

Americans touched early by AIDS, 25 years later

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SAN FRANCISCO—In those days, a diagnosis was a death sentence. No one knew how you got it, this mysterious ailment that savaged the human body with almost medieval cruelty.

Baffled doctors threw everything they had at skin cancers, brain infections, intestinal parasites and other horrific symptoms. Nothing worked.

Twenty-five years after federal health officials first recognized the disease that would become known as Acquired Immune Deficiency Syndrome, AIDS no longer is synonymous with terminal illness.

But like other wars, the early years of the AIDS epidemic produced survivors, people whose lives bear the contours of having crossed so malignant an enemy. Cameron Siemers, Lonnie Payne and Lisa Capaldini are three of them.

Three faces of AIDS, 2006 message for a country where more than half a million people have died: 25 years is not such a long time.

• Cameron Siemers, 24, infected during a blood transfusion as a toddler

Cameron Siemers had a big secret until he was 18. When he decided to give it up, he did so in spectacular fashion, telling his entire high school graduating class that he had AIDS.

"It was hard because I knew all these people," Siemers said of the commencement speech. "I just wanted to give them something because we were graduating. ... And just to get

it off my chest, to let them know."

The revelation explained why Cameron was small for his age and missed long stretches of school in the Los Angeles suburb of Los Alamitos. When friends wondered why he could never have sleepovers at their houses, he always had said he had hemophilia, which was true. That's how he got HIV.

His doctors think Siemers got tainted blood in a transfusion when he was 9 years old, but he wasn't diagnosed until he was 7. His mother gave him the news while they were playing Legos.

"I knew what it was and I knew what it meant, but I didn't think of it as a death sentence," he said.

As he's gotten older, it's gotten harder to hold onto his innocence. Siemers is among the minority of patients whose AIDS has proven resistant to the drug "cocktail" that changed the course of the disease. So even as treatment options have improved, he has gotten sicker.

He almost died two years ago after his inflamed pancreas started bleeding uncontrollably, a chronic condition associated with HIV. Recently, he was on a new drug that looked promising, but he had to stop taking it because the medication exacerbated the abdominal pain from his pancreatitis. His doctor is trying to get him enrolled in a study for another drug.

Looking back, it's easy to regret the things he hasn't been able to do that other guys his age take for granted. Asked for an example, he



If you have been sexually active, remember to have yourself checked to make sure you have a clean bill of health.

doesn't skip a beat. "Dating," Siemers isn't sure why he grew up thinking AIDS was something he had to conceal from all but a few trusted friends. After he revealed his secret, he felt blessed by all the support he received.

While Siemers has contempt for infected people who conceal their HIV status from sex partners, he doesn't think of himself as morally superior to those who acquired the virus through unprotected sex or intravenous drug use.

"I've met a lot of people with this disease and they range from every ethnicity and every gender and they are just people trying to get through it," he said. "AIDS is not prejudiced. It will attack anybody."

• Lonnie Payne, 53, diagnosed with AIDS in 1986

The same month Cameron was conceived, Lonnie Payne moved from Chicago to San Francisco with his lover, Joel Swandby.

In April 1981, the northern California city was "the gay Mecca of the United States," and Payne and Swandby revealed in the freedom of living in a place where men could love other men with abandon.

Although Payne remembers hearing about a strange illness that surfaced in the gay community that year, it took time before "the rumor started getting longer" and reality set in. Once-beautiful men walked the predominantly gay Castro District like living skeletons, their sunken cheeks bearing the telltale lesions of Kaposi's sarcoma.

Not long after the first HIV tests became available, Payne, Swandby, Payne's twin brother, Lawrence, and the brother's partner, Timothy Bollinger, decided to get tested together, "as a fam-

ily."

"In those days, there was this fear of being identified, so I remember not even using our real names."

All four men tested positive. "In '86, that was a death sentence. We didn't know how long we had to live," he said.

"On one level we were like, 'OK, we have this bug. We are going to do the right things and stay healthy.' On the other hand, there was this fatalistic effect happening, where it was like, 'If I'm going to die, why should I worry about following some regimen?'"

The signs surfaced soon enough. Infection after infection broke through the men's weakened immune systems, and the drugs they were taking had debilitating side-effects. Those years are a blur for Payne, who was taking care of Joel while coping with his own illness. In 1994, Lawrence Payne died, followed by Bollinger in 1995 and Swandby succumbed in 1996.

"It's hard to think back through that darkness for me at times," Lonnie Payne said. "I never thought I would be in a world without my twin brother. ... It was like everything I knew that was comforting was eroding."

For reasons that remain a mystery, Lonnie Payne

stayed strong long enough to benefit from a new class of drugs that hit the market around the time Swandby died. He thinks he'd be dead, too, were it not for the protease inhibitors that ushered in the era of so-called "cocktails."

"They were horrible and they were nasty. The side effects were everything you have ever heard—the diarrhea, the neuropathy," Payne said. "But for me, the reality is that they were working, and it changed my outlook on life."

"I started with an attitude of, 'I will try to see if I can make these drugs work because I'm really not ready to check out yet. There's a reason why I'm alive and the other guys aren't, and I just need to find out what it is.'"

Another decade has passed. To look at Payne, one would never know how sick he was. He retired in 1996 from his marketing job with a telephone company and volunteers as a director for two AIDS organizations. He is 63 years old when he never expected to see 40.

"I love the fact that we consider ourselves long-term survivors of AIDS and not people living with HIV and AIDS," he said. "Because we are survivors, and whatever has come up we have navigated through it, sometimes with great success and sometimes with just passable success."

• Dr. Lisa Capaldini, nationally recognized HIV expert

In her solo medical practice in San Francisco's Castro District, Lisa Capaldini sees a lot of HIV patients. She once treated Lonnie Payne's late brother and partner.

Some suffer from a sense of spiritual ennui she calls the "Lazarus phenomenon" after the figure whom Jesus brought back from the dead in the biblical story. Well

enough to know their limitations but too sick to work full-time, they are the epidemic's walking wounded, Capaldini said.

"They are a little bit lost souls," she said. "They may have sold a business or never finished school because they didn't think they would be around. Now what they are dealing with is, 'I may live another 20 or 30 years. What does surviving this mean?'"

Capaldini first encountered HIV on a medical school fellowship in 1981. Her first AIDS patient two years later was an intravenous drug user who was going blind from the disease. She remembers her tears of impotence when she sent him home to die.

San Francisco General was one of the first hospitals to have a dedicated AIDS ward, and as a lesbian herself, she gravitated to the epidemic that was hitting gay men. Even as a new doctor, she became a nationally recognized expert in treating an illness with which no one was experienced.

These days, the type of care she provides is different. A decade ago, her waiting room was full of people getting ready to die.

"I have more patients with HIV in my practice than I ever have, but I am spending less time with them than I ever have," she said.

The challenge today is not to get complacent about HIV, she said. Patients must closely adhere to their drug regimens to avoid developing an immunity.

There are complex psychological and sociological reasons why HIV patients fall off their meds, such as domestic and economic problems.

While Capaldini thinks the early years of the epidemic helped "humanize" gay men in America, HIV still carries a stigma, especially for heterosexual women.

Seniors and disasters

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preparedness information to elders and those with disabilities appropriate to their needs and in accessible formats.

• Building relationships among organizations before disaster strikes to improve coordination and communication in emergency situations.

• Improving identification and tracking methods of both people and health information.

Hurricane Katrina resulted in 1,330 deaths, many of whom were elderly. In Louisiana, roughly 71 percent of the victims were older than 60, and 47 percent were over 75.

• A key finding highlighted in the report from a Harris Interactive Survey conducted for AARP is that about 13 million persons age 50 and older in the U.S. say they will need help to evacuate in a disaster, with about half of these individuals requiring help from someone outside of their household. This proportion increases with advancing age.

"Recent catastrophic events have taught us we have to pay greater attention to evacuating, identifying and ensuring the safe return of thousands of frail older adults living on their own or in long-term care facilities," Novelli said.

Restaurants get help to fight obesity

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Americans now consume fully one-third of their daily intake of calories outside the home. And as of 2000, the average American took in 300 more calories a day than was the case 15 years earlier, according to Agriculture Department statistics cited in the report.

Today, 64 percent of Americans are overweight, including the 30 percent who are obese, according to the report. It pegs the annual medical cost of the problem at nearly \$93 billion.

Consumer advocates increasingly have heaped some of the blame on restaurant chains like McDonald's, which bristles at the criticism while offering more salads and fruit. The report does not explicitly link dining out with the rising tide of obesity, but does cite numerous studies that suggest there is a connection.

The National Restaurant Association said the report, which it helped prepare but targeted its support, unfairly targeted its industry.

The report encourages restaurants to shift the emphasis of their marketing to lower-calorie choices, and include more such options on menus. In addition, restaurants could jigger portion sizes and the variety of foods available in mixed dishes to cut calories.

Bundling meals with more fruits and vegetables also

could help. And letting consumers know how many calories are contained in a meal also could guide the choices they make, according to the report.

Simson Holston, 33, called more disclosure an excellent idea as he lunched on a sausage-and-pepperoni pizza at a downtown Washington food court.

"OK, I am going to eat junk food regardless, but let me eat the junk food that's going to cause me less damage," said Holston, an accountant. "A lot of times, presented with information, you will make a better choice."

Just over half of the nation's 287 largest restaurant chains now make at least some nutrition information available, said Margo Wootan, director of nutrition policy for the Center for Science in the Public Interest.

"If companies don't tell them, people have no way of knowing how many calories they are being served at restaurants. And chances are, they are being served a lot more than they realize," said Wootan, adding that Congress should give the FDA the authority to require such disclosure.

Dr. Andrew von Eschenbach, the agency's acting head, said the only place where he has seen calorie information listed on a menu was at an upscale restaurant in California. Still, the agency will not seek the authority to

force others to follow suit, he said.

"At this point in time, it's not a matter of more authority; it's using the authority we have," von Eschenbach said.

The report notes that the laboratory work needed to calculate the calorie content of a menu item can cost \$100, or anywhere from \$11,500 to \$46,000 to analyze an entire menu.

That cost makes it unfeasible for restaurants, especially when menus can change daily, said Sheila Cohn, director of nutrition policy for the National Restaurant Association.

Instead, restaurants increasingly are offering varied portion sizes, foods made with whole grains, more diet drinks and entree salads to fit the dietary needs of customers, Cohn said. Still, they can't make people eat what they won't order, she added.

When Americans dined out in 2005, the leading menu choices remained hamburgers, french fries and pizza, according to The NPD Group, a market research firm. The presumably healthier option of a side salad was the No. 4 choice for women, but No. 5 for men, according to the eating pattern study.

On the Net:
Food and Drug Administration:
<http://www.fda.gov/>

Year	Shirts	Pants	Underwear	Sweatshirts	Shorts	Shirts	Blouses	Loafers	Per Loss
1998	352	112	485	153	118	152	267	237	
1999	325	115	385	153	124	143	202	237	
2000	285	123	415	142	124	161	272	236	
2001	335	104	397	134	114	154	391	236	
2002	285	5	420	125	131	169	410	278	
2003	341	117	488	136	102	124	384	175	

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