

Man with HIV draws support from family to help with disease's daily challenge

Editor's Note: To protect the privacy of the man in this story, his name has been changed.

By Wendy Navratil

Dan had some difficult news to tell his father via long-distance telephone on that day in February 1986:

He had been fired from his job. He was gay.

And he had tested positive for HIV.

"When are you going to die?"

That was his father's first question after hearing his son's final revelation.

At that early stage in the virus' study, doctors gave people like Dan, who was then 20 years old and a University of Nebraska-Lincoln student, one to three years to live.

That was seven years — and several friends' funerals — ago.

Now, as he begins to close in on his 10-year anniversary with HIV, Dan is setting his sights on the survival record.

"I tell a lot of my friends, 'I'm going to live with this.' They say, 'Yeah, yeah, yeah. Everybody dies.' But there's so many medications out right now, that it (a cure) is right around the corner for me."

People can have HIV for as many as 10 years before AIDS sets in, Dan says. This means that he may have three more years before he develops AIDS.

After getting AIDS, if he could hold on for as long as one of his friends, who has had AIDS for 4 1/2 years, he says, the possibility of a cure being discovered in time to save his life does not seem that remote.

But a cure is still only a possibility. To keep getting up every morning for the last seven years, Dan has had to find a more immediate coping mechanism.

He calls his approach positive reality. "It's looking at HIV in a positive, but also a very real, manner," he says. "Right now I want to live, but right now the real side of it is terminal. I probably, in my seven years, have lost 30 to 35 friends — for a while it seemed I was going to a funeral once a month."

"The real part of HIV is I may have to go to funerals of friends I've cared for very much. But the positive side of it is that it makes you realize that we don't live forever."

The reality of being HIV-positive began to creep up on Dan when, in the fall of 1985, the gay-lesbian student group on campus received its first pamphlets on AIDS.

"I came home — I had had this blotch on my shoulder — And of course, reading some of the things in this brochure — it hasn't gone away, it's purplish, it just keeps getting bigger — and I thought, 'You know, I should get this looked at.'"

He went to a doctor on campus, who told him he had a minor skin infection. But after Dan told the doctor why he had sought advice, the doctor recommended Dan be tested.

"At first, I kind of had doubts, because I felt I was . . . I had not made myself at risk — not saying I'm a perfect angel, but I never felt I was at risk."

He went ahead with the test anyway in November.

"I waited. I waited actually several months before I got my HIV results back."

Omaha, where HIV tests were processed, was inundated with tests as people in the Midwest began to learn of AIDS. Dan's test had to be sent to Des Moines to be processed.

"Then, on Jan. 1, 1986, I got real sick. They never really diagnosed it as anything, but it was very similar to mono, a real severe case of mono."

"I had a friend who, when I was sick there, he kept saying, 'It's going to be AIDS, it's going to be AIDS.' I was starting to get real paranoid."

And on Feb. 1, the HIV test results confirmed Dan's mounting fear.

"I was shocked. I was actually blown away — that would be a better phrase for it. I felt, you know, the way the brochures read, that only the real promiscuous ones . . . that it was mainly an East and West coast problem."

"I was one of the first (in Lincoln). And at the time, there just wasn't much here

for the epidemic. There weren't support groups. The gay community shoved it underneath the rugs, and the heterosexual community really didn't even recognize it as a problem. And so my support structure was very limited."

But misunderstanding of the virus seemed to have no bounds.

After Dan's boss at the machine shop where he had been working since 1983 found out that Dan had HIV, he gave him three choices:

"They gave me the condition of either quitting working, laying me off permanently, or telling everyone on the job."

When Dan told the Nebraska Civil Liberties Union about the incident, it contacted the national ACLU about Dan's case.

"They were going to take it as a national test case. They felt it was winnable. I went through the whole process. But my parents owned a shop in Illinois, and I felt that if this was going to go national, that it would really have affected them. I probably could have made enough money off the case to support them for the rest of their life, but I felt they had worked so hard for this place, that I couldn't do it."

"So we took an out-of-court settlement."

With encouragement from his parents, Dan moved back to Illinois to live with his parents. Neither his parents nor his brother and sister-in-law expressed any ill will because of his sexual orientation or HIV.

"But my mom and dad swept it (HIV) under the covers for a long time. I put on a real good image for them. I looked healthy, but I wasn't healthy. It was hard for them to see it until I was getting sick."

He had started working full-time in his parents' shop.

"But I was sick all the time — all the time. I couldn't fight anything off. My parents were paying me for 60 hours a week when I was working 20. I felt I didn't want to do that to them."

And his doctor told him he couldn't do it to himself. At one point, his T-4 cell levels were down to 224. When T-cell levels fall below 200, doctors generally agree that AIDS has set in, although that method of measurement has been the subject of much debate.

He quit his job, and moved back to Lincoln in June of 1990, where he first had come in 1982 to study sports medicine at UNL.

"My parents wanted me to stay there. But I just can't live in a little town. People wonder. In fact, people wonder now, 'What the heck does he do that he can come home every month?'"

"Basically, it was all for (his parents') protection. And they knew I loved Lincoln, Nebraska. My support structure's here."

On his return, however, neither college, which he had attended for 3 1/2 years, nor work could be a part of his life. With his T-4 cell levels so dangerously low, his doctor told him he shouldn't work.

"It was really hard for me 'cause I consider myself a workaholic. But I was coming home from my job, barely having enough energy to eat, then I'd go right to bed. When your blood levels get that low, and you're pushing yourself, you're just pushing yourself right into full-blown AIDS."

He applied for social security disability compensation.

And yet again, he found himself waiting for an answer. It was 16 months before his case was accepted.

That period of waiting brought major changes in his lifestyle.

"I went from making \$1,500 a month to nothing. You see a lot of my nice stuff here, but it's stuff I had before I went on disability."

"I lost my vehicle. I had to turn it over to the bank 'cause I couldn't make the payments on it. . . . I hated losing that thing — I cried the day it left."

Now, Dan pays for most of his groceries with food stamps, and because his income is below the poverty level, Medicaid covers his medical fees.

Although he has adjusted to those changes and sacrifices, Dan says he often has thought about the settlement he could have won if he had pursued his lawsuit.

"But that's the way it has to be. It's made me start appreciating more the less material things."

For one, being on disability — what he calls "semi-retirement" — has helped bring



David Badders/DN

his T-4 cell levels to about double what they were when he was working. While he has been to the emergency room a couple times, he has yet to stay in a hospital because of HIV-related problems.

Even so, he must be careful not to push himself too hard with exercise, speaking engagements at schools and for various events, and traveling — he goes to Illinois about once a month.

"There's times I haven't listened to my body. And I'll get real sick. That's the way my body says, 'You've done too much.'"

At the same time, he must monitor carefully his intake of medication.

"I'm on AZT, Nizoral for thrush (a yeast infection of the mouth), vitamins and some other things I'm kind of embarrassed to mention, like stool softener. My body just doesn't function as well as it used to."

Exhaustion is a nagging side effect of the virus, he says. He needs at least 11 to 12 hours of sleep a night.

"Although sometimes I could sleep all darn day — I mean the whole entire day — I say, 'I've got to get up and do something today.'"

And at his T-4 cell level, one of his days every three months is spent at the doctor's office having blood tests done.

"It's kind of funny, 'cause it seems like the times when I feel the worst, I go to the doctor and he tells me my count is really high. And the times when I feel really good, it's the lowest."

But Dan says he takes the highs and lows in stride. Because he's had HIV longer than most, he's learned to live with the implications of the disease that others might never confront, he says.

"I claim myself a survivor. A lot of people get HIV, and they consider themselves dead. I get tired of seeing those people. A little pity's OK, but to wallow in it. . . . If they continue that way, they're doomed — if I had done that, I'd have been dead six years ago."

"I keep a good humor. People a lot of times will find me joking about the subject. One night a friend of mine came in and we were talking — she was really torked at a couple of people after the Magic Johnson interview who had come in, and said, 'Well, I'm getting tested cause I used a public restroom,' and, you know, stuff like that. So one or two of us from our support group got up and I said,

'Yeah, yeah, I got mine off a door knob.' And another got his off a coffee cup going through a McDonald's drive-through. . . ."

"I keep a good humor about life in general," he says. "Not to say that I don't take life seriously, 'cause I don't think I would have made it this far if I didn't, also. But I keep it in perspective."

Dan says his attitude and environment are responsible for his longevity.

"A lot of times, I speak about maintaining myself physically, mentally and spiritually — a lot less spiritually. I'm not a biggie on religion. But I'm kind of a health nut. I've always been involved in sports. Now it's a big part of my program. Every day I'm doing something physical — either I go down to the 'Y' and do aerobics or do a workout. Nice days I go on my bike and ride four or five miles. If I'm homebound, I'll work out here."

That physical activity, if he doesn't overdo it, takes care of him mentally, he says, by helping to reduce his stress. But his social life also is important.

"I love to dance — I really like country music. You don't find a lot of gay men who like country music. But I've got tons of friends. All of them know about my status — most of them are in the same boat. We have a real good time together."

Dating and relationships are difficult, though, he says. Trying to find someone who will accept HIV is a challenge. And at bars within the gay community, speculation about whether someone has HIV is a recurring theme in conversations.

"Especially if you're thin," Dan says. "It's sad that they have to judge people like that."

"A lot of people think when you have HIV, then sex stops, period. In fact, a lot of people think there should be a list, and if you're ever out picking somebody up or meeting someone, that HIV should be over your forehead."

"Myself, I'm still sexually active. There is to me a risk in everything we do. And I personally have never ever hurt anyone or I've never let anyone do anything that is possibly unsafe to me or ever jeopardized their life either."

"There's times I haven't let my HIV status be known. If you practice safe sex, to me, there's not a need for that. That