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Facing the challenge of disease

Krystin St. Onge appreciates the small victories in life. She has to. Otherwise, the loss becomes overwhelming.

By PAULA PETERS

In 1989, she began a career providing support to health care's easiest castaways at the Dimock Community Health Center in Roxbury. They were minority men and women infected with HIV and AIDS as a result of drug addiction.

St. Onge got into the business of trying to help addicts stay clean and live healthy, even though they often resist both, for a simple reason: If she didn't, who would?

"It's just the nature of substance abuse," said St. Onge, who is now the deputy director of the AIDS Support Group of Cape Cod in Hyannis. "The addict burns bridges. We are their last bridge."

St. Onge had reached her own limit after four years of trying to hold up a community overwhelmed by disease. The living was hard enough without AIDS; the dying was even harder.

"It was painful," she said, recalling the days she would come into the office and see another person memorialized in a chalk board advisory to the staff.

She moved on to the more empowering field of women's health to recover emotionally and snapped back like a rubber band. By 1999, when she was offered a job running the Upper Cape AIDS Network in Falmouth, she was ready to leap back into the work without hesitation.

"UCAN was small and developing," she said. "It was exciting to be able to bring it to the next level."

She faced some old challenges in new surroundings: Infected people living longer, but their quality of life often compromised by a daily regimen of dozens of drugs, many designed to counteract the negative effects of another. Next to that, a heroin



...can look tempting.

"It is still a very challenging disease," she said.

Faced with state budget cuts this year, UCAN merged with the Yarmouth-based Cape AIDS Resource Exchange and with the help of The Provincetown AIDS Support Group has formed the AIDS Support Group of Cape Cod, which serves more than 100 people from Wareham to Orleans out of its 310 Barnstable Road headquarters.

The group provides a link for those infected with HIV and AIDS to health care and social services and maintains an awareness campaign to prevent further spread of the deadly disease that plagues an estimated 42 million around the world, nearly 500 of them live in Barnstable County.

There's also a bit of homespun comfort offered to those who use the group's services.

As one consumer arrived last week for his food pantry supplies and holiday turkey, St. Onge jumped up from a mismatched dining room chair to take a call from another consumer and broke into a chorus of "Happy Birthday," followed by friendly conversation. She then returned to a table where she was being interviewed.

"Things have changed," she said. "Used to be, you quietly came in to the office, got what you needed and left."

Fiddling with a triple strand of funky glass and silver beads draped heavily around her dainty neck, St. Onge became animated as she talked about why she does such challenging work.

She banks on small victories to prevent another case of burnout.

Like the case of the active intravenous drug user who asked to get into a needle exchange program. He wasn't ready to get clean, but at least he was taking a step to stop spreading the virus.

Still, the losses are painful.

Last year the support group lost five of its clients. They will be remembered tonight as part of the World AIDS Day event sponsored by the support group at the Unitarian Universalist Fellowship Church on Sandwich Road in East Falmouth.

Red ribbons will be used to remember to the dead. St. Onge and

others like her will keep working to preserve the living.

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AIDS stigma defeats testing, treatment eff



VINCENT DeWITT/Cape Cod Times

Although Judy Burman's revelation about her HIV diagnosis in 1991 strained family relationships, she has since found friends and support in Provincetown.

■ After two decades of education, fear still leads to silence in those living with the disease.

By **EMILY C. DOOLEY**
STAFF WRITER

Judy Burman found out she was HIV-positive in 1991. The virus attacked her body and then shattered her family.

Her health is better now, but her family is still divided, fragmented by a virus that has infected 42

million people worldwide.

Doctors traced Burman's infection back to one of two surgeries she had in 1982 and 1984. Both required a blood transfusion. One was tainted with the virus.

"I remember falling to my knees, screaming and crying," said Burman, 47.

She told her sister, who immediately told their mother.

"My mom and my family kind of cut me off," Burman said. "My mom could never hold me or come near me. She said I was nothing to her."

Burman was divorced at the time and too sick to

work, so an older brother let her move in for a while.

Then he kicked her out. She lived on the streets in Newport, R.I., for three months. She bounced from homeless shelter to homeless shelter.

She moved to Provincetown six years ago, where she has found friends and support. But her family relationships are still strained.

Four months ago, Burman's mother died. Burman went to Texas for the funeral and reading of the will.

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Stigma: Fear defeats treatment efforts

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"She left me nothing but a penny," Burman recalled. "I said, 'Put it in her coffin.'"

It's been 21 years since HIV and AIDS were first discovered. Through two decades of research, education and treatment, some things have not changed. Discrimination and the stigma associated with the virus are still strong.

Today is World AIDS Day. The theme: stigma and discrimination. Their effects are universal, stretching across the globe like the virus itself.

Stigma stops people from getting tested or treated. Discrimination helps the virus spread.

It is evident here on Cape Cod, where an estimated 450 people are HIV-positive or have AIDS. Many can't tell the people in their lives because it could mean the loss of a job or friends.

Some don't even tell their children.

Mary, not her real name, has three kids, ages 5 to 16. All are negative for the virus. Only the eldest son knows his mom has HIV. Mary divulged the news when her ex-mother-in-law turned over some journals to the son. They were from his father, a drug user who infected Mary with the virus.

Her younger son and daughter do not know. Her new husband does, but his family does not.

"I pretend I don't have it, and I think that's how I deal," Mary said. "I want to protect them, and I don't want them to think I'm going to die."

Though hidden, the reality is on her mind.

"I get angry because I have this," she said. "I want to see my daughter walk down the aisle."

She is not alone in her silence.

"I have a lot of women whose children aren't aware they are positive," said Donna Mello, a case manager for the AIDS Support Group of Cape Cod, which has offices in Hyannis and Provincetown. "A lot of women don't want to talk about it because they're worried about what will happen to their kids."

Stigma hinders treatment

Health-care advocates say the discrimination has to do with the initial days of the epidemic, when HIV in this country was striking the gay community by force. Then it hit those who were intravenous drug users.

"I think the moral thing that has surrounded HIV is really the issue," said Charles Sessoms, prevention and education director for the AIDS Support Group of Cape Cod. "Because the initial group was gay men, it was very easy for religious conservatives to come out and say this was an act of God. Had this come out in the general population, we would have seen a much more compassionate and vigorous response."

As it was years ago, people today

don't want to know the results of an HIV test, because it means a certain life sentence. One full of secrets and hate. For men and women, gay or straight, drug user or not, discrimination is an added burden. It labels men as gay or women as promiscuous.

"It assaults their dignity," Sessoms said. "It gets in the way of people taking care of themselves. It really blocks their future, even when medically the disease can be stabilized."

With people less willing to test, the disease spreads through unprotected sex and sharing needles. According to the World AIDS Day organization, 5 million people will be infected throughout the world this year.

Douglas S. is an HIV-positive man who contracted the virus through unsafe sex with a woman. He's one of the 13 percent of people in the United States infected by heterosexual sex. Because HIV and AIDS are still characterized as gay diseases in some minds, it places an extra burden on positive heterosexual men who fear further stereotyping.

"In some ways, they're more closeted," Sessoms said.

At both support groups, some clients refuse to make an appearance at either the Hyannis or Provincetown office. They don't want to be seen going in because it could clue people in to their status, Mello said.

"Some caseworkers have to do home visits," Sessoms said.

Hard to speak up

Getting people with HIV or AIDS to talk publicly is a challenge. Most refuse to give their full name or their real name. It's just too big of a risk to take.

Cathy, not her real name, is a nursing assistant who is HIV-positive. The virus levels are so low in her body that it is considered undetectable in her case.

But it doesn't mean Cathy is free to tell her secret, not at school and certainly not at work.

"I work in the medical field," Cathy said. "People would not be too happy about that. I would lose my job."

Even though the possibility of Cathy passing on her virus is almost nonexistent, it will always be there, in the back of minds, hidden where fear lives.

It's unsubstantiated concern. In the United States, there has been only one case of a patient being infected by a health-care worker—a dentist, according to the Centers for Disease Control and Prevention.

"This is not an airborne disease," said Diane Marino, a nurse and HIV coordi-

nator for Infectious Disease Consulting Services, a division of Cape Cod Hospital. "Transmission can only happen blood-to-blood. In the normal act of interacting together, none of that happens. We don't go around exposing blood-to-blood with each other. It's just not rational."

Cathy first learned she had the virus 14 years ago. It was the same time she learned her husband was an intravenous drug user. That is how HIV entered her world.

It won't leave. It affects her relationships, her livelihood, her family.

Her situation is not unique. Since 1981, 57 percent of all AIDS cases among women have been because of injection drug use or sex with partners who inject drugs. For men, those activities account for 31 percent of all cases, according to the CDC.

"Just to be related to a person who has AIDS makes people nervous," Cathy said one day at the Hyannis Support Group office. "It makes them feel like death is around them."

"In a way it makes you very humble."

Even though she had a grant to pay for classes, a counselor tried to dissuade her from getting a nursing degree from Cape Cod Community College. She persevered and graduated in 1999, but the Cape's medical community is too small for her to keep the secret much longer. Many have treated her and many more will. The diagnosis will be remembered, even if she doesn't disclose.

So she is back in school now, working toward a degree in political science.

Daniel Rodrigues knows how people can turn.

Last year he marched in the Upper Cape AIDS Walk.

His picture, name and address were printed on the front page of a weekly newspaper.

That's when the phone calls started coming in. They came at all hours. They lasted for three days.

They were angry, hysterical, anonymous.

"We don't want people like you in our town," one caller screamed.

"Why don't you go back to the —ing town you came from," another said.

Rodrigues, 45, moved to Falmouth from New Bedford in 1999. He took a job in a fish market. Only his boss knew he was HIV positive.

After the newspaper came out, everyone knew. Co-workers, neighbors, casual acquaintances.

"I wouldn't come out of the house for three days," Rodrigues said. "I was worried. I was afraid my tires would get slashed. I was afraid."

Worldwide perspective

In other countries the discrimination is more blatant and public. In 1998, the Supreme Court in India ruled that a person living with HIV or AIDS had no right to marry, according to a report published in November by the Joint United Nations Program on HIV/AIDS.

That same year a young woman was stoned and beaten to death by neighbors in Durban, South Africa, after she spoke of her HIV status.

And at least 50 nations have some sort of HIV/AIDS testing requirement for foreigners wishing to enter the country, according to the U.S. Department of State.

No matter the location or program, most include education as a primary focus, hoping knowledge will wipe out irrational and incorrect beliefs.

"We have to keep coming at it in terms of education," Marino said. "People are fearful of what they don't know."

That's how Rodrigues is fighting back. He is now writing a book about his experiences and speaking to outreach groups about the virus, its causes and methods of prevention.

"People with the virus, we're just like anybody else," Rodrigues said. "We have to help people learn not to get infected."

Rodrigues was diagnosed with HIV in 1987. At the time he was a fishing boat captain with a crew of 13 working out of New Bedford. He was also into heroin, cocaine and needles. That's how he was infected.

It was also how he got a label, not an identity. It's how people can turn him away without a look. He once had an emergency room doctor put on gloves and a surgical mask just to ask him questions.

A dentist refused to have him as a patient. "As soon as I told him, he backed up really, really slowly," Rodrigues said. "He said 'I don't think I can help you here. I could see how scared he was of me.'"

Rodrigues wants to make sure others don't go through the same thing. He says common sense and a bit of understanding will make a world of difference.

"It's a pretty hard thing to catch and easy to avoid," Sessoms said. "It really is something that can be prevented, even in intimate circumstances."

"Society would benefit if we could relax our judgment about people."

The AIDS Support Group of Cape Cod is currently conducting an end-of-year holiday appeal campaign. Donations can be made in three ways: by mail to ASGCC Appeal, PO Box 1522, Provincetown, 02657; by phone to Gerry Desautels at 1-800-905-1170, ext. 48; or online at www.pasgonline.org.

"Just to be related to a person who has AIDS makes people nervous. It makes them feel like death is around them."

CATHY

HIV-positive nursing assistant