MAN: A friend asked me this why I had not told her sooner because she was like insulted I had not. And you choose the people who you feel could handle it, could understand it. Primarily, I told my gay friends first. All my friends who were HIV-impacted, whatever their status was, I sought an understanding and a comfort level. Some people get so emotional that they get hysterically crying. And it's their loss, their loss, their loss. And you're saying to yourself, no, sweetheart. You're going to be around next year, or two years from now, or five years from now. It's my loss.

WOMAN: Particularly with AIDS, I experience a lot of anger because women with AIDS are getting diseases that are not even recognized by the Centers for Disease Control as opportunistic infections. So for AIDS caregivers, it's really about not forgetting about these people. And it's about educating ourselves.

There were so many women on the OB-GYN ward who I have AIDS. But they're not considered to have AIDS, and we don't see them statistically because they don't have the classic diseases. They have chronic pelvic inflammatory disease. I look at that. I say this is very suspicious. And some of them don't even know they have HIV. They're the ones who fall through the cracks. And people don't think to test them.

WOMAN: I'm sleeping on concrete, and you want me to have my medicine lined up. And OK, it's 1:00. I got to take my pill. It's just not logical. It doesn't fit it doesn't fit in their lifestyles.

MAN: Thinking and knowing that it's OK to say, this is not a right for me right now. No. I can't hear one more sad story. I can't hear another person telling me how they perceive me to be. Being really able to say not today. I need to go for a walk. I need to go have a cup of coffee. I need to go home. And I'll come back tomorrow.

And one of the things that I was actually talking about this yesterday was how it's so important for me now to be able to feel what's going on and then just going from there. Whereas before, I felt so much that I needed to stay away from what I was feeling. Now, it's about knowing that I'm feeling whatever it is, whether it's anger, rage, sadness, nostalgia, or whatever. And going from there and then acting on that, as opposed to trying to stay away from the feelings.

WOMAN: I had been in this ministry perhaps almost a year when one of sisters is part of my community, who hasn't had the opportunities I have, said to me, what do you do for those people? And that's just the wrong thing to say to me because a piece of me just-- I bristle all over. And I said, what do you mean those people? Because I try to use it as teaching times. Now sometimes the interaction can be teaching. It causes people to say then what they're meaning. And when they say what they're meaning, you can have dialogue on it.

But this particular individual was very defensive and said, you know what I mean. And so where we are at a table with other people, I didn't want to continue the conversation. But she pushed me. And I said, I just want to say one thing. I do not do anything for them. They do for me. And that really was a puzzle to her. And she said, and what could they do for you? And I know deeply inside of myself that the answer I gave her is something I believe. I said, they have led me closer to God.

MAN: It wasn't until I had been doing the work about six years and had known a lot of people who had died and been there. That suddenly one day, it hit me like a ton of bricks. I thought, what is the purpose of my having done this if I can't hear what the message is? What is the message? What are these people telling me?

Time after time, I sat with people at the end of their lives, who were sorry that they had led their lives the way they did, or that their values had been what they had. Or I saw people blossom into wonderful spaces where they had not been in wonderful spaces before they were sick.

And it seemed to be like, well, why would I have to be sick to do this? Couldn't I learned this these people? Couldn't I learn that it's not a rehearsal. This is it. And that I can be authentic. And I can be direct. And I think it changed me in a really profound way. I don't know that it changed me. It unlocked me in a way.

MAN: My priorities have changed. I think I have a much less judgmental view of how people die. I used to think it was preferable to die spiritually. And spiritually meant in bliss and peace. I now feel like people die the way they live. And there's no error in that. I've learned a lot about my own fears. Seeing people in beds and realizing, just flashing on the fact that I could be that person as somebody who's HIV positive. What would I want if I were reversed in those roles? What would be helpful?

DR. CHARLES GARFIELD: The AIDS caregivers we spoke with discussed three general areas of concern. The first we mentioned already. The necessity to be tough on problems and tender on people. The second was what to do when they felt overwhelmed by feelings of inadequacy, by feelings of a tidal wave of clients or patients coming at them, and by profound feelings of sadness and despair from multiple losses and accumulated grief?

And the third area of concern was how they were changing as people. The idea that caregiving is a process which can sometimes result in very profound changes in your life. These are the three areas we'll focus on in this program. First, how to cope with the day to day aspects of AIDS caregiving. Second, what to do when the challenges seem overwhelming. And third, how caregiving comes full circle back to you.

AIDS caregiving addresses a wide spectrum of human needs. The practical everyday needs of people with AIDS, their medical, emotional, and psychological needs. All demand that caregivers function in a variety of roles and settings. You may be the sole caregiver for one person. Someone you love dearly. Be assured that your experiences are quite similar to those of thousands of people like you. Or you may be a member of one of the many organizations that have come into being because of the pandemic.

There are people who cook and deliver food, who offer legal counseling, who answer switchboards, who provide practical services, such as grocery shopping and house cleaning. People who drive vans taking patients to appointments, who coordinate AIDS residencies, who run support groups. People who advise on drug trials.

There are the counselors, both volunteer and professional. And the people who sit at the bedsides of those who are dying. Then there are all the people who staff and manage the organizations which carry out these functions. And then of course, there are the nurses and doctors.

We interviewed a cross-section of these caregivers. And for our purposes here in this program, we've chosen to focus our attention on a specific segment of the caregiving continuum, on people whose work brings them into direct, one on one contact with people with AIDS. And particularly those who provide psychological and emotional support to the people they serve.

This program is for professionals who have made AIDS caregiving a career. To the volunteers who work in their spare time, which often constitutes another full time job. And the individual who finds him or herself thrust into the ranks of caregivers by virtue of necessity. Like the names quilt that has become a living, growing memorial to those who've died of the disease, these caregivers and their efforts form a tapestry of service and comfort intended to spread as far as possible to cover the diverse needs of the HIV positive population.

When I founded Shanti Project in the San Francisco Bay Area in 1974, our focus was primarily on people with cancer. We developed a peer counseling model that allowed volunteers with appropriate training to visit people with cancer who had requested our services in order to provide them with emotional support. Some of our volunteers were younger men from the gay community.

In 1981, a few of these men came to Shanti meetings and asked that we begin to provide support for people with a cancer-like disease that seemed to be hitting only gay men. In those days, it was called GRID. Gay-related immune deficiency. No one knew much about it. But in the words of Dr. Paul Volberding, who was then at the University of California Medical School in San Francisco, GRID was an incredibly complex, multi-systemic, very little understood disease. And we were powerless to do anything about it.

Even though this disease was clearly being transmitted somehow between people, no one knew how. And it's a testimony to the courage and caregiving commitment of people like Paul and his colleagues at UC medical school and to the Shanti volunteers at the time, that we continue to provide support for people with GRID.

At that point, no one knew how it was spread. By mid-1982, the disease had been named AIDS. Acquired immune deficiency syndrome. What we know now is that this disease was emerging in all populations around the world. AIDS is an equal opportunity virus.

Many people people who are HIV positive, that is who have the virus in their system, may get a series of opportunistic infections. The Center for Disease Control lists 27 different ones. You'll hear a few of these infections mentioned in passing. PCP, pneumocystis pneumonia. KS, Kaposi sarcoma. MCMV, cytomegalovirus, to name a few.

Any single infection can be lethal. But with the help of drugs and medical treatment, we can often assist people back to health. The violent ups and downs of the disease bring incessant uncertainty. Uncertainty which challenges the physical and emotional limits of almost every caregiver.

In this program, we'll only address the most pressing human needs evident in AIDS caregiving. And we'll do so from the vantage point of the relationship of the caregiver and the person with AIDS. There's much to learn about this vital relationship. So let's begin.

Since the caregiver's top priority should be giving the best care, let's consider first what are the most pressing needs of people with AIDS? There's no way to make a hard and fast distinction between practical, task-oriented support and emotional support. Many people who see themselves as offering practical support find themselves also listening empathically to an emotional breakdown as they provide legal advice. Or discovering that delivering a movie video gets remembered as an incredible act of kindness. Care is care. And its value is best determined by the recipient, rather than the caregiver.

Then there's the question of what helps? What you determine as a pressing need may not even be in the top 10 as far as the person with AIDS is concerned. In a few minutes, you'll hear Carol Johnson describe the challenges of supporting people with AIDS who are also homeless, who are also IV drug users, who are also not sure where their next meal is coming from.

At the initial diagnosis of HIV, many people feel overwhelmed, and questions flood in. Who do I tell? What treatments do I choose? If the HIV virus progresses to AIDS, that person's most pressing need is how do I get on with my life? How can I live with AIDS? Can I keep working? Who will pay for all of this? What about my children?

Many people feel the loss of mobility and independence. People with the HIV virus may remain asymptomatic for years. But as we know too well, many people with the virus begin to develop opportunistic infections which sap their physical strength. These are the people that the caregivers we interviewed are most familiar with.

If a person with AIDS no longer responds to treatment and later death approaches, there are pressing needs related to basic human concerns. What kind of life will I have now? Will my friends and loved ones remain with me? Will I have to move? Will I have to ask for outside help? Is dying painful? What happens after death?

The caregiver can assist at every phase by encouraging the person with AIDS to express these needs. By asking questions and listening. Really listening. Because the person with AIDS may experience fluctuating moods and physical states, many caregivers stress the need for being consistent in their support and truthful in their responses. And because a feeling of helplessness is inevitable as the disease progresses, caregivers try to provide the person with AIDS opportunities for maintaining a sense of control. Let's consider a few of these ideas in more depth.

First, the person's need for empathy. As a person with AIDS begins to experience some of the ups and downs of the disease, he or she often has a tremendous need to talk about it, to express their anger or their worries, to cry with someone, or just to know that someone else understands. The word empathy means to feel oneself into the experience of another person.

Caregivers' most basic capacity is that they care. They feel. They share a deep understanding with the other person. They not only feel for. They feel with. Real caring amounts to challenging your precious piece of mind. Bridging the gaps that distance you from the other person. And allowing yourself, so to speak, to become the other person. To imagine yourself in their predicament.

The importance of this was brought home poignantly by Gilbert Medina, a man we interviewed who has been living with AIDS for over seven years. He's followed by Jacinta, a Catholic nun who ministers to people who are homeless or who are drug abusers who also have AIDS. Both of these people capture the need for empathy.

GILBERT MEDINA: I go out of my way to make myself look as best as I can. I've had all my clothes taken in. I weigh 106 pounds. I made sure I have my hair cut. I get color. But yet when people see me, it's like you look well. So there's nothing wrong with me then. But they never asked me, but how are you feeling? They never ask me about the feelings. And I think that is really important, is to ask the person that the caregiver is dealing with, how are their feelings?

And don't take the feelings away from them and apply it to, well, yeah, my grandmother used to have those feelings too. It doesn't matter whether your grandmother had the feelings. This person who has AIDS is having those feelings. Let him own them. He just needs to talk about what's going on with him. He needs he needs someone there unconditionally.

JACINTA: The clients have a knowledge that as a caregiver I don't have. They know how it feels to be in that position. I need to let them have those feelings as a caregiver. I need to let them be just where they are and to recognize that they are going to be the key person who's going to help me become a better caregiver. And to be willing sometimes to be told what you're saying isn't right, what you're doing isn't right. And then finding out from them why.

DR. CHARLES GARFIELD: When the person with AIDS, your patient, client, son, lover, friend, mother asks for your understanding, are you willing to get that close to share the vulnerability? You won't be perceived as a real helper, a really helpful volunteer, or professional if you're not willing to get close enough. Close enough emotionally to the person with AIDS to understand who I am and what I'm dealing with.

The need for empathy is closely related to the need for authenticity. I want a person. I don't want a role, a person playing a part. I want to hear the truth as you know it. Not some sugarcoated words that make you feel better or some professional jargon I don't understand. Danny Castillo, who's counseled people with AIDS in a variety of settings, told us a story that I think illustrates very clearly this need for authenticity.

DANNY CASTILLO: One of our clients was told early one morning by his team of doctors and his lover that he was not going to be able to return home because the lover couldn't care for him at home. And he really had quite a few skilled care needs and was going to be transferred to a hospice.

And I went to see him. And his family was giving a party. They had balloons. And some of his coworkers from his job were there. And his lover was there. And there was a cake. And they had pictures of him when he was well. And all of this stuff was happening. It was like a celebration. And I looked on his face. And he looked horrified. So I waited. And I went back later in the afternoon. And I said, you know, your face didn't match what was happening this morning. And he just burst into tears and said, I just want to go home.

And it was really one of those moments that most people sort of turn away from. But in my work at Shanti, I've learned to of hang out in those painful moments. Although he burst into tears when I said your face didn't match what was going on, I could see a release happening with him, that somewhat acknowledged that he wasn't going to go home.

And the sadness of that, I think, hanging out with pain is something that you have to practice. I certainly wasn't. I would have been with the party group six years ago. It's like any skill that you want to develop. You have to practice it. You have to practice not turning away from the truth. It's not always pleasant. It was probably easier for them to do the party thing.

DR. CHARLES GARFIELD: As Danny says, for many of us, it's easier to do the party thing. To make nice, to put on a happy face, rather than to address the way the person's really feeling. To hang out with the pain as he put it. Hanging out with the pain means listening. Listening and feeling. As caregivers, you might be tempted to race in with advice. What you heard about AIDS yesterday at a lecture or on the radio. What to do about an uncaring lover. If you've had training as a counselor, you might be tempted to turn the encounter into a psychotherapy session.

Listening well is actually a higher order skill as John McGrann points out. He's a Catholic priest who's also the founder of Kairos House in San Francisco. The old Victorian setting offers a place where caregivers can go to get support and renew their strength to carry on. John's listened well to many people with AIDS and their caregivers.

JOHN MCGRANN: In the past, when someone would come to me and share their problems, and their anxiety, and their pain, I would like feel so sorry for him. And I would think, what am I going to tell them? Who can I refer them to? What book can they read? What advice can I give them? How can I fix them? So they'll feel better. And when they would leave, I would have given them advice. And I would have feel sorry for them. But I was left with their pain. And then I would go to the next person.

And after a while, I found out that people weren't doing what I suggested anyway. Once in a while, when I had the common sense to shut up and just listen, they would tell me, you have helped me so much. I mean, thank you for all that you've done for me. And I would think to myself, geez, I didn't do anything. I was just here.

So I began to get the idea that I didn't need to do anything, and people didn't want me to fix them. And I didn't need to take on their pain. And I felt better about myself because I knew I was giving them something, but I wasn't giving myself away or taking on their problems. And I would say to people, what would you like to do? What do you think would help you? Invite them to take on their power and assume their responsibility.

DR. CHARLES GARFIELD: John McGrann's last words raise another pressing need of people with AIDS. The need for control. Having a life threatening disease often creates a feeling of helplessness, of losing control of one's life. Helping the person regain that sense of control over at least some aspects of his or her life is crucial.

People with AIDS often feel they must sort through an onslaught of information in order to make informed choices about their health care. This can be an overwhelming task given the amount of information regularly reported in the media, in medical journals, or in the alternative health literature.

There's enough confusion and anxiety already created by the uncertainty of the ups and downs of the disease itself. Helping the person with AIDS access accurate information and then listening and discussing it with the person as he or she tries to sort it out can be valuable help.

Another place with a need for control appears is simple day to day activities. People with this disease will have bad days, maybe even bad weeks or months, where they need a lot of help just getting through the day. Then they may hit an upturn where they can pretty much take care of themselves. Being aware of just how much practical help is necessary, and not overdoing it is important. Jim Coffey reinforced that idea.

JIM COFFEY: When I have been sick I have been very careful about people who have come to help me not to take over my life. And in fact, like what I've said about my mother, she helped me where I needed to be helped. But she also helped me when I wanted to get out of bed and make my own breakfast, which was a big event. So she helped me help myself. And that was very important. And yes, it's a matter of control. It's a matter of control over one's life. It's a matter, I think, of a good way to face up to any life threatening situation, where you just don't become the patient, and you become passive. It's the ability to control your own destiny as much as you possibly can.

DR. CHARLES GARFIELD: When AIDS first got public attention in the US, it was seen as a gay disease. Something confined to gay men. And it's true that the majority of people in the first wave in the US were gay or bisexual. But it wasn't long before we all found out that AIDS is an equal opportunity virus. It began to show up in other populations quickly, in heterosexuals of all socioeconomic levels.

The model of caregiving that had been set up was based on middle class, educated White men. A model that didn't always fit well for other groups. The most striking difference was that for some people, an AIDS diagnosis was not their most pressing problem. Carol Johnson, known as CJ, who works as a counselor at a large urban center for AIDS services, and Michaela Solort, who's a counselor at an AIDS hospital ward, discussed what differences they have to deal with.

CAROL JOHNSON: Most of our clients live in constant chaos. No consistency. Nothing stable. Nothing that they can count on. They can't even count on themselves. And so therefore, we're like an anchor in their lives. And they realize that there is going to be certain things that are going to be here.

Even though I have clients that I suspend, we fight, we argue about their behavior and what they're doing. They also know that I'm not being judgmental with them. I'm not going to put my expectations on them. And I'm going to allow them to say and dump whatever they need to dump and still be there to help them.

And that's what the center is about. We have people here that pretty much will abuse the center and manipulate the center. But our focus and my focus is to assist and support. Not judge, change, put my expectations on you. I have my life. These people are trying to find a life, or find a place, or find some acceptance. They may have never gotten it ever in their lives.

And what bothers me is when people say, well, he's got AIDS. He should want to-- he should want to what? Where was this person about prior? You don't disregard where they were prior. And if you have people that had never had any kind of positive stuff in their lives, and you think that the diagnosis of being diagnosed with AIDS is going to have this spiritual enlightening to them, and they're going to all of a sudden be positive and responsive to positive stuff, it's a joke.

So sitting here, we have a beautiful place. We do beautiful things with them, with the clients but for us to expect them to respond the way with gratitude, and, oh, we're going to be right, and we're going to be straight laced, and that kind of thing, it doesn't work like that. So you don't do it for that purpose.

But the stableness is that they know that will not occur. And that they can come here and say, I don't have anything to eat. I don't have any clothes. I don't have a place to stay. OK, what do we need to do? And being honest about what is this and that. And this guy was scared. He said, are you going to put me anywhere? I said I wouldn't put you anywhere where I wouldn't go.

MICHAELA SOLORT: The women I've seen are either completely alone in the world, or they're going to leave behind a family. And they're already poor to begin with. And what do you do with their children? Their concern is not for themselves. It's ultimately for their children. The women that I've worked with who are mothers, that's their major concern. And that's where their biggest anxiety is.

And in that sense, I have to play the part of an advocate to see what can be done about these kids. Where are they going to go? Who are they going to live with? And what's going to happen for them in terms of counseling? How are they going to deal with their mother's death? And usually, it's single parent families.

DR. CHARLES GARFIELD: The response to the outbreak of AIDS outside the gay White community has been twofold. In many communities, groups have formed to deal with the disease within the defined population. Groups such as the Black Coalition on AIDS, the American Indian AIDS Institute, WORLD, which stands for Women Organized to Respond to Life-threatening Disease, and the Filipino Task Force on AIDS to name just a few.

Another approach was for existing AIDS organizations like Gay Men's Health Crisis in New York and Shanti Project in San Francisco to become multicultural and create outreach programs. Esther Picasso describes the purpose of the Crossings Program within Shanti.

ESTHER PICASSO: The development of Crossings was to provide access through outreach. To that population who for cultural, linguistic, societal problems that have to do with bad experiences with different kinds of institutions of any kind governmental state, whatever. Literacy issues. Not being able to understand. And generally, the isolated issues that have to do specifically with immigrant populations.

We have a high attrition rate because we deal with people without telephones and without fixed addresses. Both of our community offices, satellites are set up in communities that we target. One right across from a large project, the low income housing. And the other one right in the Tenderloin, which is like the Skid Row.

And so that we an impact on the quality of someone's life is success for us. Because we're not a moralistic program. We don't preach 12 step. We don't preach recovery. We don't preach. When we do laundry for people, or when we clean their rooms, and when we see them on the street, it's in between paychecks or in between the welfare or the assistance checks. Sometimes, see the idea that we are consistent, and we keep appearing, and we're visible. The day they choose to reach out and deal with their HIV status, we're the ones they reach out to.

DR. CHARLES GARFIELD: Esther's last words, we're the ones they reach out to, lead us into the other half of the caregiving relationship. That's you, the caregiver. What pressing needs do you have? Why do you do this work? Or if you haven't started, why are you considering it at this point? The fact is all of us get our needs met through AIDS caregiving. The question is what needs? Are the needs helpful to the person with AIDS? Or do our needs become our agenda for the person who's already struggling with the disease?

What caregivers come to understand as one of their most pressing needs is the need to be supported by others as they do this work. We need actively to seek support for ourselves to prevent burnout, as well as the debilitating effects of compassion fatigue if we want to continue to provide meaningful care for others.

Every AIDS organization soon discovers the need for support groups or individual counseling sessions for caregivers. Contexts for sharing frustrations, griefs, and questions. You may think you'll be able to define your boundaries or set your limits. But Larry Yort found out while taking care of his brother that those concepts don't always mean a lot.

LARRY YORT: When he first started getting sick, I had done a lot of work with my therapist about the fact that it would probably be me who was his primary caregiver. And that would be really difficult for me because I'm also sick, and I was afraid it would really drain me. And I had a hard time working out that boundary.

As a matter of fact, toward the end, I lost my boundaries. And I knew it. And I was fully aware of it. And it was like, OK, I'm going to lose my boundaries. And I assume caregivers go through that. I know they do. Whereby you make certain restrictions on what you do and don't do or can and can't do. And all of a sudden, you just naturally slide into this role where you're much more involved, but it was also kind of scary because I didn't know how to not-- I couldn't stop it.

DR. CHARLES GARFIELD: Setting boundaries on how much of yourself you devote to caregiving is a learned skill, not something you know going in. The next segment of the program, we'll continue to explore what the needs of caregivers are, and how you can grow in the wisdom that only comes from experience.