

Wrestling with AIDS — health providers persist in face of risk

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16.7.91
SANTA CRUZ — For Dr. Tom Deetz of Watsonville, treating AIDS patients is like negotiating with the unknown.

"It's an up-and-down illness, people get better and get worse. It's a roller coaster," said Deetz, who treats about 30 AIDS patients.

But eventually the roller coaster slows down, said Deetz.

"At some point the drugs may not work and the patient might not respond. Then, we may not know that first question AIDS patients ask: 'Well, how long do I have, Doc?' That's a tough question we can't pin down for them."

Deetz is part of a countywide network of physicians, nurses and attendants who treat people with the human immunodeficiency virus, called HIV, and acquired immune deficiency syndrome, or AIDS.

These care givers in the county face the dangers of working in close proximity with a deadly — and controversial — disease.

But most workers say there are amazing rewards that come from participating in the care of HIV-positive people and those with full-blown AIDS.

They also say that Santa Cruz County is "far ahead" of most of the country in dealing with the AIDS epidemic.

"My vision of how AIDS is handled in the county is like a patchwork quilt," said Elaine Beardsley, a case worker for the county's Health Services Agency.

"If you stitch in a piece, you become part of the quilt. Not any one of us can do this work by ourselves. It's really a collaborate effort," said Beardsley.

Pieces of Beardsley's "patchwork quilt" include confidential testing sites, county case workers, physi-

cians, nurses at Dominican Hospital, the Santa Cruz AIDS Project's services, and the Hospice Caring Project.

The 63 people currently living with AIDS in the county often rely on several of those resources at a time.

For Beardsley, nearly 85 percent of her visits with the 20 or so AIDS patients she sees are in the patients' homes.

And she said witnessing the dying process is a "privilege."

"You get to know people really quickly at their fear level and at their hope and dream level," said Beardsley.

"Maybe we wouldn't choose each other as friends in the real world, but I've known some of these people since 1988. We are friends."

One of Beardsley's clients is Jerry Moore, 41, of Santa Cruz.

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Bill Lovejoy/Sentinel

Health worker Elaine Beardsley visits AIDS patient Jerry Moore.

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Moore has been living with AIDS since 1981, when doctors at UC Los Angeles discovered there was something wrong with his immune system. At that time, the doctors didn't have the name AIDS.

Moore said that over the two years he has been working with Beardsley, she has helped him enormously.

"When I first met her, I had a lot of anxiety because I didn't know who she was or what she wanted. I was scared," he said.

"A lot of times, just her presence can help me feel better. She's helped by just listening to me when someone else would have walked away," he said.

"I can barely take care of myself," said Moore. "With help from Elaine, I can lead a more normal life."

"Santa Cruz is so far ahead of what most communities are doing on this problem that it's really incomparable," said Dr. Arnold Leff, who has seen more than 250 patients in his six years of treating AIDS patients.

Leff, who served as interim county medical director in 1985, now treats about 100 patients who are HIV positive or who have full-blown AIDS.

He said physicians in Santa Cruz have the benefits of the latest technology without the huge numbers of cases — and professional burn-out — found in San Francisco.

Although Leff has seen many changes in understanding HIV since 1985, he said the country is still in the early stages of the epidemic.

"We have problems that we're dumbfounded about, complications that have never been tried anywhere. Every case is still difficult and nothing is routine."

Leff said he has identified three separate stages of the disease.

The first phase begins when a patient tests positive for HIV. Patients are then monitored to make sure their immune cells stay at a 'relatively healthy level, according to Leff.

"We have people we've been following for the last six years who are still in that stage," he said.

An uncounted number of people in the county have the virus antibodies, but have not developed AIDS symptoms. Mary Stonehill, a nurse at Dominican Hospital, said at least a dozen of those people are women — some with children.

The next phase is marked by some decline in immune cells.

"Those are the people who wind up on an active treatment plan, like AZT (azidothymidine) or any one of a couple of experimental drugs we have here," Leff said.

The third stage "used to be considered the time when people got treated," he said. But because people are now treated earlier, the stage is considered a later phase.

In this third stage, according to Leff, the immune cells drop to the point of requiring aid to prevent or treat any one of many AIDS-related infections.

"Occasionally we see people come into the office in that stage. They've not been tested; they've not been followed. Unfortunately, when people come in at that stage

it's very difficult to do very much, other than keep them going for some time," said Leff.

People with AIDS have better chances now, according to Leff, Deetz and other health-care providers.

"In the early days, the best we could do was hold hands and scratch our heads," said Leff. "And now, even people who have outright AIDS with severe opportunistic infections are living four and five times longer" than they were living in 1985 or 1986, he said.

"Right now, median survival time is 20 months," said Deetz. In two or three years, it may be three or four years."

According to Leff and Debbie Weschler, a county epidemiologist, more women will contract AIDS in the future.

"It's really technically obvious that that's going to happen — the mucus membrane exposure in the woman as compared to the man is greater in any sexually transmitted disease," said Leff.

The Santa Cruz AIDS Project, which grew out of a City Council decision to encourage education on AIDS, provides many needed services for HIV-positive people and AIDS patients.

"We're here to weave the net a little tighter," said Wendy Baxter, SCAP's director of client services.

The net includes counseling and support groups, help with the yard and housework, and legal services. Baxter said she also helps make funeral arrangements for patients, when necessary.

Former mayor and city council member John Laird, director of SCAP and a founding board member since 1985, said SCAP tried "to educate people so they can take some control in the situation."

Laird said medical professionals deserve a lot of credit for their work with AIDS, in spite of the danger of being stuck by needles and the challenge of working with the dying.

"I have had some needle-stick injuries," said Leff, "and I have had some staff who had some needle-stick injuries. But so far nobody's contracted the virus."

"Most physicians in this community who are taking care of HIV-infected patients, whether they are surgeons, specialists or whoever — all of them are really taking some risk," said Leff.

"It flashes through my mind when things splatter," said Beardsley. "Being a nurse, you walk in and someone's throwing up and you hand something to them. I think, 'My skin's intact, it's OK.'"

Deetz said he tests himself regularly to make sure he doesn't pass the virus on to his spouse.

But Beardsley purposely does not take the HIV test for her career and economic "survivability."

"I'm a single woman, I need to keep working. I don't have any fall-back support. If someone's law mandated that I tell people I was positive even though I was taking universal precautions, who knows what would happen."

For information on free, confidential HIV testing, call Santa Cruz Health Services Agency at 425-2671. For other testing sites, call 425-2048.