

The Face of AIDS

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Hearing the words “you have AIDS” is a nightmare for many — and for those infected, despite medical advances, every day is a challenge

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In 1994, John Petersen was a factory worker earning \$45,000 a year. His job, which required a lot of heavy lifting, kept him in better than average physical condition. When he began feeling uncharacteristically tired and fatigued, he saw a doctor. After some tests, John was told he had AIDS.

He became so weak he couldn't even get out of bed to go to the bathroom. He lost his job, then his house and very nearly his life.

John's doctors said he'd be lucky to live another six months.

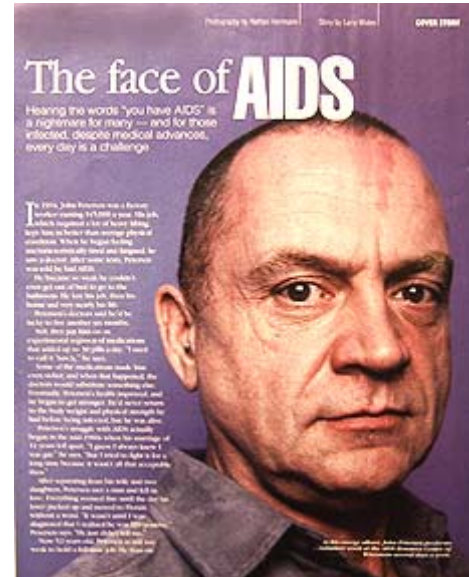
Still, they put him on an experimental regimen of medications that added up to 30 pills a day. “I used to call it ‘lunch,’” he says.

Some of the medications made him even sicker, and when that happened, the doctors would substitute something else. Despite temporary setbacks — and being handed a death sentence — John's health improved, and he began to get stronger. He'd never return to the body weight and physical strength he had before being infected, but he was alive. John's struggle with AIDS actually began in the mid-1980's when his marriage of 11 years fell apart. “I guess I always knew I was gay,” he says. But I tried to fight it for a long time because it wasn't all that acceptable then.” After separating from his wife and two daughters, John met a man and fell in love. Everything seemed fine until the day his lover packed up and moved to Florida without a word. “It wasn't until I was diagnosed that I realized he was HIV-positive,” John says. “He just didn't tell me.”

Now 52 years old, John is still too weak to hold a full-time job. He lives on disability and depends on Medicare and Medicaid to subsidize the cost of his medications, which have risen to \$35,000 a year. His income, at \$12,000, is a fraction of what he was earning a decade ago.

Still, as his energy allows, John performs volunteer work at the Aids Resource Center of Wisconsin (ARCW) several days a week. He also runs a support group for people who are experiencing what he's already been through. The one thing that was missing in 1994 was any kind of counseling or therapy,” he says. “The doctors gave you medical help, but on one was there to give you mental or spiritual support.” John says the reason he started his own group was to ensure future AIDS patients would not have to cope with a lack of emotional support. “I can't work 40 consecutive hours a week, but I can help other people like myself,” he says. “That's very motivational to me.”

John's medications are keeping his viral load numbers to a status of ‘undetectable,’ which is what all AIDS patients aspire to. He has blood work done four times a year to make sure things stay that way.



Still, he worries about catching a cold or the flu, because his immune system remains in a weakened state and as such, common viruses are much harder to shrug off.

“I’m a survivor,” John says. “I’m just grateful to be here.”

The ups and downs of treatment

John Fangman, M.D., an infectious disease specialist with the AIDS Resource Center, says patients like John have benefited from the medical advances that were made in the mid-1990s. “HIV was not controllable until 1995 or 1996,” he says. “With the medications available today, we’re able to restrict the amount of virus the body produces.”

Fangman says the treatment, while extending life expectancies, often comes at a cost.

“We need to manage the potential side effects these drugs can have on a patient,” he says. “They’re known to increase the incidence of heart disease and diabetes, among other things.” Rick Fons, Ph.R., a pharmacist with the Milwaukee-based BioScrip, says the other key to successfully restraining the HIV virus is consistency.

“You can’t take these medications some days and skip other days,” he says. “Otherwise the virus can become resistant and the meds no longer have the desired effect.”

The changing face of AIDS

Mike Gifford, vice president of the AIDS Resource Center, says historically AIDS was a disease found primarily among gay men. But that’s not the case in 2006.

“Our society needs to come to terms with what AIDS really is in the 21st century,” he says. “While it still affects gay males, a more accurate reflection of HIV is as diverse as our population.”

Gifford says the number of women infected with HIV has gone up in the state of Wisconsin over the last five years. “AIDS is showing up in women, people of color and young people,” Gifford says. “The CDC reports that half of all new HIV infections are in people 25 years or younger.”

Gifford says there are about 195 new cases of HIV infection in greater Milwaukee each year, which is down 50 percent from the 1990s. “To the best of our knowledge, there are 3,000 people living with HIV in Milwaukee right now, 2,400 of which are men.”

It’s not good news, but it certainly is better. “We’ve successfully dropped the new HIV infections from their record highs in the early 1990s,” Gifford says. “The troubling news is that HIV infections have not gone down over the course of the last seven years. That really is where we need to recommit to the fight against HIV in terms of good public policy around HIV prevention in terms of raising dollars to support prevention programs.”

Gifford says the fact that HIV has significantly expanded into the female population and into communities of color is also a problem. He says women at risk include those who are in a violent relationship or those who aren’t knowledgeable about all of the activities in which their partners are engaging.

“In just the last five years, the number of infected women has gone from 16 percent to 23 percent,” he says. “We need to ensure that HIV prevention programs meet their needs, and that they are getting the prevention messages to protect themselves and their loved ones from HIV.”

Gifford adds that women are five times more likely to contract cervical cancer than their HIV-negative counterparts.

Assisting the infected

Sheila was told she contracted AIDS 10 years ago following a blood transfusion (although today, blood is screened very carefully and the risk is extremely low.) The mother of three children, she is planning to marry her fiancée in the coming year.



“I have my good days, and I have my bad days,” Sheila says. “But I don’t feel sorry for myself and I don’t let this get me down.”

Sheila says she’s grateful her children were born prior to her becoming infected.

“They’re happy and healthy, and I’m grateful for that.”

Because her AIDS medication is so expensive, Sheila receives them with help from the General Assistance Medical Program (GAMP), as well as AIDS Resource Center funding.

Gifford says ARCW opened an HIV medical clinic in April specifically to meet the unique needs that women with the disease have.

“It’s the first clinic of its kind in Wisconsin,” he says. “It’s designed to provide both the specific medical interventions that women with HIV need and the wraparound services, like child care and transportation, the sort of things that are often barriers for women who want to avail themselves of medical care.”

Gifford says Sheila’s need for help paying for her medications is not uncommon. ARCW provides medical care and medications to people regardless of their ability to pay. In dollars and cents, that translates into more than \$200,000 a year worth of medications to people living with HIV and AIDS. “We’re the largest HIV medical clinic in Milwaukee County, with about 500 HIV patients right now,” he says. “About one-third of our patients have no health care coverage.”

Gifford says it’s the money raised from both public and private sector donations that’s vital to reducing HIV infections in the area, along with ensuring people with HIV get access to the medical care they need.

“Approximately 75 percent of our funding comes through city, county, state or federal government. We rely on the private sector individuals, corporations and United Way for another \$2.5 million a year,” he says. “Those medications we pay for are the difference between life and death for people with HIV.”

Sidebar: Understanding the disease

So what exactly is AIDS? Acquired Immune Deficiency Syndrome, or AIDS, as it most commonly referred to, is condition which hampers the body’s ability to fight diseases. AIDS is caused by Human Immunodeficiency Virus, or HIV. When a person becomes infected with HIV, it will show up in a blood test. The blood, vaginal fluid, semen and breast milk of people infected with HIV is enough to infect other people. The majority of HIV infections come from having sex with an infected person or sharing a needle with someone who’s infected. Not everyone who is HIV-positive gets AIDS, but left untreated, the likelihood is that the disease is damaging a person’s immune system, even though they may feel fine. Many people with HIV are healthy for as long as ten years before they develop symptoms. HIV officially becomes AIDS when certain cells in the blood drop below 14 percent per milliliter. Fevers, night sweats, diarrhea or swollen lymph nodes are just some of the symptoms that may appear.