

Interview with Jay Adams

Title: HIV in West Virginia

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Michael Nobel Kline: Could you say, "My name is."

Jay Adams: My name is Jay Adams

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MNK: And you live?

JA: Here in Wheeling.

MNK: Okay. Tell me a little bit about your current position and, and your state-wide program.

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JA: I first got involved with HIV as a volunteer, but I moved on to become HIV care coordinator for the state of West Virginia. And that began in 1990. So that means that I administer a grant that comes through the federal government, as well as the state government. And it's for direct care dollars for people with HIV. So I have three case managers who work for me throughout the state. And we maintain basically the entire caseload of people who are HIV infected who are looking for services.

MNK: I'm sorry. Can we have that other mike. Okay, let's start, let's start again.

JA: Okay.

MNK: My name is.

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JA: My name is Jay Adams.

MNK: And you are employed?

JA: I'm employed by the state of West Virginia and the AIDS Task Force, the Upper Ohio Valley. And I run a program for the state of West Virginia for people who are HIV infected. And it's a program for direct care to people who have HIV. And three case managers and myself provide that service throughout the state.

MNK: Um hmm. And the funding?

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JA: The funding comes from the federal government, the Ryan White dollars, as well as 100,000 dollars in the state of West Virginia. And although it sounds like a lot of money,

it's a minimal amount of money for 414 clients. So it's a difficult program to manage, but a program that we enjoy working with a great deal.

MNK: And of these 414 clients, where are most of them?

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JA: I would say they're throughout the state. Primarily when we began the program back in 1990, we found that most of them were in larger cities. So--Particularly about eight cities across the state. But I would say now that they're in the small hollows of West Virginia. Some of my directions include three dirt roads and parking your car and climbing half a mountain to get to some of my clients. So it's been an interesting ordeal just trying to maneuver the roads of West Virginia and get to know some of the areas.

MNK: And into roughly how many counties of the state's fifty-five total does your program reach now?

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JA: Fifty-five. All fifty-five. It used to be that my farthest client was six hours away. But once we were able to hire a additional case manager, I can now reach most of my clients in about three and a half to four hours.

MNK: What is the response of, of local communities around the state to this deathly disease?

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JA: I think it varies. We've made some progress over the past years. But we still see some people who are gravely in danger if they would disclose their diagnosis. We have a person who lives in one of the southern counties who actually has people come around anywhere from midnight to four in the morning and shoot at his trailer just for the fun of it, because people know that he has HIV. And we have other areas where we know that, it's just not the community response but even the family response, where if the family knew that the person had HIV they'd be put out of the house and would be homeless. So it can be very difficult when you're talking about rural areas. Some of our larger cities have homeless shelters, and we have a couple of AIDS residences across the state. But when you're talking about rural areas where traditional support is either family or church and both of those turn their back on you if they found out it's HIV, then there's additional challenges that we face. It's a much different program to work in than if you were working in New York City or one of the larger cities across the nation.

MNK: And why is that?

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JA: Well, sometimes identifying doctors--Sometimes you'll have people travel a hundred miles just to get to a doctor who is experienced in HIV. Where you're in a larger city and you have a list of twenty or thirty doctors and you try to pick the one that's closest to your neighborhood. Instead, now you try to pick one that has

accessible a hundred miles away or close to interstate or that somebody's willing to drive those particular roads. People will travel two and three hours sometimes for a dentist for specialized services.

MNK: But also I gather that there might be, you might encounter less hostility in other places?

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JA: Yes, there are certainly areas of the state where we find people are more open, but I don't think that there's anything or any place in West Virginia where it's totally safe. You cannot make any assumptions at all with HIV. You cannot make assumptions that your family's still going to love you. You can't make assumptions that your minister at your church, that your church that you've belonged to for twenty or thirty years is still going to welcome you. You can't make assumptions that your very best friend is still going to be there for you. So even when we get into larger cities where you think the values might be a little bit different and people a little bit better educated, we don't find that you can ever make an assumption.

MNK: Is this then just a matter of educating people?

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JA: It is a matter of educating people, but sometimes there are really in-grown, I think, hostilities, such as hatred and bigotry, discrimination. And when those things are there, I, I seem to think that education falls on deaf ears.

MNK: Uh huh.

(062)

JA: We will have people who are extremely religious and will make all kinds of quotes just constantly to people who are HIV infected. And just basically condemning them for their diagnosis or how they acquired the disease. And no matter what you say to them they never abandon those basic instincts that they have. I think that every person who goes through HIV infection probably starts off with three emotions, fear, shame and guilt. And it's up to each and every one of those people to see how much they're able to claw their way out from underneath that cloud of those three emotions. For some people they're there for the next ten years. For some people it's a difficult process of ever getting to see light again. Other people will get their head above water, and suddenly someone comes by and just mows them down again and gives them more reasons to be afraid or more reasons to be ashamed. And so basically it's a process with people who are HIV infected that every single

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time that you have a new encounter those emotions can pretty much come up, and you have to deal with them. Whether it's going to a new doctor, whether it's going to meet a new social worker, or there's a new home health care worker coming to the house.

Just little slight comments where a nurse might come in and say, "I don't approve of your lifestyle, but I'm willing to treat you." And that's just a little bit of a turn of the screw that says, "You should be ashamed, and I'm doing you a favor. And--But God sent me here, so let's not worry about it." And my comment to all that is, "Who asked." "Who asked," when people make these comments. So basically no matter where you go, whatever service you're getting when you're HIV infected, from day one to the day that you might be dying or to the day that you have to go to a funeral home, you never know for sure what the reaction's going to be. You might have never really attended church, and suddenly your family approaches a

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minister and says, "Will you do this funeral service." And suddenly you might meet a brick wall simply because the person realizes it was HIV. I've attended funerals where ministers have not even mentioned the name of the person who died. It was very clear in their head that they had made clear decisions that this person was condemned. And they asked that they pray for the parents and the brothers and the sisters and the cousins and the fifth cousins. But they never once asked that you pray for that person who died. So those kinds of reactions you see in larger cities and you see them in the small cities and small towns. And I think when you are isolated in a small area, it's probably more crucial. Because when you're in a small area and there's only one denomination of your particular church, then you're kind of stuck. If that minister says that you don't, you're not welcome in your church, then it's very difficult to suddenly find that same denomination. You either have to

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change or you stop going to church. In larger cities you might have five or six different churches on different corners that are the same denomination. And you can at least choose another church if you hit a brick wall with one of those ministers. And the rural areas, you're just stuck. We had a ninety-year-old grandmother who used to climb the stairs with her, with a meal. And she would put the meal on one step, and then she would climb a step. And she'd put a meal on one step, and she would climb a step. And her basic life was her church. She truly believed that the community was the church. And all of her activities were centered around church. And she was caring for her grandson, and she took him to church. And she was told on the day after Sunday, the Monday, that the minister just simply asked her not to come back because of an HIV diagnosis. And what you find in those small areas is that people are unwilling to fight back. I went to this grandmother, and I said,

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"Well let me do something about this." Being a good activist and advocate, I, I knew the hierarchy of this particular denomination. And I knew how to get to the right people to

have this person reprimanded. And the response was, "No, that's okay. I'll just sit home and read my Bible." And I wanted to scream at the top of my lungs, "That's not okay." But it was okay with her, and there was nothing I could do. And this same minister then performed the funeral service. And how abominable that this person would even want to perform the funeral service for a person he banned from his church. These are the kinds of issues that, when you're in rural areas, you just hit a dead stop. You stop going to church. You stop believing that God loves you or whatever the instance is. At least in larger cities then you have some other recourses.

MNK: Is that because people associate this disease with the gay community?

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JA: I'm sure it is. That and injecting drug use community. I think that there's a lot of homophobia out there. There's a, a fear of drug use and drug users. Basically people who are even in recovery are still classified with those people who have been out there robbing stores or will steal your purse if you're sitting on the corner to get their next fix. So I think there's fear of both. But I don't think it's really fear of the, the gay community. I think it's much more a hatred and a condemning attitude that's just been ingrained in them, particularly in some of the rural areas.

MNK: But AIDS is no longer limited to members of the gay community.

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JA: Certainly not. When I first got involved with HIV, which was back in '84 which just amazes me that I've done anything for eleven years because I've never done anything for a commitment of eleven years, but when I first got involved it basically was gay, white male. That was pretty much the definition of AIDS in West Virginia. And now it is completely changed. I walk into homes and there, there might be two children infected and a father might have already died. And the mother is severely ill. And we're starting to look at child care issues. I might walk into a home where both parents are infected and the infant child's infected. And we're looking at children who are going to survive who are going to be orphaned by HIV. So I think every issue that's ever hit the nation, as far as a group of people and the issues that are going to be there, orphaned children or parents who are infected, has hit at West Virginia by this point. We've had mothers who have lost babies. And we've had parents who have infected each other not knowing they were infected. And so--I mean I think all the issues are there. And it's certainly not a gay disease anymore.

MNK: Absolutely no respecter of person.

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JA: No. HIV doesn't care whether or not you have stocks or bonds or CDs or whether or not you even know how to read. I think the very first time I ever actually met people who were illiterate were, was starting my period of time with HIV. And I met two

people, one who had thirteen pill bottles and one who had fifteen. And I like to sit down with those people and diagram this disease. And I like to write down all the medications and tell them all the symptoms and give them wads of paper and books and positive living and everything I can give them to get them from day one to the last day of this disease. And it was all totally useless with two people who, who were illiterate. They just had no understanding. And they--No matter what you said to them, they weren't used to complex issues. And they weren't even used to, you know, watching the clock to take pills. And neither one lived real long. On the other end of that spectrum, though, I've had five persons with PhDs. And one of them who
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very proudly could stand up and talk about neoclassical art and music for hours without notes. And if he had a classroom, he wouldn't give them a break till people's heads would hit their desk in total boredom. I mean sometimes it's hard to suppress a yawn after a half hour as you listen. So it just doesn't matter. It--This disease and this virus has no regard for whether or not you've had education or you're able to read or write. And also financially it has no regard. We've had people who have homes that are appraised up to 300,000 dollars, and other people who make it for a little bit more than 400 dollars a month to next month, you know. Sleeping room where they share a bath with six other people. And some people have six baths in their household. And this virus just doesn't care whether or not you have to stand in line for almost a week to get into the bathroom or if you have enough bathrooms for every day of the week. It just doesn't care. It doesn't look at your pocketbook. It doesn't look at your stocks and CDs. And it doesn't look at your education.

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This virus has no morals. It, it's a very smart virus. We've learned it knows how to mutate. It's a very fragile virus. It dies out in the open air after a while. But it has no morals, and it's not looking for a specific people. And I think that when we look at our country as a whole, we're a country that likes to take risk. We have, over the years, been told so many different things and we continue to take the risk despite what we've been told. For example, we once had a speed limit that was fifty-five miles per hour because of the oil crisis. And suddenly people petitioned their legislatures, and they said we want to go sixty-five. And all the data was out there that proved that fatalities finally had come down when the speed limit was fifty-five. But people said we want to take that risk. And you find people who curse under their breath when they drive into Pennsylvania or into Maryland. They're going, "Gosh, it's fifty-five again." And where, where do the police sit. And, you know,

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what risk am I willing to take of even getting a ticket. We have a seat belt law. But you

still look at people in the cars, and they don't have their seat belts on. And they've proven that if you have your seat belt on you don't die as readily in an accident. People will take their hard-earned money and take up to a counter and plop it down, and say give me a package of that stuff that had, names all those diseases on the side, emphysema and cancer. They've been told that smoking causes cancer, but yet people are still willing to take the risk. And while we don't judge all those other people, we don't say when you come into the emergency room, "If you didn't have your seat belt on, we're going to put you down at the end of the list because you are a guilty person." With HIV immediately people look to see how did you get it. And, "Are you one of the guilty or one of the innocent." And it's one of the few viruses out there that we've ever treated that way. Until we treat it the same as other diseases,

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we're not going to be able to have the confidentiality laws and things like that released. I think it's a very politicized virus. And it's a virus that's been preached at the pulpits where people say that, "AIDS is the wrath of God here to eradicate a group of people." And, you know, if that's true then this plan has gone so awry because I've had four-month-old babies in my arms who have died. And I've had two year olds and twelve year olds and grandmothers. I've actually held over 170 people as they've died with AIDS. And you just can't see this as part of God's plan of eradicating a group of people. No one I don't think who ever actually sees HIV up close and sees what the devastation is, how it rapes the body and how it just takes a family and sometimes destroys it or takes a family and puts it through so much pain, even though it may unify it more with love, could ever think that this is a plan that's out to eradicate a group of people.

MNK: It's amazing to hear you talk about this.

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JA: HIV's something I got involved in eleven years ago because I thought that things weren't right. I have always been one of those people when I've been sitting around a table I'm real fast to stand up and say, "Well that's not right." Then you look around and no one else is standing up and no one else is nodding their head! And no one's even looking at you with even some sense of agreement. So I probably was involved with HIV from '84 to at least '88. And I would go off on my little trips to New York almost every weekend because they had real low air fares. And no one knew what I was doing up there. Most people thought I was just going up there to, for Broadway shows, and I was volunteering at St. Vincent's Hospital. And then after '88, as I started to see local cases, I got involved in the local scene. And then I've had very little time to do anything nationally because the epidemic has just gotten so great. When we look at this disease it's sad to see it come home. I first got involved with HIV because I saw brothers dying. I remember the first time I saw any

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information about this virus on the cover of the *Advocate Magazine* I just had chills because I realized it was personal and now was attacking people that I was close to. And then I put that magazine down, and I don't think I saw anything about it for maybe six months or eight months. Because none of the other magazines were talking about it, it was just the gay press. And then when I found the first case in New York from a college friend, I, I saw the truly--This disease just devastated. The lesions that can sometimes cover your face and, and swell your eyes shut so that all you can do is maybe squint or maybe not see at all. Or PCP that makes it so difficult to breath. Or AIDS dementia complex that takes you from the wonderful person you once were and just creates a little shell. And you're treated as if you're a one year old or even younger by your parents and by your loved ones. And no one can even

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relate to you anymore because you don't know who they are. Those are the things that I saw that made me get involved. I was an English major. I had no knowledge about viruses. I had one science class at Wheeling College when I was there. It was at eight in the morning. I worked until four in the morning. I don't even know if we talked about viruses. And I was not a morning person. I'm still not a morning person twenty-five years later! But when--But this virus really caught my attention. And early on I cared very little about the molecular structure or transmission. I just wanted to be there for people who were hurting. Since then I've gotten very involved in doing lectures on transmission because at some point people have got to stop coming to me and saying, "I have HIV." At some point this virus has to end. So I realized that I had a, a part to play there in reducing transmission too. I tell people when I'm out doing talks that if five or six years ago I had, someone said to me, "You're

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going to be doing a talk in front of a group of people in Wheeling, West Virginia, in 1995 about sex," I would have taken every dollar I ever planned on making in my entire life and said, "Let's double it," you know, two to one, "I will never be standing up in front of any group of people talking about sex." It wasn't in my plan. But people were dying because of sex, and it became part of my plan. And so for two or three minutes people need to get comfortable with the idea of talking about reducing transmission while I'm out talking. And I think if you do it in a non-offensive way, and you do ... humor, people become comfortable. But hopefully the message gets there. To this day I won't say it's my favorite area to talk about. My favorite area has always been psycho-social issues, the people who are infected and what life is like for them. And I think things have changed a great deal, even in our valley, because of that. I hear nurses tell me that. Had a hospice nurse once tell me

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that she had some attitudes about a workshop. I did a workshop one time for hospice. And I remember leaving thinking that just didn't go so well. And there wasn't anything I could really put my finger on, but I think it was the energy in the room. That these people just did not like this person coming in on their white horse telling them that you have to be compassionate to people with HIV. And they didn't want to hear about the issues. And I left that workshop thinking, you know, what did I do wrong. And I couldn't think of anything. And I always basically, by the time I get half a mile away from the workshop, I always just tell myself you did your best, let go of it. And that's all you can do because sometimes you have people who have hatred. And I had a nurse who told me, about three years later, last summer she told me what a impact I made on her life. And she is one of the people I respect the most across the state as being compassionate to people with HIV. And she told me

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that it was that talk that had started changing her around. She, she said that when I left that talk that she was just so angry at me for telling her that she had to be compassionate. And when she looked at those issues later on, she realized that I was right. That she had no right not to be compassionate, to take a select group of people and say you don't deserve care. Or if you do deserve care, you only deserve this portion of the care, not the loving touch, not the, the heartfelt feelings that hospice is so well known for across the state. So as I hear those kinds of comments, I, I think that things have changed. Back in '88 you went to local hospitals and there was just so much paper and so much latex. People would stand outside a room and put on three and four layers before they walked into the room. Consequently, you would find people who would bring meals and they would think, "Well, I'll just leave the meal outside the room here. I'm delivering these meals, I don't have time to get all this garb on to

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take this one meal in. And the next person who comes in will take the meal in." And maybe nobody came around to take the meal in. So we saw meals being left out in the hall. Now you see people going in with no paper and no latex. And they go in, and they plopp that meal down. And they're opening up the silverware, and they're touching the person. And they're asking them, you know, "Do you like this? Do you want me to get you something else?" Just very caring staff. And some of those people tell me that my talks about psycho-social issues helped changed that. That's very rewarding to know that I've had some part in making life a little easier. Every five years I basically kind of look at my life and say what do you want to do for the next five years. And I have two years left on this commitment. I would like to think that this virus is going to be gone in the end of two years, but it won't be. We're going to have a, a vaccine maybe in the

year 2002, 2005. It's estimated right now we have a million and a half people in this country alone who are HIV infected.

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But then they tell us by the year 2000 that we'll have ten million. West Virginia will have their share. I look at a state that has a problem now, a major problem with the Medicaid system. And I see that seventy-two percent of my clients are on Medicaid. And they tell me it's going to quadruple just in the next few years. And you wonder where these people are going to get their care. Will they ... services. There for a short while we had dental services for people who are HIV infected. And then it just took one strike of the pen, and the services were taken away. We had vision services for people who were HIV infected. It took one strike of the pen and those services were wiped away.

MNK: They have those for people on death row.

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JA: Yes. Yes. And, and when you look at this it's a dollar and cents issue. And when you look at the political climate across the country, it, you're not real optimistic about what's going to happen. And when you look at the numbers. As an AIDS educator, if I was out there only doing education about transmission, I think it would be difficult to get out of bed and go do all those educational presentations each day. To think that, here I am putting my heart and soul into this, doing all these talks, trying to prevent the transmission, and they tell me that in less than five years we're going to go from a million and a half infected to ten million. I mean it doesn't make you feel like when you go to bed that evening that you've done a real good job of reducing transmission. But when you sit there and you talk to people, particularly about the psycho-social issues, and you see a tear that goes down a cheek of someone, or you see some people nodding or some people come up to you afterwards, I do see some change of the psycho-social issues. I've no idea what, what impact I have on the transmission area. I have no impact at all perhaps. I--It's hard to tell. But the message is always out there.

MNK: The psycho-social issues are?

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JA: Talking about what it's like to be infected, the fear, the shame and the guilt. Talking what it's like to be abandoned by family. To come into a hospital and to have a whole new care team every single time you come in because nurses are either rotated or you're on a different floor. And what it's like to have people walking into that room and you have to share your secret with these people at a most vulnerable time in your life when you're stuck in a hospital bed, perhaps with two IVs and a catheter and things hooked up to your heart and your lungs. And you have people come in and writing things and you don't have any idea what they're going to do with that information. As

we've been able to get the message across to health care workers, what I've said to them is that when they are in your presence, when people who are infected are in your presence, you have the opportunity to say, "When you're with me, there's no reason for fear. When you're with me, there's no reason for shame. When you're with me, there's no reason for guilt." And if we can

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get every single person on a hospital staff to promote that kind of feeling, then suddenly the hospital starts to feel like home, and people aren't afraid when they go into the hospital. I see nurses, when patients go in they say, "Hey, it's great to see you. I wish you weren't staying, but it's great to see you. How's your mother doing, and how's your brother's new baby?" And they remember. On the local level, we had two patients in at Christmas time one, one year. And the head nurse on the floor, Sue Miller at Wheeling Hospital who is just one of the gems of this valley as far as HIV care, made sure that those two rooms were decorated for Christmas. And those were the only two rooms that were decorated by the nurses for Christmas. It's that level of love that's going to get us from today to tomorrow. It's that level of love that gets people from this moment to the next moment. Doctors and researchers are going to do their part for a long time to come up with prophylactics to prevent

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infections. They're going to come up with all different types of research that eventually is going to make the society safe through a vaccine. But until we make this a chronically manageable disease on the psycho-social level, until we make this a disease where you want to live from this moment to the next and from one hour to the next, until tomorrow, even though the researchers are doing everything without even asking you. They're trying to prolong your life without asking you do you really want to live. Is it worth living. You know, do you really feel the support from your family that you want to stay around. Are you afraid to take your garbage out on Wednesday night because the neighbor kids are there taunting you or throwing rocks at you. Do you have to park your car two blocks away because people slash the tires. Until we change all those issues, it's not chronically manageable. But when we change them one person by one person, which I think we have, then we start

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making it chronically manageable. I think we have gotten to a point, here in Wheeling in particular, where if a person is HIV infected and they contact the AIDS Task Force or someone from the task force, we can actually guide them through the system without a bad experience. We can get them to the right psychotherapist. We can get them to the right minister or priest. We get them to the right doctor. We make sure they get on the right floor of the hospital. We make sure everything just goes real smooth. But for that

person who didn't reach out, who went through the road by themselves, oftentimes we have doctors who say, you know, "There's nothing I can do for you. You're going to die in two years." And we still have people who send cards to that doctor five years later saying, hey, happy anniversary, I'm still here. So it's the attitudes that we change. And as we change those attitudes, I think that's where we

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make our progress. But as long as those things are out there, this disease is not a chronically manageable despite what researchers do, despite what pills do. Why would you want to stay around if it's one more Christmas when your family says, "Well, why don't you come home in January instead," knowing full well that the neighbors are going to be uncomfortable if your lesions or your difficulty in breathing or it's going to be very noticeable that you're emaciated. If your family's ashamed of you, then why would you want to stay around. I see people who come home and live with their parents and, and you think it's unconditional love and you listen to the stories and you see how much love is there. And, yes, it is wonderful the family said yes, you can come back and live with us. Perhaps there were disagreements in earlier years. And then you sit there and you listen. And you hear them say things such as, "We've decided not to tell anybody what he has or what she has." The message

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there is you need to be ashamed of what you have, so we're going to keep it quiet. If it was cancer they wouldn't do it. If it was a brain tumor they wouldn't do it. And sometimes elaborate lies are created. And sometimes those lies get blown out of the water. They'll tell people that it's a brain tumor, and suddenly you have ... lesions that show up on the hand. Well brain tumors don't spread to the hand. They'll say it's lung cancer, and suddenly you start having lesions on your face. So as we see people telling these lies, there's usually something underneath there, whether it's fear of how people are going to react or whether it's shame that they don't want people to know. Those are issues that, until we are able to eradicate those completely, it doesn't become a chronically manageable disease. And despite all the progress and despite we are creating a circle, we still have to rely on some of those traditional values. We live in a country that's governed by a Bill of Rights. We live in a country that ... Judeo-Christian values. And when it's HIV you throw

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them both out the window and you start at ground and step one and saying, okay, is this one there. Is this one there. And you, you very safely take that step. And I watch people who lose all their friends because they're HIV infected. And their new friends are people who are infected. And when your new friends are people who are infected, your friends die. And that's unnatural for somebody in their twenties or their thirties or

their forties to have their whole circle of friends die. And you go through those grieving issues. And as we put people into support groups, you sit at a support group table and you look at the person across from you and that person has lesions covering their body. And it's very visible. And you, you see all these purple marks. And you say to yourself I hope I don't get that. And you look at this person across from you who's slobbering and is making inappropriate

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comments. And that person has AIDS dementia complex. And you say to yourself, gosh, I hope I don't get that. And you see a person who had a difficult time just walking two steps into the room or walking across the room who's recovered from ..., a rare type of pneumonia. You think, gosh, with my floor plan in my house I don't want to be short-winded. I hope I don't get that. And you see somebody else who's trying to eat and they're chasing their peas across the plate because they're blind from CMV retinitis, and you think, I hope I don't get that. So even when you have your friends, you often are fearing the very things that are happening in your friends' lives. So it's very difficult for a person who's infected. I'm not saying that you cannot live positively with this disease, but it takes a huge, overwhelming task of overcoming the fear and the shame and the guilt and living day to day, hour to hour sometimes, to make it through.

Different than larger cities.

MNK: You have held a hundred and--

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JA: Over 170.

MNK: Seventy people.

JA: I stopped counting.

MNK: As they were, as they were dying.

JA: Um hmm.

MNK: Have you been able to avoid infection yourself--

JA: Yes.

MNK: With the amount of close contact?

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JA: Oh, there's no risk of contact in holding somebody who's HIV infected. I have had some, probably some scary moments of--I've been tested for TB quite a few times, which would not have given me HIV infection. That's usually my greatest risk, is the TB because I'm right down there in the face of people who are HIV infected. And unless I know they have active TB I'm not going to be wearing a mask. And oftentimes in autopsies or after death we're told that several people need to be tested. And I'm usually on that list because I've been right there in the face of people, but I've always tested negative. But as far as HIV, I have no fears at all. I understand how this virus is

transmitted. And holding a person, no matter how close to my body, unless they're bleeding and I have an open cut myself, I have no risk of infection. I mean I've--The closest I ever came to even having a risk of infection in care giving was when a person was actually vomiting blood and some of it went in my eye. And that

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was the closest that has ever occurred. And I, I guess that when I look at HIV I don't look at this infection as being something that I am constantly trying to avoid, but I always assume, I guess, that in how I take care of myself because of HIV that I, I almost take care of myself because I am infected, even though I'm not. What I mean by that is I, I take a lot more different aspects of life and I look at them differently. You know, I don't care anymore whether or not the grocery store forgot to double my coupon. I just don't care. It used to be something I talked about for the rest of the evening. Now I walk out of the store, and it's not even worth turning around for. I don't care about little, minute issues of whether or not somebody was supposed to bring an apple pie to dinner, and they showed up with peach and half the people didn't like. It just doesn't matter to me. And I don't get involved in all the, the squabbling and the heavy issues. So in that way, how we try to teach people to live and to

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look at life differently, I probably live my life as if I was infected. If I was infected, though, I would certainly take better care of myself! I would get more rest. I would eat three meals a day. All the things my mother told me to do forty years ago and is still telling me to do, I would probably would at least start trying. But I don't do those areas. I don't do those areas. I don't take vitamins. And sometimes dinner is at nine o'clock at night, and sometimes it's at midnight, and sometimes it's three in the afternoon! If I was infected, I'm sure I would look at those areas differently. You have to preach and follow what you're preaching for people to follow that. But, no, I have no fear of infection from holding people. The only thing that I've ever caught by holding people was that intense love of connection from heart to heart. And it's the most beautiful connection that you can have. Sharing those moments with people is just absolutely wonderful and intensely painful, intensely

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painful. Some of these people you come very, very close to. Other times I've been called by a family, and I've not even known the family or the person who's infected. And they've asked me to come in and do a transition, a guided meditation, visualization to help a person die. And I've done that for complete strangers, and I've only been in the house for maybe twelve, twelve hours. And yet, people, I'll see them three and four years later, that family, and they still just feel such a deep bond with you. Because, one, I taught them how to say good-bye to their son or their daughter and created a

beautiful moment out of a moment of havoc and pain. I believe personally that birth is probably a terrible experience. Being a man I will never know the pain of giving birth. But just the thought of coming through a very tight orophus out into a, a world that you know nothing and know, basically really don't know anyone but that mother. And the first thing that somebody does is slap you. And you felt so

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secure for nine months, and suddenly, you know, it's a different environment. And it's a cold environment. And death is something that we can plan. We can plan who's going to be in the room and what music is being played and what incense is burning and what flowers are there. And it can be a beautiful experience. I always try to talk to families about death. And I say, you know, if you were going somewhere and you were going on an extended vacation, wouldn't you think it was strange that, you know, actually we're packing your bags and as you were preparing that no one was saying to you have a good trip or good-bye. And that's what we see sometimes. And when people are dying everybody goes out of the room. And they talk about it, and they come back in. They just stand there, and they stare at the person who's dying. And no one knows how to do it but the very orchestrated thing, very orchestrated. And sometimes I've been able to go in and teach people how to do that. But again,

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some of those are very painful experiences because you've known the family and you've become very, very attached. And sometimes I've even said to the person, "Take, reach down inside me and take whatever you need and take it with you. And I'll call it back whenever I need it." And other times it's, I won't say a more cold environment simply because I don't know the person at all, but it's more just a teaching experience and, and being a spirit guide. So it just depends on each situation. But I'd say well over a hundred of those have been people that I've been very, very close to. And each one's different. Often they're very humorous. People often think that death is going to be such a, you know, quiet thing and something that has no humor in it. And I've seen some extremely humorous situations. I've had one person in particular who--I, I gave him a code. I told him that all these people were going to come

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in and say good-bye to him. And he was very reluctant at first to think that he was going to go through this ordeal. And I said, "Don't worry. I'll come in between each and every one of them. We'll, we'll talk about what happened and see if you need a little break. We'll--I'll take care of you all the way through this." And I said, "And if anybody gets in here and they really start crying," because he was uncomfortable with people crying and crying and crying, I said, "let me know." There was one person we really expected to do this. I said, "Just tell them that you need Jay. Tell them to go out of the room and go

find me.” And things were going fairly well. He would look at me at different times, and he would say, “You know, well it’s tough, but, you know, it’s also nice to have these people come in and say how much they love me. And we, we talked about old times.” And finally this one person who we expected to do a lot of crying come in. And she must have been in there about forty-five minutes. And suddenly he said to her, “Go get Jay. I need Jay.”

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And she came to find me. And I walked into the room, and I said, “What do you want?” I forgot completely that we even had a code set up. It was the first person that I’d ever done this with. And he looked at me with these eyes that I will never forget. It’s like, I can’t believe this. I’m dying, and you can’t keep this straight! You know, it was just one of those attitudes. I’ll never forget that look. But it was such a loving look too because he gave me those looks every so often when I couldn’t get the diaper on right or, you know, I spilled Jello on his chest, you know, whatever. But a lot of humorous situations. And a lot of promises that people make. I always tell people in the dying process that there are three things to do, and then you can do anything else that you want to do. One is you have to promise the people who are dying that you’re going to be okay. It doesn’t mean that you have to say to them, oh, I’ll be all right,

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don’t worry about me. You might tell them that you think that this is the most painful thing that’s every going to happen to you, but through the support of the family and through the support of hospice or whatever, that you’re going to make it. You tell them also that they have permission to die, that you don’t want them to stay around for this anymore, that you think that they have gone through enough and it’s time to go. And the third promise is that you will

see-- (noises) And the third promise is that you’ll see them again. And anything else you want to do in between. You can laugh about picnics. And you can talk about movies. And you can talk about credit card scams that you’re involved in or whatever it was that you did. All those things are fine. But those three things are the elements of saying good-bye to someone. And when everyone that that person feels really attached to has given that person permission to leave and everyone has relieved that element of where that

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person thinks that despite the fact that they’re in diapers and despite the fact that they have a temperature of 105 and they can’t swallow food, and despite the fact that they’re keeping their parents up twenty-four hours a day, but somehow in their twisted mind they think that their parents are better off if they stay around for another day of this. You know, once you get rid of that element that the parents are going to be okay,

that you don't have to worry about them, then that person's usually ready to go. Suicide's been an interesting concept with HIV. I think they're putting more suicides with people when they're first diagnosed than later. The reason I say that is I think that once people get into a support system, particularly where there's a support group or some people they can talk to, the suicide rate and the urge to commit suicide aren't there. But when you feel totally alone and you're sure that your family is going to reject you, even though perhaps they're not going

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to reject you, the suicide rate, I think, is up there in new diagnoses. Had a person once who asked me to help him commit suicide. And he had told me that he had actually ordered some pills from a friend. A friend was going to mail him these pills. Of course in his mind he actually believe his parents were going to bring them in from the mailbox to him, which obviously they weren't going to do. But he really wanted off this planet, and he told me about his medications. He said, "Which one of these can I take and how many do I take to die?" And of course I couldn't tell him or help him die. I actually answered his question. I said, "Well, this particular pill, if you took ten of those it probably would kill you." But what I said to him was that, you know, "If you really want to die, I don't think you need the pills. I think all you're doing--You're so concerned about the, the mode of committing suicide, what can I find to kill myself. I think if you actually just convince your body and convince your mind and convince your spirit that you don't want to be here

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anymore. His body was ill enough. And sure enough, less than eleven hours later he had died. And he never got the medication. And his family had not given him access to those extra pills. And it was just a matter of being convinced that he just didn't want to be here anymore ... place to go. He was so concerned and obsessed with the mode of committing suicide that he wasn't really thinking about the fact that he just didn't want to be here. Death has been interesting. I remember when a grandparent died and how different people in my family--I was always the perfect person to arrange the food and the flowers. I was really good. I mean if there was a funeral, call Jay. I was really good with all those things. Now I could care less about the food and the flowers. I want to deal with the feelings. And--

MNK: That was years ago when--

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JA: Years ago, years--When I was a teenager and younger.

MNK: Is that here in Wheeling?

JA: Yes. Yes, I grew up in Wheeling. I've only lived out of Wheeling for three years and that was down in Huntington for graduate school.

MNK: Um hmm. Have you had much contact with the gay community here in Wheeling? Could you give us a little background or, or history on that?

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JA: Well, I think the gay community in Wheeling is fairly closeted, and probably rightly so. There's probably a lot of discrimination out there as far as jobs. There are not too many people in Wheeling who are openly gay. When we look at the valley we usually see that it's a fairly active gay community as far as socializing. I--There are some different cliques. There's some different groups of people who get together on a regular basis. For quite a few years now there's been a gay bar in Wheeling where people are able to go and meet each other. So I think that there is a gay community. As far as organizing them, I think it's probably difficult. But they have been very, very kind to the AIDS movement, at least in the gay bar scene. The gay bar owner, as well as the community, is always there for our fund raisers. And I would say they usually average somewhere around 2,000 to 3,000 dollars a year that they contribute. And sometimes the people who are very active in doing that are also even people who are infected. This is one of those diseases where

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you have the sick taking care of the sick sometimes. But the gay community is a community that has educated itself traditionally across the nation. And the risk factor's reduced as far as the number of people becoming infected through sexual transmission. But there's some real concern about when we look at the gay community, not just locally but nationally, of people who are just coming out of the closet, people who don't believe that HIV is still a risk out there, people who don't know someone who's died. You take a twenty year old and tell him that he or she can't do all the things that a person in their forties once did during the sexual revolution of the '70s, and they say right, you know. "You're just like my parents saying I don't want you doing this, this and this." And then you, you still get to go out and do it. But this time it's a matter of life and death. So sometimes it's hard to convince some of the younger people that the virus is real, that it's out there. In addition, you have

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people who are burnt out. People who have been AIDS volunteers in the gay community for a while, and I think just the grief issue can be overwhelming. So when we look at that, sometimes that's difficult for protecting that person. When you are grieving sometimes you abuse alcohol, you abuse drugs. And when those things become involved, then you also reduce your inhibitions and the risk of transmission of the virus is greater.

(side two)

JA: The fastest rising groups of people with HIV across the nation are adolescents and

women. Those are the two fastest rising groups. Those are the groups we're really trying to reach, but certainly trying to get the message to the gay people. I'm not sure that the gay community is the kind of community that you might find in larger cities where it's much more organized and there are a lot of different organizations for them. For example, in Pittsburgh you have a bowling league and you have a softball league and you have AA groups and just about everything specialized for the gay community. But with the access to Pittsburgh I'm not, people are able to get to some of the services. And certainly there are things out there if a person really, truly will reach out. Being with the AIDS Task Force occasionally we'll all get phone calls, whether it's a person who's just visiting Wheeling saying where's the gay bar or it's a lesbian who says, you know, I, I'm looking to find out how to meet someone.

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And I remember looking at that issue a couple of years ago thinking I don't know where to tell a lesbian where to go meet someone. But I realized that we were one of those agencies out there that felt the most safe to call. You know, if you're new in town or if you don't know where to turn. Well, AIDS traditionally was a gay disease, so maybe I'll call them and maybe they'll be kind enough to answer those kinds questions. So we get those kinds of questions from people. And it's nice to know that sometimes when I've referred them to a therapist or referred them to a social organization I hear later, "Hey, I'm the person who called you two years ago and, and now I'm in a relationship. And, hey, thanks for referring me there." And that's nice, even though that's not the, the impact that we're attempting to have with our agency. It's one of the side effects. I think if we stayed limited with the things that we started out to do with the AIDS Task Force we would have missed out on a whole lot of valuable experiences.

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MNK: You said that you had found it difficult to discuss sex with, with public audiences--

JA: Yes.

MNK: At first, but that you had found out ways of making it maybe more humorous or more accessible information. Could, could you give us some examples of, of what you say to people about it?

(027)

JA: Well, when I talk about condoms I often refer to the fact that the most difficult thing that people often don't realize is that they have to take that little sucker out of the package. We have people who bought condoms, and they're carrying them around in their purse or their wallet or the glove box of the car for sixteen years. And I just say, "Throw them out, they're expired." So just talking about opening the package and not opening with their teeth so that there's a tooth hole every time they unroll the condom where the virus can jump through. Usually when I mention some of the oil-based

lubricants such as Crisco Oil and Wesson Oil and Vaseline Intensive Care, I usually hear some giggles. And you realize some people, you've hit some notes with some people. And I usually indicate that I've hit some notes. Getting people to feel comfortable with the issue, I think, is important. But probably the biggest problem is just for me to get comfortable talking about sex. And it's not

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something in our society that we're taught to do. And it wasn't something we were taught to do in my family. After sixteen years of Catholic education I was not prepared to go out and do lectures on sex! And abstinence certainly was the only word I would have understood real well. And now I say that C word a whole lot, condoms.

MNK: Questions?

Carrie Nobel Kline: How do you sustain yourself, Jay, doing this kind of work?

(042)

JA: Sometimes it's very difficult. Part of it's having an excellent staff. My case managers are very in tune with--We pretty much are on the same wavelength all the time as far as the level of service that we want to offer, getting involved with the families and feeling so attached. So that we understand that when one of us says so and so died today, that you don't move on to another topic. You don't move on to the next sentence. You ask how that person's doing. And having a staff that cares about each other, and we're constantly in contact with each other, oh, that's been real helpful. The other thing is just having some, I think, some values that you accept death. And you have a, a pretty deep spirituality, I think, gets you through. If I didn't do my grief work after every single person died, I, the next transition I went to I would be like a robot. And I would go in there, and I would just talk about seeing the light. And I would walk out, and I wouldn't have felt anything. But

(054)

I do feel something every single time. It's because I have done my grief work every time. And that--Sometimes that means crying your eyes out. Sometimes it means fighting the depression to get out of bed. Sometimes it means just taking some time and taking a weekend trip or going away or listening to some favorite music. When I look back to how I used to take care of myself, sometimes I can really see that I'm not doing a real good job at the moment. And you look at the things that are out there and the demands, and you wonder how can I do anything different at this particular moment. And so you make a plan that perhaps at the end of the month you're going to take a trip. And knowing that you're going to do that seems to, seems to work. Just a real deep belief in spiritual values. I truly believe that people do come back and visit me. I believe I have a real strong bond with them, that I can talk with them any single time. So they're not always gone. I stay in touch with families.

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Sometimes that's very painful because oftentimes they're holding on to very painful memories. And sometimes I move past some of that pain and expose ... each and every time that you go in there. To walk into a house and have a father pounding his fist on the counter every single time you walk in, saying I just don't understand, keeps pulling you back to that place where that person died. And, and I oftentimes have moved on. But I would say overall just being very conscious. If I realize that I'm feeling depressed or I realize something's happening in my life, either lack of appetite or change in my health, I usually, the very first thing will say, well, what's happening. It's not running to the doctor. I usually know that there's something on my mind that I'm either not trying to deal with or, or suddenly I realize that tomorrow's the anniversary of a good friend's death. And I had not even noticed it on the

(075)

calendar, but somehow inside, biologically, it was affecting me. And paying attention to those surroundings usually gets you through. Because you know that two days later that that day will have passed. And you get through it the best you can the next day. ???:

CNK: I don't think so.

(080)

JA: *Feeding the Flames*, a tape that was done by gay men and women as well as HIV infected persons. And that's quite good. Michael Callen, who was HIV infected, came out with, I believe, two albums. And some of his music addresses the HIV issues. They, they range in high energy to beautiful ballads. Romanoski and Phillips have come out with a couple of songs, one *Living with AIDS*, which is very beautiful. Lynn Lavner came out with a wonderful song called *Anna Fank* and compares, basically the life of Anne Frank to the life of people who are HIV infected and the hate that's out there and the fear that's there. So there's some music. I think that probably the area that's really grown the most is literature. I remember having a real short little reading list when I first went out to do my early talks. And now I have a page that's completely filled with wonderful books. *The Band Played On* is a wonderful book for telling you the history of HIV, done by a friend of mine, Randy

(094)

Schultz. And basically will make you very angry at our government for the, the lack of response to this virus. I mean after all, they responded to legionnaire's disease in forty-eight hours. And we had a president who never even said the word AIDS for six and a half years. And our nickname for him, as, as a country, was The Great Communicator. If that doesn't tell us something, that we didn't even want him to communicate perhaps the word AIDS to us. Another wonderful book by Paul Monet, who also recently died,

Borrowed Time. The first line of the book, I believe, is "I hope I live long enough to finish this book." And it's a story of him taking care of his lover and what it's like to go through the ordeal of AIDS. Melody Peabody wrote a book called *The Screaming Room*. And that book is about a mother taking care of her son. There's another book, and I don't remember the author, called *Good-bye, I Love You*, the story of a woman who had divorced her husband

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because he was gay and took him back because he had AIDS. And beautiful story, has a beautiful guide of meditation, visualization at the end of it that--I've used something rather similar one time for a funeral. So there's lots and lots of literature out there. And lots of good information if people are willing to reach out for it.

MNK: Great.