Lucinda Worthington and Kristen Shantz 2009

L: My first memory of HIV and AIDS is when my nephew, who was 27 at the time, died, and it must have been November of 1985. Yes, I think it was, and my brother, my nephew's father was my brother, and my brother told me that his son died of pneumonia. I said, "Pneumonia? Just pneumonia?" I knew what it was, I just knew, I did, but my brother, he couldn't do that. He couldn't say anything about it. He just could not go there at all. So that was my introduction to knowing more personally about HIV and AIDS. Well of course you had known some stuff by then...

K: Well what year was it? '85?

L: '86? Because my nephew had died in November of '85.

K: I was in Arizona when I first started hearing about it, working there. The story I remember is hearing about this strange disease that was infecting gay men in San Francisco, and, I think, New York was how I heard it and that, the story I remember, is a story about a hospital in either one of those cities, I can't remember... and people being afraid of the infected and the infection... and refusing to go into hospital rooms, putting trays of food down and pushing them into a room. I remember feeling horrified as to the behavior, and not even knowing what it was.

L: Everybody was very afraid.

K: In Arizona, there was TB. That was the infectious disease so you gowned up, put masks on, you treated it as an infectious disease. So, I didn't understand, I was mystified by....what could it be that people were treated so horrifically.

L: I felt so badly, so badly.

K: Then I came back here. In 1986 I started working at Outer Cape Health Services as a registered nurse and I remember one of the questions in the interview was... it was not about HIV... it was about, "So, what do you feel about infectious diseases?" I remember thinking, "Huh? Well I know about TB and I'm ok with that." and that was it.

L: Isn't that interesting.

K: Funny. The hidden question was about HIV and it was just really hitting the community then.

L: Nobody really knew what to do, as I recall. None of us knew what to do given the circumstances that we had. There was never any training as a social worker; there was no road map for a nurse or a social worker. We didn't know how to proceed, how to talk to people to try to find out what was going on with this peculiar, strange thing that was happening to people. We couldn't grasp it.

K: There was... I remember that there was so much going on, all at the same time, in that there was this fire storm sweeping the country that was this disease and people were so polarized. I remember that this community, and even just Provincetown as a community, I wouldn't say that now, I would include the Outer Cape, but really Provincetown as a community was responding to it in a very compassionate way. It was, as a health care worker, it was an exciting time and it was also a really devastating time.

It was so devastating and horrific and you were... I remember feeling... understanding that we were all on the edge of a powerful period in time in medicine and in society, but also being totally overwhelmed because we couldn't define it. All you knew was that people, men in particular were coming in, one after the other. "Why are you here?" "I have night sweats." "I have weight loss." "I've been kicked out of my home."

L: "My mother won't talk to me anymore."

K: "My family won't talk to me. How do I tell my family I'm gay and I have this disease?" There was shame and grief and fear and anger and desperation and... (sigh) .... and we were carving something out of nothing, like you said.

L: That's right; none of us knew how to proceed from one day to the next...

K: And yet this community proceeded from the heart.

L: That's right.

K: As well as the intellect. The science that was going on here was also really very admirable....the dedication of everybody was something to be very, very proud of.

L: It really was. I remember the meetings that we had in the Penn Conference room in Provincetown and there must have been, as I see it in my mind's eye, I think there were like eight or ten people in that room at a time from different places in Provincetown, primarily. Pat, whose last name I forget who was the town nurse. Remember her? (Pat Lynch)

K: Yes, I do.

L: I forget her name. She was there and Alice (Alice Foley) was there, Lenny (Dr. Lenny Alberts), a whole bunch of us. You were there.

K: There were patients there, as consumers.

L: That's right, there were. Exactly right.

K: The activism was really impressive, as much as it was hard at times, it was a really...

L: It was a coming together of all of these people from different places, basically, to work on one common goal and that's what we did.

K: And worked on it.

L: Boy did we work on it.

K: So that we had to learn how to communicate with each other. We had to learn to put differences aside, meet on common ground, really be able to talk and listen and it was a real strengthening of the community.

L: It was… it's no wonder we're so bonded all these years later. Really, it's true. Our friendships were carved during that time.

K: That is true.

L: I hadn't thought of it until just this minute, but I think it's so.

K: They were forged out of that time.

(Catherine Russo, Director: "So the community really came together?")

L: Very much so.

K: And in that coming together there was also strife which was interesting to me because it was very dynamic. It was....

L: And we had different points of view, of course. How to go after something or how to find out the answer to a question.

K: And how to look at it beyond the immediate impact, that immediate impact being a patient who's infected, basically, and how to try... I remember, also many meetings that we're saying, "Ok, so we have this, and this is an acute, critical situation that needs to be responded to. How do we prevent it?" How do you move beyond that and see how it's affecting the community at large and respond to it in a proactive way. There were amazing people in the school systems at that time, that caught the vision and understood. I think of Angela Norton, the school adjustment counselor who was able to see that. People in the police department where community policing was, I guess, coming into favor at that point... but that was to address hate crimes. This disease that was infecting and killing people left and right was also a springboard for action in a very broad sense. That call to action was overwhelming at times.

There were people, a few brave people, and it's amazing to think of them as brave, but they were. There was a phys ed teacher at the Nauset school system, a woman, I can't remember her name, but she got us down there to show a video, Ryan's Song. Do you remember that video?

L: Oh yeah.

K: To show a video to the students and we would go down....I went down, Andrew Rigg a physician at Outer Cape Health Services at the time and with consumers, with patients to go down to show this video, to elicit conversation with the students at the high school and this woman was just able to slide under the wire because this subsequently was not approved. But there was those brave people that actually saw that this also had to do with community and what is a healthy community. Because there were people who wanted to say, “This was a gay disease.” The judgment that went with that, and also, the shame, but there was also among that... the community was not responding to women, it was not responding to people of color. I mean the community at large, the nation at large, the medical community. There were activists talking in the ‘80's and ‘90's. I remember at conferences saying, “We’re not looking at women. We’re only looking at men and we’re not looking at immigrant populations, we’re not talking about sex workers, we’re not talking about IV drug users.” You know, there was a hierarchy to dealing with the illness that was also interesting.

L: Oh gosh, was that hard.

K: Yeah, it was very hard. Women, at this time, were being overlooked because women’s symptoms presented differently than men’s and so, while it was amazing what men were doing, what gay men were doing, and their ability to mobilize was saving lives essentially. Meanwhile, women and minorities were being left behind.

L: Yes, they were, for quite a while as I recall. When we were doing the counseling and testing it was ninety-nine percent men who came in to be tested for HIV. As time went by, of course, that changed, but it was a while before it changed. That was, for me, the hardest part. As Kristen just said, not knowing where we were going or how we were going to get there with this insidious, horrible thing that was happening in our community and worldwide. In the counseling and testing program, which I ran at Outer Cape Health, telling people that they were positive for the infection and then having people die, left and right, and I mean left and right. How many deaths did we have in a week in those days? Four or five? Three or four?

K: It seemed like it.

L: I think it was.

K: It seemed like it and that was just the deaths. That wasn't the people coming in that you were telling...

L: And they were people who were here, many of them were people who were here in this community in those days.

(Catherine Russo, Director: "So what was it like to tell somebody that they were positive and what they went through.")

L: It was very, very hard because, as I said, initially there was no road map for how to handle this kind of situation. I tried very hard to have people become as comfortable as they possible could, having already talked at great length in the pretest counseling session. This is now the post test counseling session, and I would talk with people and try to get them, as I said, as comfortable as possible and then I would ask them if they were ready to receive their results. A couple of times people said, "No." and they left without ever knowing. But most of the time people said, "Yes." they were ready and they could do that. And telling them they were HIV infected was really, really... I can't tell you how painful it was many times, I can't tell you. Some people cried, some people got furious, many people just became silent. There was a range of emotions that came and I never knew which way it was going to go. At that time, I remember, after a while, I always wanted people to be able to talk to somebody after the session, whether they were negative or positive, basically, but mostly positive... to have someone that they could share their feelings with - then, not the next day, not that night, not two weeks from now.....but now. A lot of times people didn't have somebody they could talk to. So, I thought about that for a time....I think you remember this... a few people in town who were HIV positive, were willing and able to come over to the clinic and take a person out for coffee or get in the car and go for a drive, a friend to the now newly infected, or newly known infected person.

That was the most wonderful thing that happened, that was just beautiful. It really was. It was so wonderful and it just sort of came out of... I don't know... nowhere. I didn't plan on it.

K: It was the response that we were also feeling within the community, an understanding that, not only did we have to process as health care providers, but that patients needed somewhere to turn.

L: They really needed someone and they didn't have someone many times. Because also, as time went by, when more and more people came to be tested, they didn't want people close to them to know that they were coming to Provincetown to be tested, from Up-Cape. That was another side of the coin and that was very hard sometimes, very, very hard.

K: People knew that they were safe here and would be taken care of without judgment. It was... Just talking about it my heart starts to feel heavy again. I actually remember one day, being in exam room 3 and a young man coming in and having him telling me the litany, you heard it in your sleep, the fevers, the weight loss, the cough, the da da de da da da de da. I just remember that. It was becoming da da de da to me. It was routine, and I remember stopping what I was writing because it hit me, "Oh my God, this is becoming a routine to me." and it got me out of that but it was. It wasn't that I took it for granted but I think it was indicative of how many men, young men, boys, the ages of people, coming in with this and being diagnosed.

Their pain, their grief and trying to figure out what to do. The doctors coming down from Boston. The doctors at the clinic. I mean people were dedicated to figuring this out. The medication....I remember when Bactrim was killing people, remember?... and it breaks your heart, it breaks your heart. I mean, you deal with people no matter where they are in their living or dying process with comfort and that was happening within the clinic and it was happening within this community. It was happening with people that were infected, not infected who would give rides, who would cook meals, who would go provide twenty-four hour care because this was still in an atmosphere where people were being treated horrifically in society. This community was an oasis, there weren't many in the United States at that point, three or four, this was a place where people were coming to die.

L: They could come, knowing that they would be cared for.

K: To end their lives with dignity and with people who were compassionate.

L: There were so many interesting pieces.

(Catherine Russo, Director: "Do you want to talk about...")

L: It was extremely difficult at first for me because I hadn't had any experience talking with people about their sexual orientation and how they felt about that and their families. A young man by the name of Chris, who came from a family of eight, all of whom were alcoholics, except for him. He was for a while, but then he got sober and lived for a while longer. His father, as I recall, had not talked with him for years. His mother was empathetic and compassionate, but nobody else in the family was really and he had a very, very difficult time. I tried, from the social worker point of view, I tried to help him with his own sense of self, so that he could let go of his humility and the embarrassment and the shame and what he was feeling about being gay and being infected. Now that's a big job. Very, very big for any young man. It worked though, it did work and he was reconciled with his family. His father spoke at his funeral and his father then jumped into being an active participant in helping other people in the same situation. So that's just a brief bio of what you asked.

One of the things that was most difficult, well there were several things that were most difficult for me, and I know Kristen remembers this. There were two or three deaths in a week. I know there were because I can remember and I could go to Kristen and say, "I can't stand this, I can't stand it." Remember that... and she would comfort me because it was just getting to me. People were in and out, you know, dying, and I had trouble coping with that.

Two other things that were difficult, that were personal for me, just for me. I would be at the A&P, and I'd see somebody who I knew was coming to see me tomorrow, and I knew what his test result was and I had to go past him in the A&P. That was not comfortable. That was very hard to do, very hard and there were people I'd also see around and about, whom I had given test results to. They were HIV infected and I never knew whether to speak to them or not, so I didn't. If they spoke to me that was fine, but I didn't make any overtures to anybody. Sometimes people walked right by me, which was fine, really fine, because they needed...

(Catherine Russo, Director: "At this time, the seriousness of it that these people were probably going to die relatively soon, so it wasn't just that they had an illness.")

L: That's exactly right.

K: And it's the beauty and the burden of living in a small community, that you know something so intimate about people where you're sharing final moments with people is a very humbling and sacred position to be in. And sometimes you knew things about people that were kind of funky, so as a health care person, for anyone, you wanted to give people their space. So somehow letting a patient take the lead, I know that this was the same for all of us, was you wanted to give a person their privacy and identity.

Because in a small community, and the Cape as a whole is just a long skinny community. Everybody needed their space, so whether it was ducking down another isle at the store, it was maintaining that balance of both a community event with something so intimate, because you were talking about death. You were talking about sexuality, behavior, maybe or maybe not substance abuse. There were just so many issues and to help people live well and protect ourselves.

L: That was so hard, it was very hard to do. I was in such pain sometimes I just didn't know if I could even go to work again the next day sometimes, but I loved it. I grew to love what I was doing. I just loved it. It was so rewarding.

K: I agree with you on that. It was very rewarding, because it felt sacred.

L: It was actually, it was. It was sacred.

K: To work with people on that level about truth, if they wanted it, in a good way. You know, to help people and you never lost sight of the fact that this is a human being in front of you bringing their life story to you.

L: That is such a sacred trust, isn't it?

K: Yeah, it really, really is. Just as we're talking there are so many faces and scenarios that are going through my head, making my heart swell right now... it just...

(Catherine Russo, Director: "What was your every day experience like, the details of what you would do with the patients.")

K: My job at Outer Cape Health Services was, I was hired as a nurse, as a staff nurse, so in the beginning, we did everything then, from that point of view, from a medical, clinical point of view to be working in a community medical health center at that point in time was, it was just so much fun. You really felt that you got to do nursing and that you could do health care, so, as things came up in the community, you could respond to it. It was a very dynamic time in that sense. As nurses we were working in a situation that came on the heels of the Drop-In Center. There was a community health movement in this town that served the community well. We were used to creating something out of nothing. We were out here in the "boonies", considered rural, fifty miles from a hospital that many of us did not really feel was a viable community resource. As I said, we were used to creating something out of nothing. HIV became a call to action along those lines. We were poised for it.

L: By that time we were already a team.

K: We were a team. We were poised for it. I don't know what it would be like in this day and age, the way medicine has changed.

L: I don't know either.

(Catherine Russo, Director: “How was the bureaucracy at Outer Cape Health Services?”)

K: Very supportive, I felt it was very supportive.

L: Fantastic.

K: The leadership. I felt that way. There were times when people thought the leadership was not moving fast enough. Sometimes people lost sight of the fact that this was a community health center and it was just not about HIV. So it was interesting because even though the health center was a showcase for how to deal with the epidemic, there were other things to deal with. There were kids, babies, family health. Within the health center I know that there were co-workers that felt, “How come HIV is getting all the attention?”

L: We had the WIC program at Outer Cape at that time, remember?

K: Yes, yes, there was a lot that went on. So within the health center, there were co-workers that felt that HIV was getting too much, too much of the pie, so to speak. And then there were people in the community that sometimes felt that the clinic was not responding fast enough from a medical perspective. It was interesting because there were all these little land mines we were kind of walking around... and then there were the patients. Do you remember when this first started... because the community was red lined, which meant that, literally red lined and it was a term that came out of what insurance companies... people would be denied insurance coverage, they were red lined and this was by virtue of being from this area. So initially we went through hoops to keep the information about HIV and about counseling and testing in separate, remember it was in a separate locked box.

L: Oh my gosh, I forgot that.

K: So the medical records at that time... there was some sort of code, I don't even remember what it was but only we knew about, that was very innocent. So this could have been anything. So in a person's record it wouldn't even say if you were being tested for a sexually transmitted disease because if there was anything in a person's record that came out that possibly they could figure out that you were a gay man or, I guess, an IV drug user, then you potentially were red lined and not eligible for insurance. You could not get medical coverage.

L: I remember that so well.

K: So, even within the clinic, there were only a few people that knew how to get into that locked file. We figured that out all by ourselves and that came out of a sense of wanting to protect our patients and, "We need to do something so our patients are not acted upon in a way that they're going to suffer, they're not discriminated against where they're going to suffer even more."

L: I had forgotten that altogether, but you're right. Boy, we did go through a lot, just amazing when we look back on it.

K: Remember how long it took for the test results to come back?

L: Three weeks, three weeks... oh my word, it was agonizing. Three weeks.

K: It was agonizing.

L: Wow, in those day the state sent us the bar code, not the bar code, they gave me numbers. We didn't have bar codes in the beginning.

K: It was numbers, everything was so... secretive, and it was done for the right reasons, to protect people, but at the same time there was a burden to that. It helped to make it this... this other thing... it helped to illuminate the shame of it. At the same time it bonded all of us... cause you felt like you were in this kind of crusade at some point, you know, but it also had another, sort of isolating sense too. That's why we had our support group. As staff we had to have support groups, not only to deal with the death and dying but to deal with the secret of it.

L: Those support groups were just the best. They were.

K: Yeah and there weren't a lot of people in the medical community that were... there. You know, the full impact of it was not realized, so there was a lot of isolation.

L: Well, we were very different from any place else, weren't we? At that time.

K: Yeah, and I think that was the administration, that was the staff, that was the community. We were very different. There was that feeling of, "Well, come on, let's respond, let's figure this out." It was creative. Through the horror of it, we were very creative.

L: It's amazing when we look back on it, isn't it?

K: Yes, there was a lot of satisfaction in that wasn't there?

L: Yes, a lot. I was looking for some of my old papers that I brought home from the clinic. I found a Tri-county AIDS Consortium booklet, the whole big thing that I had for years. I looked at it and I looked at some of the minutes from those meetings and I was just blown away.

K: Were you? Why?

L: Well, there was just so much going on. We had so many people come to the Consortium, consumers as well as everyone who did anything around HIV. It was fascinating what we did. We made all these changes regarding their health care, their medicines, their social workers....everything that was happening with people. Their family care program was so involved, remember that?

K: Yes, yes I do. It really changed how people dealt with each other within the medical system. It changed, so aside from this virus is around, and people are trying to understand it, and who's infected or affected and all those things, it also changed how patients and nurses and doctors and social workers and phlebotomists and everybody... how people dealt with each other. It was really interesting and I found that that was also changing within the medical community itself. I found that even as a nurse. That my relationship with physicians... the change was throughout the system, at least through our system... how you spoke to one another, cause we were coming together on something that was so much bigger than all of us. Patients were coming in and they were empowered to question. They empowered themselves. I mean, it was out of fear, they were dying and no one was paying attention to them. So that meant that, all of a sudden, I'm going to question you, which was huge. It was huge. It changed things. It had a huge impact on how we all dealt with each other.

L: I was just remembering as you said that about taking the clients down to the lab from my office to have their blood drawn. How I would walk down the hall with them and usher them into the lab. One of our two technicians would smile and say, "Come on in". Nobody knew anybody's name. It was all done by numbers and it was just... as I look back on it, it was so kind and so sweet. It really was.

K: There was a lot of crying that we let ourselves do with patients without stepping over the professional relationship.

L: That's true.

K: Yeah, a lot changed, I think. A lot of hugging and touching. I think that we learned a lot from each other. I know that we did.

L: I do too. I learned a lot.

K: If you let it happen, you learned a lot.

L: We struggled so. That's the amazing part to me as I look back. We struggled so to come to grips with this, that was happening with our community, our community and our clinic, and none of us knew what we were doing. We were kind of going by the seat of our pants.

K: We were lucky to live in Massachusetts

L: That's very true.

K: As a state, politically and socially, as a state. We're very lucky to live in this state.

(Catherine Russo, Director: "So Provincetown was one of the places in the country to experiment and define where a cure was going or a healing happened?")

K: Healing, you bring up a very good word because we clarified healing, what that meant as opposed to cure, or treatment, non-treatment. Healing was another piece of it that occurred in this community on a large level. Again this was a place where gay men could come to and there were not many places. It's not the way that it is now, even though there's still shame and prejudice. I don't minimize that, the way that it is today. In the country, this was a community haven, that people flocked to. There were... I feel like more stories than I can even remember of people... men coming in... they're sick, if you can just picture it, they're sick and they're scared. Their families won't let them into their house. Their one parent, or family member might be supportive, but then other people aren't so you're sick, you're more than likely going to die. You have this burden and it became our burden to a certain extent.

L: It did, it did. We were there to help

K: It became the community's burden because we were all there to help people.

(Catherine Russo, Director: In that sense, to me, it was very heroic.)

K: It was very heroic because it was being done initially in the face of huge prejudice and judgment, huge prejudice and judgment throughout most of America, all aspects of America, and because we didn't know how it was going to end.

L: We didn't know where we were going.

K: And we were saying, "We're Ok, come to us, come to us." This community did that as a whole.

L: Absolutely, everybody came together.

K: It was an honor, it was an honor to be a part of that. You could hold your head up as a human being and know that we were doing the right thing even though we were forming it.

L: We didn't know what we were doing, but we were doing the right thing. We learned.

K: It something... I'm sorry for all those deaths and all that pain. I don't ever lose sight of my gratitude for being a piece of those many people's lives.

L: Me too, me too, I couldn't agree with you more. I loved my work. I loved everyone I worked with, but those closest to me, I loved. I loved a lot of people. I loved some of the clients so much. I really did. I was so happy to, and warmed and rewarded to know that I could help them from time to time. In the beginning, I wasn't sure what I was doing at all because, as I said earlier, there was no road map.

K: And there was so much fear. Fear about "Oh how is this transmitted? What's going on?"

So you were... we were all looking to educate ourselves as to what needed to be done and how do we keep ourselves educated as a community... and not buy into the fear, but also buy into what's real.

You know, separate them out, so it was always this balancing act of dealing with this devastation on the one hand and then wanting to move forward in the best possible way on the other hand. How do you deal with a community that's dying and deal with life... and keep a community alive at the same time.

L: Well, it was a challenge, wasn't it?

K: And it took all of us. The Soup Kitchen came out of that whole movement and that whole time. The community mediation program came out of that. These wonderful, sort of, little pieces came out of the whole thing as we learned to....

L: And fund raising, the Support Group, all of that... the Chef's Table, oh my gosh. That was unbelievable, it still is.

K: The community, I remember, was looked at by other communities on the cape as (finger is in a cross). The team, remember; the kids on the sports team were ostracized. They were made to feel badly about themselves because they were from "Provincetown". The kids in this community, I remember, suffered by virtue of living in this community. You know it was really a weird dynamic in that sense. So you felt like you wanted to protect one another beyond what was that immediate concern, which was this amazing virus that was doing things that we weren't understanding. To live in Provincetown, live and work in Provincetown carried, in many circles, you were looked at...

L: Yeah, that's right. Absolutely, a little like (tilt of the head and disapproving stare), "You live in Provincetown, do yuh? Are you safe to be around?"

K: I remember going to work with students here and working with students in the Nauset region and going to the school board with them. Helping them to find their own voices, which was one the great things, but going to the school board at Nauset, because they wanted to have condoms. This brought up the whole thing of, "Who's at risk? Who's at not risk? Oh, you have to talk about sex? You have to talk about homosexuality? This isn't going to happen to straight people and this doesn't happen in this community, this is a gay man's disease and women who are prostitutes." The prejudice around it was mind boggling. So going to the school board with the students and sitting in that audience, I was so proud of them as they stood up and read their papers about why they wanted condoms in the school. Why they wanted to try to move this through in their school and empower them, themselves, to say, "You know what, we are having sex. You know what, there are homosexuals in the schools." Of course, the school board couldn't do it.

L: No, they couldn't handle that.

K: No they couldn't do it at all and we couldn't tell them that we knew there was.....positive....you couldn't say anything. I mean you wouldn't.

L: What was the name of that program that you had there? You invited me one time..

K: The Peer Leadership, the Peer Leadership, training students to be peer leaders to one another and training students to talk about sexuality with their students. That's right. We did it in Provincetown, we did it in Nauset.

L: What did I talk about?

K: I think probably about counseling and testing, and having to talk about behavior...I don't really remember.

L: I don't either.

K: But none of us ever thought, I never would have thought that I would stand before the school board, and I didn't talk about condoms in such graphic detail as I might talk about them in front of students. Or to talk about them with adults, in counseling and testing, or in talking just to a patient in the room. You'd be talking about how to put a condom on a penis, that you'd be talking about all kinds of sexual behavior... that would just... here I am... it was great, it was a great education, but it was, none of us were really prepared to do that, nor were clinicians prepared. The whole thing about sexuality, whether you were gay, straight, both or whatever, it didn't matter, those were the things that needed to be blown out of the water. Whatever your age was, people were not used to talking about sexuality and it was one of the things that had to be done.

L: That was a good program, wasn't it?

K: It was a very good program because by empowering the students, we were also doing it to ourselves. It was really good.

L: I don't know how the counseling and testing is being done as we speak. Is it the same way?

K: Well no, people now sign names. It's more normalized, in a sense.

L: Oh, it's more open?

K: In that sense.