

Being afraid: A personal account of the AIDS epidemic

I was devastated. I was as good as dead. I wanted my death to be quick. I was afraid.

BY WES LUTTRELL

Imagine waking up at 4 a.m. crying, sweating, and feeling tense — so tense that you think you will break if you move. Unable to go back to sleep, you move to the couch, turn on the TV to interrupt your thoughts, and fall asleep again.

Imagine getting ready for a shower and undressing with your back to the mirror because you are afraid of seeing something on your body that has not been there before. Imagine washing yourself under your arms and keeping the soap between your hand and armpit for fear of find-



The Roseburg Report

ing lumps. Imagine taking your shower with the lights off so as to avoid seeing spots or blotches.

Imagine that you are losing weight — not a lot of weight, just a pound or two a month, but enough to notice. Little do you realize that your fear of losing weight is causing you to burn calories that you don't need to burn; therefore, you lose more weight.

You catch a cold and develop a sinus infection. Your doctor pours potent and expensive antibiotics down you, but they don't work. He tells you that your nose has been broken and that he wants to cut it open to fix it. A routine pre-surgery physical indicates that your lymphocyte count is indicative of AIDS. Then the doctor tells you to get an "AIDS test" and says, "If it's negative, do you still want the surgery?" You say to yourself "to hell with you" and walk out. The other physician, who gave you your physical, prescribes an inexpensive medicated nasal spray and your sinus infection disappears.

You don't get the antibody test, but you know that you must be a "positive" because two of your friends are "positives" — one has lymphadenopathy — and you had sex with them. You vow to have safer sex or no sex.

The previous paragraphs describe what I went through during the winter of '85 and '86. I feel that I have first-hand knowledge of hell and its horrors.

During November 1986 I developed an occasional sharp pain in my lower right chest. A doctor — supportive of the gay community — x-rayed my chest; a "spot" was visible. A bronchoscopy failed to show the presence of pneumocystis pneumonia, but the drug Pentamidine was prescribed. This medicine was administered once a day by IV drip from a bottle hanging from my living room ceiling. It caused a burning sensation in my arm and made it swell and the veins blacken. I recovered from the pneumonia and returned to work after six weeks.

In August 1987 I lost several pounds and became short of breath. At times just walking to the bathroom would put me down on the floor hacking and coughing. The doctor referred me

to a lung specialist who referred me to a doctor familiar with AIDS. He said I had pneumocystis pneumonia but ran tests just to be sure. The first test was a gallium scan. They injected a radioisotope into my veins and watched it go through my chest to seek out the infection. It did not indicate pneumocystis. The second test was a sputum specimen. It was negative. The third test was another bronchoscopy — also negative. I spent four days in the hospital hooked up to an oxygen supply and with IV drip every eight hours. I went home, took antibiotics for ten days and recovered.

My T cell count was low — 295 — but not critical. I was diagnosed as having pneumocystis pneumonia even though the tests were negative. These two things qualified me for the AIDS diagnosis.

I was devastated. I was as good as dead. I had better get my papers in order. I didn't want my death to cause any legal or monetary hardships on my loved ones. I wanted my death to be quick. They had agreed to take care of me at home until I died, and I didn't want to put them through a lengthy ordeal.

I was afraid, afraid to die. I have seen people die. I've even taken care of them after they died. I never imagined it could be me shoved into the cooler on that cold tray. I was afraid of not being able to care for myself — personal things like going to the bathroom and showering. I felt like throwing up. I did throw up. It didn't help. Neither did crying.

In September 1987 the Douglas County AIDS/ARC Council sponsored a lecture on death and dying given by Elisabeth Kübler-Ross. It had been only two days after my AIDS diagnosis when I met her. I felt like I had a thousand pounds lifted from my shoulders. What a relief! I slept all night.

I decided that yes I am going to die; everyone does, but they really don't know when. I've got some time left, maybe a lot of time, maybe not. But I'm going to spend this time productively. I'm not going to waste it crying and moping around the house. I am not going to die from AIDS. I'm going to live with AIDS.

I'm fortunate in a lot of ways. I'm surrounded by wonderful supportive friends. I have insurance that covers about 85 percent of my medical bills and AZT. The people I worked with are supportive. They all — about 500 — know that I'm gay and have AIDS.

I've received a disability retirement. It was fairly easy to get with an AIDS diagnosis. I miss work, but I'm getting over it. I liked my job and the people I worked with.

I'm doing well and feel better now than I have for two years. The doctor has threatened to put me on a diet. I have only gained 30 pounds. Go ahead, call me a fat faggot. I love it. I only have to see the doctor once a month now, but I get a blood test (white cell count) every week.

It's great to get up in the morning after a full night's sleep, turn on the lights, undress while facing a mirror, and see a smile instead of fear.

Wes Luttrell is a native Oregonian who has lived in Oregon all his life. He is a founding member of GALA and is chair of the Switchboard Committee. He is also an active member of Mixed Company.

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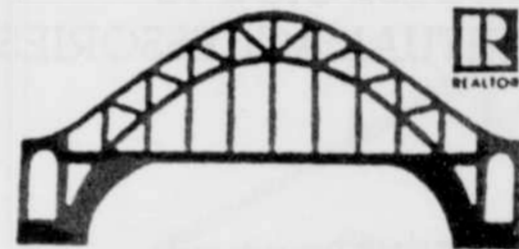
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