers that knowingly distributed an infected product. There is a lot of like anger in the community, and there's a lot of in-fighting within the hemophilia community.

People are just really polarized. It makes me very sad, because I think, more than ever at any time in our history, we need to unite as a community, and we need to not only unite within the hemophilia community, we need to unite in the broader HIV/AIDS community and start being a cohesive group.

**FN:** You know, when people are listening to and reading these tapes years from now, they should probably know that there's a lawsuit pending right now, and it involves not only some of the providers of the blood products but the National Hemophilia Foundation, am I right?

**SW:** Right.

**FN:** How does it feel of being in the position of executive director of a local branch while members of the hemophilia community are suing the national branch?

**SW:** Well, there is a class-action lawsuit out of Chicago. Last Thursday, a class action lawsuit was decertified, so there is tremendous grief in the community. People are ready to give up. They're just very discouraged. I don't feel as though I've compromised my beliefs at all. I think that the National Hemophilia Foundation, back in the early eighties, made some errors in judgment, definitely. They were not an advocacy organization for the hemophilia community. But do I believe that naming them in a class-action lawsuit, which would virtually destroy this national organization, is the best thing for the whole community? No, I don't. I think what I've chosen to do is get involved and volunteer at a deeper level, and that's what I've done so that I can make
sure that my voice is heard, that women that I represent, that their voices are heard, really be an advocate within the community.

But to destroy an organization? There are children that are unaffected by HIV. They're just approaching the dawning of a cure for hemophilia with gene therapy. To see all of that destroyed, I think, would be a greater tragedy. I think that there needs to be accountability, but the accountability lies in part with us to get involved and have our voices heard, and not be apathetic and not allow an organization to make decisions for us. We allowed that, as a community, to happen, and if we really want change, we need to get off our butts and do something about it and get involved and start speaking up and work for that change.

FN: Does anger play any role in your activism?

SW: I'm very angry. My anger is directed at the pharmaceutical companies. Decisions were made purely out of...

FN: So you're angry with the pharmaceutical companies.

SW: I would like to see the way business is done change. I would like to see far more consumer involvement. We recently had a recall of blood products in our community for a new—well, it's not a new disease, but it's called Cruxfeld-Jacobs [phonetic] disease. It's a rare, fatal neurological disease. A long-time [blood] donor of the Red Cross died from this disease. They traced all his blood and which lots of blood products were made from that, and of course since the hemophilia community's factor products are pooled from 20 to 100,000 donors' blood, they had to recall all the lots of blood made from his blood. So that's really affected the hemophilia community.

The FDA, once this blood product was recalled, sent the information to the Blood Products Advisory Committee asking for a recommendation. The Blood Products Advisory Committee is made up primarily of blood bankers, and they decided that there was no known transmission by blood, so that they would re-distribute this blood product. That is very déjà vu to the early eighties, the early warnings, the early things we heard about HIV. There was no known transmission by blood products. There was no known sexual transmission. That's
stuff in the early eighties that was put out about HIV in the hemophilia community.

It just angers me, because I would like to know: Would these physicians, these blood bankers on this committee, want someone that they love dearly to receive this blood product? That's how I want them to look at this. So this [congressional] bill that we have proposed would be to expand that committee to five community members. We have members in our community and hemophilia community that are directly affected or have hemophilia and HIV, who are M.D.s and Ph.D.s, scientists, researchers, and who are very capable of serving on that committee and talking the talk that they have and being very credible. I would like to see that happen, very much so.

We need to be very integrated and involved. We can no longer sit back passively and be complacent about our health care or about the safety of the blood supply. We need to be active.

FN: Were you raised to question things like doctors?

SW: Absolutely not. I was raised to conform. "Good girls don't question anything." This did not come naturally for me, but I felt very passionately about it. In fact, I feel as though I'm really defining myself; I'm becoming who I really was meant to be.

FN: How does your community support you in that transformation?

SW: You know, the women are very supportive. I actually thought I'd get some resistance from the men, because whenever we have community meetings, it always seems that I'm the one conducting things, and I am sometimes a little uncomfortable on how am I perceived. Am I perceived as this bossy woman, you know, or what? Actually, the feedback that I'm getting from the men in the community is they want me to do that. "Someone needs to do it; you do it, Shirley. That's fine. We want you to do it." So I feel supported by the community members in being the activist, and I'm not the only activist, that's for sure, but if I feel very passionately about something, I cannot sit in a meeting and not say anything.

FN: And would you have before?
SW: Before I would have been so terrified. I mean, my throat would swell up, I would turn beet red, I wouldn't say anything. Now it's like, "No, it's far more important [to speak, no matter] how uncomfortable I may feel." I still feel uncomfortable in front of large groups of people, but I go through it, say what I have to say.

FN: How long do you think you're going to be able to sustain this kind of commitment? Do you worry about that at all?

SW: I think I'll be able to sustain it until the fight is over.

FN: How?

SW: Because it energizes me. Like when I'm with Andy at the AIDS clinic and I see people I don't know but obviously are ill. There was a man there one time, I think he was maybe Hispanic, I'm not sure, just a sweet young man, and he was going up to all the nurses and asking for hugs, and he said to me, "You know, my sister looks white like you do." He said, "Would you give me a hug and pretend you're my sister?" And I thought, "Yeah, why not?"

It's times like that, or the time I went over to the Minnesota American Indian AIDS Task Force, and Bertha and I were talking. We had been on a panel previously together, and we were talking about the panel and just talking about things in general, and she looked at me and she said, "Shirley, would you be my friend?" Those are sustaining, energizing times for me that affect me so deeply that I can't even find the words to accurately articulate how they touch me. I feel very much in the stream of life working in this area, and it seems contradictory, but it really isn't.

FN: It sounds like it's been a real learning experience on a lot of different levels.

How do you define felicity? What makes you happy? Where do you find that? It sounds like those moments give you some

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5Bertha Iron Boy was a client and then served as a case manager with the Minnesota American Indian AIDS Task Force until she died from AIDS-related complications in 1994.
sense of joy. Where does the other joy come from in your life?

**SW:** Joy comes from feeling as though I'm doing my part to make any small contribution I can, to be a part of it. I don't like the center of attention, nor am I the center, but I very, very much find life and energy from being a part of a community, a team, a group, even though it may not be a formalized group, but all of the champions working in HIV/AIDS. I feel a part of that group, even though it's like somewhat undefined. That gives me happiness to feel that I'm making a small contribution.

**FN:** What about outside of your work? How do you find happiness when you just go home? How do you rejuvenate yourself there?

**SW:** I love spending time with Andy. Many times we just sit. We don't have the radio on, the TV on, no noise, and we just sit, and we may have long periods of silence or we may talk. Just being with him I find great joy in, because time is very precious.

I find extreme joy and am really energized and moved spiritually being in nature. In fact, that was the beginning of my spiritual journey, I think, in nature, and I find that to be real fulfilling. Being with my grandkids. I just love being with them. They see life from such pure eyes that it's like re-experiencing the same thing over and over, and I just love being with them, and I learn from them. They learn from me, also, but I also learn from them. I enjoy spending time talking with my son. My son is in prison right now, but I do enjoy spending time with him. He's really grown a lot as a young man in prison. So, I enjoy spending time with him.

I enjoy spending time with friends, although that seems to be so rare that I have the time to do that. I also have recently begun massages through the Minnesota AIDS Massage Project, and that is wonderful. That is like a big treat to myself, that and being connected with my own body, and I started taking nice long, hot baths with lavender oil, and that feels really like I'm really taking good care of myself.

I really have a desire to learn, to gain the somewhat academic skills that I need to even further articulate myself, to really express, because I feel that the words I
use are so inadequate to describe how I really feel, so I want to learn how to do that, because this is just too inadequate, the words I'm using. It's so much deeper, and I really want to be able to accurately describe how I feel, how I'm impacted, how my life has been altered.

**FN:** Tell me what you think about the United States. When you think about America, what's your vision of America today?

**SW:** Well, I used to have this Pollyanna view about America, but I don't have that view anymore. When I look just within our country at what America, the United States, has done to the Native American community, it really disgusts me, how we have been, as a country, so inhumane. I look at their health care system and that really disgusts me. My son--his biological father was a full-blooded Chippewa--I look at my son being in prison and wanting to participate in some of the Native American spirituality like sweats and what a fight it is, but if he were a Norwegian and wanted to attend like a Lutheran service, he'd probably have full access. It disgusts me how, as a country, we're so racist and sexist and homophobic. It really disgusts me.

I'm really concerned about some of the views I've heard of Republicans and about their view of HIV/AIDS. I think it's a cop-out for people to keep saying that it's a "gay disease." However you define your family, whether it's two men, two women, whatever, AIDS is a family disease, and I think until this country starts looking at it as though it were a family disease... If we don't start educating our children on safer sex, and not just, "Here's a condom, use it"--I mean, that's pretty progressive; there's areas that won't even do that--but if we don't really start educating and empowering our children with information, we are going to be totally devastated by HIV/AIDS.

**FN:** How do you think America is impacted by you, by your activism?

**SW:** Unfortunately, I think that because I'm a white heterosexual woman married to a man with hemophilia and AIDS, I think I get the sympathy I don't want. I don't want that sympathy. It disgusts me. I really, truly believe that everyone is guiltless, there is no guilt to be placed on anybody that's HIV positive, but hopefully some of the message will be heard. I think people hear what they want to
hear. They pick out what they want to hear.

I think I have more access to talk to groups or to be heard by groups because I am a white female, which is unfortunate, I think, but I think that's the reality.

FN: Did you ever think you'd be an activist?

SW: No, but, you know, it's what I truly am.

FN: You're a darn good one.

SW: I think it's always been in there. It's truly life to me.

FN: What does Andy think, watching this transformation? I know that I've witnessed it in the years we've known each other.

SW: I think Andy's very proud of me. I'm also a tenacious activist for medical care. When Andy is in the hospital, I am there with him and I am his activist, and I will stand up to a head of any department and tell them they will not do this procedure or whatever. My views of the medical profession prior to all of that was that they were like mini-gods and that they knew exactly what to do. If you did it exactly like they said then everything would be fine. Well, my views radically changed. That's not true.

I think medicine is not a science; it's more of an art than it is a science. I think that as consumers of the medical profession, or patients, that we have the right to be partners in our health care and to make those decisions in a partnership. We also have responsibilities with those rights, and that's the responsibility to take good care of ourselves, if we're having symptoms, to make them be known. If there's something that a physician wants to do that we don't feel comfortable with, we need to say, "No, this is not what I want."

FN: And is that transformation really taking place across the hemophilia community?

SW: I think that the individuals themselves, whether they're men or women with a bleeding disorder, have had to have that degree of assertiveness with their health-care providers all
along or they wouldn't have survived it, particularly women. In the community of women with bleeding disorders, nationally there has been a high, high incidence of unnecessary hysterectomies, and for women that are HIV positive, virtually no care for their HIV, so I think that the individuals with the bleeding disorder themselves have been that way.

I think now partners, older children, parents, have had to be more of an activist, a medical-care activist. They've had to be more outspoken, but there still is a lot of apathy, a lot of people in the community who want to let the physician make the decision. "Oh, this is what he says is best," or "Whatever she says is best." What people just need to know is that it is okay to be a partner. That has to come from peers, from peer to peer, encouraging and promoting each other to stand up for themselves, just like I think the most effective way to do risk reduction. Even like home infusion, universal precaution, proper disposal of needles--I think it's far more effective if it's done from a peer to a peer, compared to a health professional telling you, "This is what you need to do when you go home."

It would be far more effective, if somebody were starting TPN home therapy, for myself or another peer to go into their home and say, "This is how you do it." You speak in the plain language. You know exactly what needs to be done. You tell them what needs to be done, you write out the instruction. Organization is key, to be organized, but that's far more effective than having a health-care professional tell you in their office how to do it. It's peer-to-peer education.

**FN:** Switching gears a little bit, what do you fear the most right now in your life?

**SW:** The moment Andy dies.

**FN:** What do you think that will be like?

**SW:** You know, every now and then I'll let myself think about it, and it's like I get a glimpse of it. I don't know what it'll be like. It will probably be very different than I imagine, but I feel like I will lose the most important thing in my life, and it terrifies me. Will I be able to function afterwards? Will I want to function? Will I care? I don't
want to lose him. I don't want him to die. I want him to live.

**FN:** How long have you been married, been together?

**SW:** Seventeen years. And he's very loving and accepting. He's been really good for me.

**FN:** He's a character.

**SW:** Yes, he is. He's a wild man. My biker. [Laughter]

**FN:** What do you hope for? You talked before about a cure. What do you hope for?

**SW:** I hope that they can continue to develop new drugs so that folks like Andy could continue to live. The quality of life he has now is not the level of quality he had two years ago, but I would be very happy with this, and I think Andy would, too. I hope for that in the short run. In the long run, I hope that they can find a cure for AIDS. I hope there is, on the horizon, a vaccine.

**FN:** What do you hope for for yourself?

**SW:** It's really been very important for me to be in the community. I really feel such gratification from serving the community, so I hope that that will continue. I hope that there are more and more people in my life that I'll have an opportunity to love, and I hope on a personal level that I get over my insecurities, just get over it and go beyond it.

**FN:** How do you think this time, looking back, will be remembered? Fifty years from now, how are we going to look back at this?

**SW:** I think I personally will look back at this and say, "How did we possibly go through that?" I hope that I'll look back and say this community really united, and when I say community I mean everybody affected by HIV/AIDS really united and bonded together and advocated for the social change that needed to happen, and for our health care, and really I think that demonstrates a high level of self-love and self-esteem.

My hope is that we can look back on this and say we learned the lessons that needed to be gleaned from HIV/AIDS, and in
regards to blood-product safety that the mistakes were not made again, because the potential certainly is there. I hope that people can rise to the occasion and learn from the mistakes that are right before our very face, and that we not miss it, and that we learn.

FN: How do you want to be remembered?

SW: As someone who cared.

FN: Those are all my questions. Thanks so much for your time.