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HEADLINE: 'I Just Started Crying';
People With AIDS Struggle to Live in the Shadow of Death

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BODY:
For months, Kerry Shapiro had been feeling tired -- neither well nor sick, "just this constant mild fatigue." His only outward symptom was a swollen lymph node on his neck below his left ear. No weight loss, no night sweats, no diarrhea, no fever, no blotches on the skin. His doctor attributed the tiredness to depression and prescribed antidepressants, which didn't help.

Then, a year ago last April, Shapiro had the lymph node removed. Four days later the surgeon called him at home to tell him he had a rare malignancy called Kaposi's sarcoma. He was sent to the National Institutes of Health for more tests.

While checking in, he noticed what had been written in the blank under diagnosis:

"AIDS."

"I just started crying. It was the first time it had been said or I had seen it. No one had ever said to me, 'You have AIDS.'

"Deep down I knew, but I had been trying to fool myself into thinking it was something different."

At age 25, after months of chronic fatigue, uncertainty and hoping-against-dread, Kerry Shapiro finally knew he was dying of AIDS.

Today, he lives alone in a pin-neat efficiency apartment off Connecticut Avenue, clinging to what remains of his independence and privacy even as his strength dwindles and the realization grows that he cannot take care of himself much longer.

"Every day I feel worse and worse, and my energy level goes down," he says. "For me to get up and get showered and dressed and maybe go out and run one small errand uses just about all my energy. If I go out to dinner, that wipes me out."

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Unlike many patients with Kaposi's sarcoma, Shapiro has almost no lesions on his skin. But he has had internal lesions that burn in the back of his throat and upset his stomach after most meals.

One of Shapiro's kitchen cabinets is a miniature pharmacy, filled with antibiotics, painkillers, sleeping pills, ulcer drugs and other medications. He gives himself daily injections of interferon, a promising but still-unproven treatment.

He weighs about 100 pounds, down from 128 before he got sick. Last spring, following radiation treatments to shrink the lesions in his throat, he went nearly two weeks without eating a full meal and fell to 86 pounds.

Shapiro, who quit his job as an optician more than a year ago, spends more and more of his day at home, resting or sleeping, watching TV or talking with friends on the phone. He says he can feel his attention span getting shorter, his mind becoming less keen.

And watching friends die, it gets harder and harder to keep up hope.

"People mean well, and they try to keep your spirits up," he says. "They tell you you're going to get well and they're going to find a cure. You just sort of let it go in one ear and out the other.

"You really know the truth."

AIDS, he says, "leaves no part of a person's life untouched -- physical, psychological, emotional. And it's not a quick disease, either. You see people linger and suffer. These are people, for the most part, who are young and previously healthy.

"It's very saddening. It's very maddening."

One of Shapiro's friends is Sunnye Sherman, 34, who was diagnosed as having AIDS nearly two years ago. She is something of an anomaly among people with AIDS -- a woman, one who never, before she got sick, took intravenous drugs.

Sherman is all but certain she contracted the disease several years ago during a relationship with a bisexual man. She has many close friends in the gay community and has dated many bisexual men.

"When I first came down with AIDS," she says, "people thought I must be a lesbian, because it's perceived as a homosexual disease. Actually, lesbians are the safest group of all from catching AIDS."

When Sherman, a legal secretary, revealed her illness at the law firm where she worked, she says the first reaction was: "Don't come back, and don't tell anybody why."

She had always been overweight. In her twenties, she weighed up to 210 pounds. She loved to cook, party and go out dancing, but was self-conscious because of her weight.

"I couldn't take the social pressures of a straight bar," she says. "But when I went with a gay man to a gay bar, I had no problems. There was no role-playing. I could be myself."

Today, her weight hovers just above 100 pounds, no matter how hard she tries to force down fattening foods.

"When you're fat, your dream is to be able to eat anything you want and not put on weight," she says, softening the irony with a laugh. "Now that dream has come true." A person with AIDS, says Caitlin Ryan, program director for the AIDS Education Fund at the Whitman-Walker Clinic, "is someone who's losing bit by bit."

Their natural immune systems ravaged by a mysterious virus, AIDS patients such as Shapiro and Sherman are prey to a host of common and exotic infections. They learn the relativity of health and measure days in tiny steps.

When she's feeling well, Sherman sets goals for herself, such as "Today I'm going to take a walk down to the trash room," or "Today I'm going to go pick up the mail."

A good day is "being able to get up and fix my meals and walk around the house without huffing and puffing and having dizzy spells." A bad day is when she lacks the strength to get out of bed and her stomach is so cramped she cannot bring herself to eat.

A trip to the bathroom can be exhausting. Stairs are out of the question. It's a struggle to fix French toast.

"First you take out what you're going to fix, and then you sit down to rest. Then you put the French toast in the microwave, and then you sit down to rest. Then you take it out and walk back to the living room and eat it, and then you lie down and rest.

"Everything's done in little stages."

"The key rule in this disease," agrees Kerry Shapiro, "is one day at a time.

"I can't plan ahead. The bottom could fall out the next day."

Sherman is one of the few AIDS patients known to have survived three bouts with pneumocystis carinii, a rare pneumonia. Another bacterial infection, present in dust and carried by pigeons, robs her of appetite and energy.

"We're all exposed to it," she says. "Your immune system can fight it off. Mine can't."

A powerful drug called amikacin sulfate held the infection in check last year, but had to be discontinued because of a frightening side effect: Sherman started to go deaf.

The infection returned, however, Sherman began losing weight again, and last week she and her doctors faced an agonizing choice. If they resumed using the drug, she would lose her hearing altogether. If they didn't, she would risk death from weight loss.

Last Wednesday, she began taking the drug again.

Sherman talks about such high-stakes dilemmas with disarming equanimity, even humor. She continually uses the word "lucky" to describe herself. Lucky to have her mother, Ina, nearby. Lucky in her friends, her case manager, her doctors and nurses at NIH. Lucky to have lived this long -- 22 months -- since her diagnosis.

"Sunnye is a trouper," says Kerry Shapiro.

One of the things that keep her going is the challenge of educating the public about her disease. As much as any other patient, she has gone public with AIDS. She has been a formal or informal counselor to dozens of Washington-area AIDS patients. She has appeared on network television and on the cover of Life magazine. Fan mail arrives from across the country; a couple in their sixties in Alaska keeps sending her picture postcards and, for reasons she still can't fathom, sticks of Doublemint gum.

"People call me and say, 'Is this Sunnye Sherman, the star?' I say, 'No, this is Sunnye Sherman.' "

"Sunnye has been a rock for most of the people she knows," says Jack Sanders, a volunteer from the Whitman-Walker Clinic who has become perhaps her closest friend and confidant. "If they were in trouble, Sunnye was there. She's been lucky in being able to turn that around for herself, through all the grief and terror and sadness she has known."

As Sherman's case manager, Sanders checks up on her almost daily by telephone or in person. If she's feeling well, he may take her out to a movie or for a drive. If not, he may drop by to fix a meal or share a pizza or watch "Ryan's Hope" or "All My Children" or just talk. He has almost never seen her cry, but sometimes she gets quiet and he can tell she is depressed and they lie together on the bed, arms around each other, saying little or nothing, just holding and being held.

"There's not a whole lot of people from my support group I talk to anymore," Sherman says. "Most of them are dead."

Several months ago, Sherman and Jack Mitchell, a member of her original support group, volunteered to speak to a group of visiting nurses. The two talked firsthand about the pain, isolation and fear of AIDS.

"You feel like pieces of your life are being taken away," Mitchell, 37, told the nurses. "You reach the point where you don't have any control any longer over any aspect of

your life."

In a barely audible voice, Mitchell described how he had been fired from his job as a hairdresser, how he had lost his credit and been forced to file for bankruptcy, how he had not had an intimate sexual relationship since his diagnosis, how his only brother also was dying of AIDS, how he had tried to take his own life, how he feared for his parents who, were losing the only children they had.

"We worry more about the people we're leaving behind," Sherman says. Three weeks ago last Saturday, Sherman went to Wolf Trap to hear Mozart's opera "The Magic Flute." She had bought five front-row box-seat tickets months before, hoping she'd be well enough to go. She invited four guests: her mother, her case manager, Jack, and his lover, Bruce, and Kerry Shapiro. They wheeled her wheelchair from the parking lot to the dinner tent for a gourmet picnic, and then to the amphitheater, where they parked the wheelchair and escorted her down the steps to her seat, Jack on one arm and Bruce on the other.

It was a rare, wonderful evening out, a reminder of glamor and life before AIDS.

But Sunnye Sherman knows the odds. Of the dozens of people with AIDS she has met, only two others have survived as long as she has.

"My mother always says, 'You're going to be the first to get well from AIDS,' " she says. "But I've got to be realistic and look at the statistics -- I was diagnosed almost two years ago -- and be grateful I've lived that long."