

When AIDS hits, family suffers, too

By Chris Burchard

You might have met Todd Sukstorf if you've gone for a drink or to catch a blues band at the Zoo, where he tends bar at night, or if you've eaten lunch at Inn Harms Way, where he waits tables during the day. If you have, you know the 31-year-old Lincolnite lives on positive energy.

"When people are around me, if they're down, I'll usually get them up after a while and make them comfortable," he said. "I enjoy life and I enjoy being a happy person."

He's so laid back and fun-loving that it's hard to imagine, after being around him for any length of time, that AIDS is slowly grinding his brother's life away.

The phone call from his mother in October 1988 irreversibly changed Todd's life, he said.

"I knew, as soon as I found out my brother had AIDS, I'd never be the same. Nobody will ever understand what I'm going through unless they've been there, and I hope no one — none of my friends — ever has to go through what I've gone through."

Todd said she used to go out to San Francisco to visit Eric, but she'd just cry all the time there, too. "My brother couldn't handle that, and it wasn't good for her. It was a waste of a trip."

Todd said he has mediated the problems and differences between his family members to keep the lines of communication open.

"I'm the foundation that supports the family," he said.

And he's been lucky in that others have always been there to support him, he said.

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Todd holds a photo of him and his brother Eric taken in front of Eric's apartment in San Francisco.

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Brother's disease inspires Lincolnite to begin educating others about affliction

jewelry and clothes.

He changed his last name to Jazmen to sell his wares.

Todd moved to Lincoln in 1982. Since then he's bounced back and forth between Lincoln and Fremont, where his mother still lives.

Their parents are divorced and his father now lives in Omaha.

"We're not a close-knit family," he said. "We never have been. But this has brought us all closer together."

Learning that Eric had AIDS was hard on his parents, he said.

"My mom was . . . like a lot of people and parents who didn't like to say their son or daughter had AIDS," he said. His mother even told him to tell others that Eric had leukemia.

"I said, 'No, I will not do that. I love my brother and I'm proud of my brother. My brother has AIDS.'"

When people are sick or terminally ill, Todd said, they need all the support they can get.

"And I'll be damned if I wasn't going to be there for my brother."

His mother and father have come to support Eric, too, he said, but it took time.

"My mom was always crying like he was dead. I'd say 'Mom, he's still alive. We could die before he does.'"

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"My friends, the people I've known, have never backed down. That's how you find out who your friends are: If they

won't associate with you now, they weren't your friends to begin with."

That support helped him through the shock of learning that his brother had AIDS, he said. And something else helped, too. He had prepared himself for news of terminal illness or death in the family long before his brother contracted the disease.

"I've been doing that since I was a kid, because I've seen people's lives ruined (by death)," he said.

Todd's 19-year-old cousin had a sudden aneurysm shortly after she left Todd's family's house with her newborn baby. She fell through a plate glass window and died.

Todd said his aunt has suffered greatly from that and still has not recovered completely.

When Todd was 20, one of his friends committed suicide. The man's mother was severely hurt and never will be the same, he said. He decided never to let that happen to himself.

"I prepared myself for death so it wouldn't ruin me."

While Todd said news of his brother's condition was painful to bear, it would have been much worse if he hadn't been prepared for a family tragedy.

But nothing could have prepared him for the news that his brother's condition would include dementia, he said. Like hundreds of thousands of AIDS patients, Eric was diagnosed with ADC, or AIDS Dementia Complex.

"It's like Alzheimer's," Todd said. "Alzheimer's is a form of dementia; this is AIDS dementia."

It is a state of confusion, he explained, in which those affected often have trouble reading, speaking quickly, constructing sentences and retaining information.

Once, after Eric's friend helped him with his grocery shopping, they brought the food home and, Eric thought, put it away. Later in the day Eric was hungry and decided to make dinner but couldn't find any of the groceries. He searched his

kitchen and his entire apartment before finding it all on the stove, in pans and skillets. He had sauteed the chicken and steamed the vegetables hours before.

In another incident, Todd said, his brother went on a shopping spree.

"He just got out a piece of plastic . . . and started spending, spending, spending. And he had to take the stuff back."

But there are darker sides to ADC, Todd said.

"It will act up a lot of times when there's stress. And when you or I, or when healthy people get angry or frustrated, they hit a wall."

With dementia, he said, it's different. "At one time Eric started hitting himself, and he didn't stop. He drew blood. It wasn't because he was crazy, it was just stress."

People don't understand dementia, Todd said. Even medical professionals misunderstand it sometimes. Once, after Eric stayed up with a dying friend for more than two days, the stress and fatigue caused his virus to act up. He went to San Francisco General Hospital to get help.

"As soon as he said he had AIDS dementia, they strapped him down in the psychiatric ward. They had him strapped down for 20 hours," Todd said. Not until a nurse familiar with Eric's case found him was he released.

"That type of stuff makes me angry, very angry, when you mistreat people like that."

It is that type of ignorance that prompted Eric to make a video tape about ADC. The 80-minute video, entitled "I Still Am . . . Dementia: A New Understanding," is a presentation in three sections, two of which are interviews with Eric. The middle section is a panel discussion concerning AZT and other drugs, which may curb dementia's effects.

In the interviews, Eric looks fine. That's strange for a person who has had AIDS for more than three years, Todd said. He responds to questions in his slow, halting speech, often having to close his eyes to



Todd Sukstorf holds a picture of his brother, Eric Jazmen. Eric, who has AIDS and AIDS dementia complex, produced a video called "I still Am . . . Dementia: A New Understanding." Todd uses the video in presentations around Lincoln to educate people about the diseases.

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begin educating others about affliction

concentrate on forming words and sentences. He describes what it's like to have dementia — what it's like to wake up one day and not be able to recognize printed English. What it's like to constantly forget things and the confusion that causes. What it's like not to recognize friends he's known for years.

And although those things are inherently depressing, he discusses them openly and with humor, smiling though it seems to pain him to do so.

Todd does his part, too. He said when he first learned that Eric had AIDS, he decided he was going to learn about the disease and do what he could to help.

That help comes in the form of what he calls the "I Still Am Project," in which he takes his brother's video, along with some messages of his own, to area schools, hospitals and organizations.

"What my brother and I do with AIDS is the humanizing of the issue," he said. Increasing awareness of AIDS and AIDS dementia is his goal.

There is only one problem: People aren't interested.

"I found out how people, how our government, how agencies and medical people, don't care about this issue," he said. Instead of giving his presentation a chance, they turn him away.

"I'm not bad-mouthing them, it's just that here's a person who offers their free time, who knows a lot of what's going on," he said. "I happen to know a lot about dementia. It's on-the-job training."

Eric even sent a letter to Barbara Bush requesting her help with the project, which she denied, and a packet of material to Oprah Winfrey, who returned everything, Todd said.

It becomes frustrating when the project won't take off or people won't take the time to listen, Todd said, yet those are just some of the things that weigh on him daily.

"There's a lot of pressure on me," he said. It's taxing just to listen to his brother's problems, such as when he has bad doctors or when people say they'll help him

only to ignore or forget about him later. Worrying whether Eric was even alive also used to plague his thoughts, he said, and that was a load to carry.

"A couple years ago I used to be scared to come home because he was having some tough times," he said. "I'd get scared to see the light flashing on my answering machine, thinking it would be a message from the hospital that he was dead."

Todd said it was about then that the frustrations and worries, as well as all the time spent on the project, began to take their toll.

"It's a day-to-day struggle, and I don't really have anybody to dump that on. It becomes hard when you have to find ways to release that, and if you don't — if you let your guard down — you're going to have happen to you what happened to me."

Todd described an incident in which he finally "cracked" under the pressure.

"One Saturday I was walking home from work and something just left me — the emotions just left me. I didn't know whether to cry . . . or just sit there — I didn't know what to do. I just walked around being depressed for a long, long time."

Since then, he said, "I haven't cried in close to two years. That emotion is gone."

Anger, he said, remained.

"I was lucky a few times at work I didn't go pick a fight."

He said his co-workers at the Zoo had to hold him back sometimes when customers got out of hand. If he would have grabbed someone when he was in that state of mind, he said, it would have taken a lot to pry him off.

"I was looking for a way to vent my frustration."

Eventually, Todd said, he decided to see a psychologist.

"I knew I needed help. Things were too tough for me — I wasn't myself and I got tired of going through life not being happy."

Unfortunately, the first psychologist he went to was horrible, he said.

"She started telling me some of her

problems. I was like, 'I didn't come here to hear this shit.' And then she brought in this lady whose husband and brother-in-law were HIV-(positive). This lady was a nervous wreck! She was bringing me down really bad. And she was angry, too, really angry. I couldn't wait to get the hell out of there."

On his second try, Todd said, he found a psychologist who actually helped him. He was glad he went, and he returns when he thinks he needs it or just wants to "spill."

For whatever reason, be it the psychologist, some inner drive or realization, or a combination of the two, Todd began to surface from his depression.

"I'm finally getting back to the way I used to be before all this," he said. "I was happy everyday, nothing got me down. And for a while there, the child in me, the little kid in me, left. And that's what drives me."

"It would have been a hell of a lot easier . . . just to sit in my apartment and be bummed out, day in and day out. But that's where the work comes in. You've got to dig deep down and say, 'Hey, I'm not going to be this way. I'm going to get out — I still have a life to live, myself.'"

He said he'd learned from his mistakes, and found that he couldn't let himself become so immersed in his brother's illness or the project that it interfered with his life.

"I've learned to protect myself — how to keep my guard up," he said. "Once you let your guard down you're opening yourself up to a lot of problems."

Now he tells himself, "Don't worry about those things. That's the way it's going to be, don't take it so seriously. Just go back to the way you were: a carefree, happy-go-lucky person."

With that outlook, he's continuing the project in a more relaxed manner, he said, without getting "all out-of-whack" when people won't listen.

"Thankfully, he said, some people finally are. He's set up a number of speaking engagements recently, including one

at Millard North High School planned for the middle of April.

"That helps a lot — when I go and speak. That's my therapy. Just to know people are glad that someone came to talk to them — that's a big plus. That's what it's all about."

While Todd may have reclaimed his positive outlook on life, something still lurks behind his thoughts. One night he will have to come home to that message on his answering machine.

"I know he'll never get better," he said. "I mean, he could die right now; you don't know when, so I don't think about it. You can worry all you want, but it's not going to extend your life or his life."

Todd said he was fortunate his brother had lived so long — more than three years since he was diagnosed with AIDS. The average life span after diagnosis is, he said, 17 to 19 months.

"As each Christmas goes by you expect it to be the last, and each visit out there I'd expect to be the last," he said. "You get in the van to go to the airport, and through the window you wonder if that will be the last wave you ever get."

But Todd's been preparing himself lately, he said.

"Everything dies. There's two things we're guaranteed in life. One is that we're here — we're born. The other is we die."

"Sure, you're scared and you don't want anyone to go. But I believe in an afterlife. I believe in God."

He and his brother have discussed death, he said, and it's helped both of them deal with the inevitable better.

"When you know somebody who has something like AIDS or cancer . . . they and you know they're going to die, so you can talk about things. If I found out right now my brother's dead, I wouldn't have any regrets, because we've said how much we care about each other."

"I'm going to be sad, and that might be the time I'm finally able to cry, but it will be a relief," he said with a smile. "A very big relief."

I knew, as soon as I found out my brother had AIDS, I'd never be the same. Nobody will ever understand what I'm going through unless they've been there, and I hope no one — none of my friends — ever has to go through what I've gone through.

— Todd Sukstorf, brother of man with AIDS