NARRATOR: Michael found out he was HIV positive when he was 17. He died when he was 24. During those years and especially towards the end, Nina learned all she could about AIDS, and the issues concerning a person dying at a young age. The feeling of being overwhelmed must have been tremendous for Nina at times, losing her only child. But she spoke poignantly of how Michael taught her so much about how to be there for him.

Many if not most of the people we interviewed spoke about learning and encyclopedias worth of knowledge in their early caregiving experiences. After Michael's death and a period of mourning, Nina volunteered at several community AIDS agencies and now provides care to two people with AIDS, both of whom are benefiting considerably from what she learned with her son.

NINA: And I knew that my son was so lucky that he did have me and he did have some really close friends that were there. And I also knew there were people who did not have this. And I could not imagine how anybody could go through this alone. And that used to really bother me thinking about somebody having to try to go through this process alone. It was just horrifying to even think of it.

NARRATOR: There's no substitute for on the job training, but most of the people you're hearing from would agree that having more formal training specific to AIDS caregiving is also vital. The training model that I developed for Shanti Project 20 years ago and that still used today was based on the premise that men and women from many different backgrounds who volunteered to be peer counselors could learn to be extremely talented caregivers.

That is if they were given a solid training program at the beginning of the work and also had training opportunities that were ongoing for as long as they were volunteers. After a careful pre-screening to weed out people whose current capacity for caregiving was suspect, volunteers are given extensive multiday training, not just a one or two day orientation. This training included at some of the topics we've touched on already.

What are the pressing needs of the person with AIDS? What are the pressing needs of the caregiver? And how do you deal with some of the tougher aspects of the role of caregiver? This audio program is not a substitute for a comprehensive training experience, but let's explore for a few minutes. Some of the issues that come up in my advanced caregiver support group.

As the illness progresses, caregivers may spend increasing amounts of time with the person or persons in their care. Your sense of time changes as you get more and more absorbed by care responsibilities and your perception of what's important in life may narrow. Yet, there's more to life than caregiving. You've got a personal life, work, other people who need you.

Sometimes something like a holiday can become a burden rather than a joy. Chuck Landis described his conflict as he prepared to fulfill a commitment to meet his family in Florida for Christmas, while his lover Ed was in San Francisco with AIDS.

CHUCK LANDIS: Ed was pretty sick at that time. I didn't have any diagnosed specific problem, but it did look like he was slipping. So I lined up friends to check in, make sure everything was OK. I made sure that the meds were there. We had an adequate supply of all of his medication.

I had gone to the 5 and 10 to buy small envelopes. And I poured his doses into the envelopes for morning, noon, and night for each day that I would be gone with the times on it and the day. So that when I came home I could tell by the torn envelopes that in fact all the medications had been taken. So I basically covered all the bases that I could before I left.

Went down to Florida for Christmas and we had a pleasant Christmas, but there was this underlying anxiety. And even though I was calling home every day, Ed typically would tell either me or the doctor that everything was fine when, in fact, things could be haywire. My anxiety was seems to have been well founded because I got back to San Francisco at noon on Christmas Eve day and by 1 o'clock, we were at Saint Francis Hospital and he was being diagnosed with his first bout of PCP.

Do I regret having gone? Not really because I think he probably-- he may have had PCP before I left and it didn't manifest itself until the night before I got back. And we did everything we could. We have safeguards in place and fortunately it turned out well.

NARRATOR: Despite the enormous amount of work, many caregivers do to help someone manage AIDS. They will still be days when you feel helpless just not able to do enough. It's not unusual for a caregiver to say that this is the hardest thing they've ever done in their lives. That nothing even remotely prepared them for this. Sometimes they wonder if they'll ever recover.

Having such feelings is common, particularly in periods of acute illness and times of multiple griefs. Let's consider for a moment the added burden of being HIV positive yourself. Several of the caregivers you've heard are in this situation. We asked two of them to comment on it. First is Larry [? Hewert ?], whose brother died of AIDS. After Larry, you'll hear from John [? McGran ?] who founded an organization to support AIDS caregivers.

LARRY: I was supposed to die first. I was diagnosed six years ago. He was diagnosed six months ago, literally. I was supposed to die first. That was the way I had wanted it. That was always my theory. And instead, he died.

I was really angry because I was supposed to die first. I was just really angry. I was angry that he left me. And also, I also know that had he stayed, it only would have been harder for him and everybody around him and he knew it. So if you're going to die, great. He was blessed by not having to linger through it with a disease that could have been months in the making of awfulness for everybody. But I still wanted to go first. That was the way it was supposed to be. I didn't want to have to take care of all of this and I've had to.

JOHN: I think I do my work with more love and compassion because I am HIV positive. And I'm a gift to people that I never imagined I would be. I mean, I planned on teaching people and guiding people and fixing people. And here I am a wounded healer. I'm broke and I'm fragile and I'm just a totally human being that has very little control, but people connect with that and they get in touch with their own pain and there's a more self-acceptance for me and for other people. And that's a big thing to accept. Life as it is to accept ourselves as we are.

NARRATOR: As a caregiver with HIV or AIDS, you may be forced to give up your end of the bargain temporarily or even permanently when you need to take care of yourself. At times, your role as caregiver may need to be renegotiated. Paying attention to yourself and reevaluating your capacity for caregiving in a given situation is not just a nice or useful thing to do. It's a primary responsibility. This idea is so hard for less experienced caregivers to get, whether you are HIV positive or not.

Simply put you become less effective as a caregiver, the more you compromise your physical strength and resilience and your mental stability. Caregivers and others debate constantly about whether a careful considered focus on your own well-being means you're self-centered or if you take a break, seek counseling, or ask another caregiver to help out for a while, it means you're not as committed as other people are. It's not self-centered, it's smart.

As caring continues, as hospital visits, and home responsibilities mount as you struggle to deal with your increasing anxieties, work, and financial pressures and a growing sense of loss, you may be forced to the conclusion that you're nearly depleted. You find yourself feeling angry, moody, or depressed outside the context of giving direct care. And tears seem to well up in your eyes at the drop of a hat.

Other people may begin to ask you, what's wrong? Or if they know what's wrong, they may offer advice or support that you reject out of hand. You find yourself answering their inquiries with I'm fine, I can handle everything. Knowing full well inside, you're on the verge of falling apart. Or you may say, I'm fine and mean it. But the central truth of the matter will become more obvious, even when patience and equanimity or qualities that you've spent 40 years cultivating as Jacinta did, you can still not know where your limits are and when you've exceeded them.

JACINTA: We had had a client here who as a result of a gay bashing had died. This was his last January. I was extremely angry over everything that happened and I was horrified when I saw his condition. He didn't die right away. When I saw his condition as a result of what one human being can do to another, I have never seen that before.

I didn't realize that that was one thing I didn't know how to cope with and I buried it. And if people told me that because of his death, I was acting differently. I would say no. I wasn't. And both my supervisor and our executive director had told me one day that I needed to take time off that I was edging up to burnout. That I wasn't really being myself even with the clients, but I still denied it. Till the next morning I was coming to work on the bus and some woman just tried to get on the bus ahead of me and I gave her a good hard shove and got on the bus.

And I said, wow, they are right. And I took a two-week leave of absence. And I did realize then in the course of that from a counselor that it was not being able to have dealt with Eddie's death and having denied some of my own feelings in it. So once again, it was getting back to my own feelings letting myself get together so I could come back.

NARRATOR: For Jacinta, the sign of overload was shoving someone who cut in front of her as she got on the bus. Here are some direct statements from some of the other caregivers you've heard so far. I gained 150 pounds. I got in a car accident. My 20-year relationship with my husband ended. I started drinking heavily. Are these signs of burnout? Maybe. But let's look at the notion of burnout more closely.

It will be important as you self-monitor your stress level and well-being that you're able to identify accurately what's going on. Burnout is a term most usefully applied to situations where the caregiver has experienced a loss of concern for the people with whom she or he is working. Besides physical exhaustion, burnout is characterized by emotional exhaustion in which the caregiver no longer has any positive feelings, empathy, or respect for the person with AIDS.

I'm not talking about transient temporary feelings that everyone experiences when they have a bad day or when a situation takes a turn for the worst. The term burnout is accurately used only to describe a persistent chronic condition. The caregiver experiencing burnout often develops a very cynical or dehumanizing perception of their care recipients. Labeling them in derogatory ways and treating them accordingly.

The burned out caregiver may start offering their psychologically defended coping style as advice. Don't get emotionally involved with the people you're caring for. I haven't seen as much real burnout as you might think, even in the bowels of the AIDS crisis. Although, burnout undoubtedly occurs among AIDS caregivers, there's another phenomenon which constantly gets confused with burnout. It's known as post-traumatic stress disorder.

Post-traumatic stress disorder is characterized by symptoms of extreme stress following an event or events outside the range of usual human experience. Perhaps the most common situation is the experience of multiple and continuing deaths in one's immediate surroundings. The debilitating symptoms leading up to post-traumatic stress disorder in caregivers, I'm going to label compassion fatigue.

What I'm saying or people staying at the front line of the pandemic and who are still caring still emotionally involved, yet evidencing some of the same symptoms as those who are burning out. Those symptoms include depression, anxiety, hypochondria, being on fast forward all the time instead of focusing on the present, having frequent arguments with clients and coworkers, and so on.

But again, the essential difference between compassion fatigue and burnout is the presence or absence of caring and compassionate feelings in action. Those caregivers on the road to burnout begin unconsciously to suppress or wall off more and more of the strong feelings that accompany their work.

Caregivers experiencing compassion fatigue or its most advanced form post-traumatic stress disorder are able to monitor this decrease in empathy and feeling and remain emotionally accessible. But they describe greater and greater difficulty processing these emotions. They report feeling more like reverberating chambers with fragments of strong emotions, images, and bad dreams intruding throughout the day and night.

Too many deaths, too much grief, pain, and sorrow all mostly unresolved can lead to a state of ongoing fear and emotional engulfment. The distinction between burnout and compassion fatigue is an important one in terms of deciding what to do. Someone burning out needs to stop, withdraw, or even take a long break. If you don't, then something or someone will force you to. An illness, an emotional breakdown, an accident, or someone telling you in plain English to leave.

What about compassion fatigue? The first thing to do is not to let it advance to post-traumatic stress disorder or the symptoms pile up and you may reach the point where you're tempted not to care anymore the road to burnout. The phenomenon of post-traumatic stress disorder that occurred in many Vietnam era veterans has alerted psychotherapists to the occurrence of this disorder in people whose battleground is in working with people with AIDS.

Professional therapists are just beginning to develop treatments for the traumas they're seeing, and the success rate has not been spectacular. The stark reality that more Vietnam vets died from suicide after the war than were killed during the war points to the seriousness of post-traumatic stress disorder. It's important to be aware that a similar outcome may be awaiting AIDS caregivers who stay at the front line enduring compassion fatigue and receiving little or no adequate support.

I simply want to make the case here that burnout and compassion fatigue are different. And if compassion fatigue goes unaddressed, post-traumatic stress disorder can occur. Now this leads me to a brief discussion of self-care. There are ways for you to diminish the burden of stress that comes with AIDS caregiving of long duration. You need to rediscover that not everything in the world is terrible and nightmarish, no matter how awful things are in the caregiving situation.

I'll mention some things you've heard before, but I ask you to consider each one carefully. Do some regular exercise that you enjoy or use regular stress reduction techniques three times a week or more. Make a commitment to weave certain activities into your life that you enjoy. Ones that are renewing and nurturing.

Don't sacrifice everything to caregiving. In AIDS caregiving as in life in general, things can sometimes seem grim, but not necessarily serious. One of our interviewees said when he watched a man with AIDS dementia pulling a toaster around by the cord as if it were a dog because he was taking it for a walk, he couldn't help but laugh.

Check your laughter quotient and your sense of humor. How often do you experience honest, deep belly laughs? Sometimes, I go for weeks without a good laugh and when it happens, it almost feels strange. I remember, oh, yeah, that's how it feels when I laugh. Build in timeouts or time offs so that you can vary the intensity of your work.

Even if you're the sole caregiver for someone you're close to, you can take a break of several days. Remember also that you're part of a caring team of people. If you're a sole caregiver, you can reach out to AIDS agencies for help. One note of caution, make sure that your role as caregiver isn't usurped by well-intentioned professionals moving in. This can increase rather than decrease your stress.

If you're one of those professionals or a very dedicated volunteer, keep in mind that you don't have to do it all by yourself. Caregivers are frequently overly individualistic and self-reliant folks who too often assume that they can be Superman or Superwoman. I can't overemphasize the importance of joining a support group. If there isn't one in your area for caregivers, start one or ask an AIDS agency to start it.

Consider looking at what I'd like to call your spiritual side and more depth. Whether or not you've been a spiritual person historically, it doesn't matter. Don't confuse spirituality. The sense of communion with something larger than yourself with organized religion. You may find spirituality in an organized religion and you may find that on your own. Can you make a commitment to considering your own spiritual development?

In the final segment of this program, we'll look at this question more closely. Besides the physical exercise, the meditation, the vacation, the novels, and the occasional movie. All the usual and necessary health maintenance and stress reduction techniques. It is precisely during the most difficult times that you need to ask yourself, where am I going with my life? What do I want from life besides the benefits that come from AIDS caregiving?

Work toward a meaningful life goal changes the feeling of life sometimes substantially. No more are we just reacting, feeling like helpless pawns in a struggle against the disease. If you have a deeper life goal that demands that you grow in self-awareness and compassion, progress toward that goal simultaneously allows for a greater capacity to serve others.

Sometimes you may feel like saying to yourself, who cares about your narcissistic preoccupation with personal goals and ambitions. Just do the work. Certainly, I'm not suggesting shifting the focus of your life energies and direction from caregiving to self-serving aims. The point is this, it's not an either/or choice, but rather one that's both end. The more self-aware and resilient I am and the more I develop my capacity to learn and grow, the greater will be my capacity to serve others.

[MUSIC PLAYING]

If there's one idea and only one idea that you hold on to from this discussion, I would like it to be this. Experiencing burnout or compassion fatigue does not make you a bad person. We often misattribute the stress we experienced to personal problems or inadequacies. Burnout and compassion fatigue are not conditions that manifest in bad or inadequate people, rather they are the result of bad situations that you may have given your heart and soul to.

If you assume a personal cause that you're guilty or inadequate or to blame, then you'll look for a personal solution instead of a situational one. Only by sharing your feelings and experiences with fellow caregivers in a support group and seeing what's common to all of us, can we get a better perspective on the situational sources of stress? Sources like inadequate resources, insufficient funding, dysfunctional organizations, or simply too many people to serve and not enough caregivers to do the work.

One of the areas in which this is particularly true is when AIDS caregivers experience multiple griefs. Each new death opens up all the previous graves again. Feelings and memories of others you've cared for may surface. There's no such thing as a full working through of grief when there's no time to work it through, unless your caregiving is confined to one person and you have the time off to grieve after the death.

For many of us, grief is a backdrop. A constant fact of life rather than something to be fully worked through. I offer three guidelines for caregivers who are going through multiple griefs. The first is to know your own limitations in terms of number of people with whom you can work intimately at any given time.

Also, getting feedback and supervision on your caregiving work is invaluable. Remember just sent this story earlier about not heeding the warnings of her colleagues. Second, when a person dies, it's important to go through a period of active grieving to experience the sadness and other feelings after someone dies, but not to feel guilty for not grieving to the same degree for each person.

And third, reach out and identify personal sources of support. Many times, caregivers find it much easier to help others than to advocate for themselves when they need help coping with grief. It's important for us as caregivers to acknowledge our humanness. To recognize our fear, anger, grief, resentment, or despair, and to find healthy ways to express the thoughts and emotions associated with these feelings states.

Important to find someone to talk with. Important to give ourselves permission to cry and rage. It's only when we've cleared a path through this heavy emotional terrain that we can begin to think creatively. That we can begin to make constructive choices in response to the changing needs of people we care for and to our own needs as well.

[MUSIC PLAYING]

DANNY: It used to really bother me sitting in on the daily report meetings at the hospital with the doctors, nurses, [INAUDIBLE] staff and the social workers because a lot of times, the doctors or the nurses would give the prognosis for the patient. And I'd meet the patient and that wasn't their take on their situation at all. The doctor would say, well, this patient is going to live through the weekend and I go see the patient and I'd say, how do you feel? Do you do you feel like death is near? And they say, no, I'm going on a RSVP cruise in March or I'm going to see my mother next April. And many times these people would walk out of the front door of the hospital.

NARRATOR: One of the striking ways in which advocacy for people with AIDS has changed from the 1980s to the 1990s, is captured in a shift in the language we use from dying with AIDS to living with AIDS. One reason for that shift is the situation Danny [? Castelao ?] just described. People who get one of the opportunistic infections that AIDS makes them vulnerable to can be close to death and then pull through and regain a relatively decent level of health.

For part of the '80s, it was assumed that the majority of people who were HIV positive would die shortly. But estimates of the number of people carrying the HIV virus who have had no symptoms for over 10 years range from 10% to 35%. For caregivers, this raises the concern of how best to support a person who is HIV positive or who has AIDS in order to extend their survival or even beat the disease.

The shift from dying with AIDS to living with AIDS was captured dramatically in the San Francisco AIDS Foundation educational campaign called Be Here For The Cure. Michael Lee, who's director of client services said that when the campaign began in 1992, there was general support for it. Except that he and some others were worried that it might somehow offend those people with AIDS who are clearly not going to be around for the cure. So they decided to go directly to them.

MICHAEL LEE: We tested that campaign in the reception area here because I wasn't convinced that our clients wouldn't be offended by it. So the first few days that we had posters up and made posters available, I personally asked clients when they would ask for a poster. What do you think about this? What does this mean to you? And I got an overwhelming positive response from clients even to the point of some clients saying, I know I won't be here for the cure. But I hope this helps other people to be here for it. And I thought, you couldn't ask for a better endorsement.

NARRATOR: The Be Here For The Cure campaign fits in well with some new areas of research in medicine and psychology. There's been so much written lately on the power of the mind to influence the course of a disease that a whole field has sprung up Psychoneuroimmunology.

In his book, *No Time To Wait,* Nick Siano mentions a study conducted by Dr. Mary Ann Fletcher at the University of Miami. She found that a routine of exercise, meditation, and stress reduction increased immune function and T4 cells in AIDS patients as much as the drug AZT did for a similar group and within the same time frame.

Although, one study certainly does not allow for a definitive conclusion, it does point out a fruitful line of research for the second decade of AIDS. In his book, *Surviving AIDS,* Michael Callen offered his version of the characteristics of long-term survivors. One of which was that they tend to have extraordinary relationships with their health care providers.

They spoke of having a healing partnership with them. The question that comes to mind is, how do you know whether it's more supportive to be talking about Be Here For The Cure or more helpful to be discussing what unfinished business the person has that he or she would like to take care of as death approaches? Penny Chernow gave us a beautiful response to that question.

PENNY CHERNOW: You got to be with a client if-- if the client believes they're going to be here for the cure or brown rice is going to get rid of HIV in their body, you need to support that. Not by encouraging it, not by say eat more rice or-- of course, you're going to be here for the cure, but not changing that. That's what they need to believe.

In my experience is that when they stop believing anymore if they get sick enough and tired enough, they'll cross over into dying. But you got to go with them when they go. And I believe that the disease itself crosses them over, you don't need to do it. And that they'll look at it and plenty of time to take care of things. And if they don't, so what? They got to die the way they want to. It's their last piece of dignity. It's their last choice.

And if you're standing around with an agenda about how you think they need to do that or what you think they need to know, or what you think they need to believe, or how much denial you think they shouldn't have. You're going to burn out quicker than they will. I just go where they are. If they're feeling great things are going to live forever, we talk about it at that time.

The next day if they come in and say, jeez, I got fevers, I don't think I'll be here for a month, I ask how does that feel? What do you need to do to take care of that? Do you have things you want to do to finish things off? The next day come in feeling great. We're back that they'll be here for the cure. I don't need them to be consistent. They need me to be consistent.

I'm not there to make them do anything except support them in some advocacy. I mean, I see myself as an advocate for them whatever they need. And that changes because their health changes, and I need to be able to go with that. I mean, I saw a client said goodbye to him and two weeks later, I saw him at the mall. When I say goodbye, I mean goodbye.

I mean, this person's going to be dead. I'm never going to see him again. Two weeks later, I saw him at the mall. I mean, you know, you just don't know. And if you got this idea that you do know, you'll burn out real fast and you'll make your client crazy.

NARRATOR: I appreciate the wisdom in Penny's remark. The disease crosses them over. You don't have to make any hard and fast decision on any particular day about whether to talk about cure or improvement or death. You let the person with AIDS make that decision. A decision about dying, well, they may talk about it openly. And more frequently through stories they tell the tone of their voice and through other nonverbal messages.

And this decision may change from day-to-day, even hour-to-hour. All the effective AIDS caregivers I've met have been advocates of life whenever possible. And for as long as the person with AIDS wanted to fight for life. And if the disease crosses the person over into preparation for dying, the caregiver is still there as a continuing supportive presence.

I hope that the life affirming vision captured and be here for the cure does not become part of some politically correct dogma. I've heard an unfortunate confusion among people who don't understand the psychological and psychosocial aspects of AIDS, which goes something like, if you're skilled and prepared to be with a person who's dying, then somehow you're rooting for that outcome.

Throughout this program so far and I'm sure in your own experience, you've heard caregivers forced to come to grips with the fact of death. Some people have given deep thought to it. Some have read a lot or gone to workshops on how to be with a dying person. And yet, we still hear from a few that when caregivers are prepared for that outcome, it means they're rooting for death, not life.

This mistaken impression is based on the delusion that there's no such thing as a terminal patient. That is if the person you're caring for dies, you'd have to conclude after the fact that the time before death was his or her dying time. Such folks believe that denying the reality of death is somehow rooting for life as if the caregiver can only side one way or the other.

The fact is that if your denial caused you to miss the dying time of the person you've cared for or you didn't address this time in any coherent way, then you may have missed out on one of the most powerful psychological events in the person's life. And this may be experienced by the person with AIDS as abandonment.

When it's clear most especially to the person with AIDS that all attempts to reverse or slow the course of the disease are not working and that his or her decline is obvious. Then the caregiver's ability to be with the person during the dying time is what's needed. Too many AIDS deaths, too rapid and too soon, absolutely. Yet, this is also about recognizing what is that dying has happened to every human being who ever lived and will happen to all of us living now.

I'd like to close this segment by offering you the idea that being humanly correct is more important than rigidly adhering to what's politically correct. In the final segment--

JEWEL GRAY: OK. There you go. You've been listening to *After Hours* of the AIDS caregiving tape. You can find that at some of your local bookstores. This is Jewel Gray, and we're wishing you a good night and stay tuned for Eric with the carbon dating game.

ERIC DEUTSCH: Yeah.

SPEAKER 1: Yeah. Yeah.

SPEAKER 2: Yeah.

SPEAKER 3: Yeah.

SPEAKER 4: Yeah.

SPEAKER 3: Yeah.

SPEAKER 5: And that was week three. We've got next week will be week four, the last week. And that, in fact, next week is going to be the music show.

SPEAKER 6: The music, that's right. Five weeks.

SPEAKER 5: Fifth Saturday. Yeah.

SPEAKER 6: So we're going to give this to Eric? Which button? Is this the only button I have to push? Goodnight.

SPEAKER 5: Wait a minute.

SPEAKER 6: Goodnight.

SPEAKER 5: Goodnight.

[MUSIC PLAYING] (SINGING) Hi, I'm not home right now, but if you want to leave a message, just start talking at the sound of the tone.

HOST: It's 10 o'clock, Friday night, and I'm at the station doing my radio show. Esoteric Adventures where my co-host and I bring you the oddities and highlights from the recorded universe. So hang up, tune in to 90.1 and don't call back or you'll wake up my fish. Don't forget, that's Esoteric Adventures with your flight attendants, Jim Squared on KPFT Houston.

[MUSIC PLAYING] (SINGING) Home. Ha, ha, ha, ha, ha, ha. Well, you don't know me. Ha, ha, ha, ha, ha, ha, ha, ha. But I know you. Ha, ha, ha, ha, ha, ha, ha, ha, ha. [INAUDIBLE] Ha, ha, ha, ha, ha, ha, ha, ha, ha, ha, ha. [INAUDIBLE] Ha, ha, ha, ha, ha.