Words to Die By

September 1, 2001 By Walter Armstrong

“Man has created death,” W.B. Yeats immortally wrote. And while wild-eyed poets and other artistic types are famous for living in fantasy worlds, their compulsion to create can lead them into those dark, too-real regions of mind where the rest of us fear to tread. Death is one such place. *POZ* asked eight artists and activists with HIV to share what they see there.

John Kelly

Home: New York City
Age: Old enough to be your brother
Job: Experimental theater artist
News: Right now it’s Radiohead, Louis Armstrong, 2-step dancing. And my new book, *John Kelly* (2wise Books)

Closest encounter? To my knowledge, there were three instances:

In 1982, I was hanging out in clubs, smoking clove cigarettes, doing drugs and drinking. I came down with viral pneumonia (not PCP) three times -- I just wouldn’t give my poor lungs a chance to heal. One night I had a 106-degree fever. I calmly ran a cool bath and submerged my body. I then wrote a letter declaring that, and explaining why, I did not want to die.

In 1990, I once again had viral pneumonia and had to be hospitalized. The attendant asked if I wanted to be in the AIDS ward. I said, “Yes, please put me in the belly of the beast.” While I was there, my very silent roommate, a middle-aged black man named Wilfred Smith, died.

In 1995, I was booking a trip to Paris. I wanted to leave on Tuesday but had to postpone the flight for two days. It was TWA Flight 800. The Tuesday flight crashed -- the Thursday did not. All the stewards wore ribbons. They had changed the flight number. As this flight was quite empty, it was the one time I was able to lie down on four empty seats. I felt oddly privileged. And I wept.

Imagine it? I like to think I’ll have the time to take a deep breath, close my eyes, think about the life I lived and quietly smile with absolutely no regrets.

Afterlife? When that door opens, I’ll enter it. I don’t see any point in attempting to comfort myself by projecting my desires onto a mystery. We just don’t know. And we will all find out. That freaks some of us out.

Best attitude? To honor death’s reality and inevitability, and then get back to living. Death isn’t

good or bad -- it just is.

AIDS taught you...? AIDS has brought death closer to my doorstep, though it has taught me more about life. There is *nothing* to learn about death. We can feel its effects if we are caught in its wake, but we won't know it till we do it, and then we won't be around to talk about it. Funny, isn't it, that they call keeping watch over a corpse a "wake."

Epitaph? He went for it.

Andrew Sullivan

Home: Washington, DC, and Provincetown
Age: 37
Job: Writer, www.andrewsullivan.com
News: No comment

Death thoughts? Rarely.

Closest encounter? Watching a good friend die in front of me.

Imagine it? Relief -- the lack of anything more to do.

Afterlife? I hope and pray for the presence of God.

Best attitude? Realism and hope. Death is terrifying, but it's a release from the ordeal of consciousness.

AIDS taught you...? That death is closer than we think. That it can liberate as well as end. That dignity is possible. That we make our own deaths.

Epitaph? How I want you to remember me after I die is the same way I want you to think of me in life: I don't really care.

Michelle Lopez

Home: Bronx, New York
Age: 33
Job: Treatment educator at a community health-care network
News: I was just nominated as a "hero" by Lifetime's new channel. My daughter, Raven, age 12, is blossoming into a *señorita* and has taken control of her own HIV treatment.

Death thoughts? Right now I think about death all day, every day, because my aunt passed three weeks ago. It kicked up a lot of old issues for me about having HIV and dying. It also pushed me to get life insurance and my living will finalized. The day I close my eyes I need to know I have a burial plot and my kids are taken care of. I want to rest *in peace*.

Closest encounter? In 1994, I was on my deathbed from a slew of HIV infections, including MAC.

I had three kinds of IV therapy. I was in a stage of my disease that I knew nothing about, and the doctors weren't telling me anything. Part of me was ready to let go -- it just seemed like what was supposed to happen with AIDS. But my two children, Raven and Rondell, pulled me out of it. When they saw their mom so sick in the hospital, they were devastated. And my family was not loving or keeping care of them. When my kids' faces flashed in my mind, I said, "You know what? I gotta live. I gotta take them home."

Best attitude? Each and every one of us knows that final moment is going to come. We have to embrace it. When my aunt died, I felt at peace knowing that *she* was at peace after a lifetime of turmoil and struggle and being the backbone of her family. But what hurts is the thought of losing my kids and my partner. How can I ever accept I will no longer be able to laugh and cry and share the good and bad days with these people I love? So I am sad, but not fearful.

Imagine it? When I was dying in 1994, I saw the white light at the end of the tunnel and all the rest of it. That motivated me to get off my ass, get centered and get to where I am today. There were so many things I still had to fulfill for my family and the community. But the last chapter for me is to become an American citizen and to vote. Coming from Trinidad, voting is something deep in my heart that I want to have before I leave this earth.

Afterlife? Oh, yes. I'm planning on reuniting with all my loved ones who passed before. But if I go to hell, I'm gonna have fun there, too, because so many friends are there. Who knows, we'll probably end up fighting the politics down there!

Epitaph? Professor. She taught her family peace, tolerance and how to live right.

Judith Billings

Home: Puyallup, Washington
Age: 61
Job: HIV-ed advocate and legal consulting
News: Just back from the UN special session on AIDS and about to leave for a meeting of the president's AIDS council

Death thoughts? I think about *living* every day. As for death, I think more about my 93-year-old dad's mortality than my own.

Closest encounter? Favorite aunt, other relatives, fellow members on the president's AIDS council.

Imagine it? I imagine I'm peaceful, ready, and it's a passage. The best thing about death is, of course, getting free of all life's frustrations. The worst thing is not still having relationships with the people I love.

Afterlife? I believe in the eternal nature of the spirit. After death, there is a different level of experience.

Best attitude? Look upon it as the natural order of being. It is inevitable for all of us, so be prepared. The worst feeling would be sheer terror of it.

AIDS taught you...? I got my AIDS diagnosis in 1995, when the life expectancy was, at best, two years. That made me think much more clearly about how to live my life, and about life's sanctity and preciousness.

Epitaph? She cared about other people, used the talents God gave her and believed in the joy of living.

Tory Dent

Home: New York City and Deer Isle, Maine
Age: 43
Job: Poet
News: My husband and I are going to try to have a baby

Thoughts of death? At least daily. From 1995 to 2000, my CD4s were below 50 and my viral load a million. Technically I was dying. We tried treatment after treatment, and nothing worked. Because I lived so close to death for a long time, death feels very familiar, almost like a friend. Sometimes I feel closer to death than to life.

Closest encounter? I was very near death three times. The first was when I went into anaphylactic shock in 1993 from an allergic reaction to an antibiotic. I had all the near-death experiences one hears about: In the ER I heard a faint voice exclaim that my hands were blue and that they couldn't get a pulse. I saw myself from afar, doctors and nurses rushing around, heared that my blood pressure was falling fast. After that, I was never as afraid of death again.

The second time was when I was diagnosed with both PCP and TB in 1995, hospitalized and quarantined. I could feel my body cope with death, ebbing in and out. I tried to let my body balance on its own in its fight, without creating stress by willing myself to live. I was relatively at peace, which I believe helped my survival.

The third time was the spring of 2000 when it looked really hopeless. My doctor, husband and I talked about hospice care and living wills and when to stop trying. What was foremost in my mind was dying with dignity and not being bedridden. I was ready to die -- I was very weak and my eyesight was going. The only reason I wanted to live was to be with my husband. It seemed a shame to leave our marriage when it was so young. I had let go of everything else.

Imagine it? I don't have to imagine it -- I know it. When I was so sick, I spent a large part of the year up in Maine. There, I could feel myself merge with nature as I deteriorated physically. My body was breaking down like a dying animal or flower into mere matter. I derived a lot of courage and peace by looking at the ocean, which embodies eternity for me. I remember thinking, "Why should I be afraid?" Simultaneously, I felt disenfranchised from modern life and New York City and the drive to succeed and acquire. I was too sick to compete. But I also felt a solidarity with nature

that seemed to put everything into perspective in terms of what's valuable in life. And that would be love.

Afterlife? Nothing. I don't believe in an afterlife or that things happen for a reason or any of that crap. The only thing you have control over in life is how you react to its cruel, unfair and arbitrary nature.

Best attitude? Dying from a long horrible disease is terrible. Sudden death is to be envied. But one can take comfort in knowing that at the moment of death the stress of dying releases an enormous amount of endorphins causing you to experience a blissful and confident state of mind. It's the prelude to death that's tough, especially if you're in pain. But you can tough it out if you know the last feeling will be a happy one.

Leaving people you love is the only bad thing about death. Still, the consciousness of dying can be very painful until you come to terms with it. Initially death seems unbearably lonely. But I've come to know death as not lonely at all.

AIDS taught you...? AIDS is such a hard, long, drawn-out disease that the confrontation with death is protracted and all the complexities have time to unfold beyond such cliches as "Life is short" and "Be in the moment." I've come to hate those expressions. They're placebos for the worried well to cope with their momentary contemplations of mortality. Certainly I am stronger for my experience with death, but I will never call AIDS a gift.

Epitaph? When I was dying, I thought a lot about how I wanted my husband and friends to feel after I died. I wanted them to know that they did everything they could for me, and when they thought of me, they should be comforted by that thought as well as the knowledge of how much I loved them.

Jerry Herman

Home: Beverly Hills and Palm Springs, California
Age: 69
Job: Broadway musical writer
News: Working harder than ever on revivals of *Hello, Dolly!*, *Mame* and *La Cage aux Folles*

Thoughts of death? None at all right now. But when I was first diagnosed, I thought about death a lot -- I was upset and panicked. Now, because of the protease combos, I no longer think about leaving prematurely. Having AIDS has made me appreciate every second on Earth. I look positively at something horrendous like HIV because it made my life more valuable.

Closest encounter? When I had open-heart surgery four years ago. It was a very serious operation that oddly had nothing to do with HIV.

Imagine it? Going to sleep

Afterlife? More sleep

Best attitude? Death is a natural part of life. I will accept it. I have no choice. It's like accepting HIV or winter -- I don't look forward to it but I will make the best of it. No morbid feelings. Once I got a hold of myself and this disease, I determined to do everything I can to fight this. It is like a failure on Broadway -- you get back to work and hope the next one is a hit.

Epitaph? Keep singing my songs.

Emily Carter

Home: Minneapolis
Age: 40
Job: Freelance writer and community educator
News: My collection of stories, *Glory Goes and Gets Some* (Coffee House Press), is due out in paperback this month.

Thoughts of death? Two or three times a day. Except when I'm driving through the suburbs -- then it's constant. They are full of blank, empty spaces and golf courses landscaped like cemeteries. Also the malls are like giant tombs packed with some dead pharaoh's stuff.

Closest encounter? Various people whose bodies I came across after they overdosed.

Best attitude? For me, it is a delicate balance between acceptance and denial. The worst part is no backsies -- you can't come back. The best is no more boredom.

Imagine it? After struggling with pain for as long as I can, I will be given some strong opiate that will separate me from the life around me. Eventually the daze will become a doze, the doze a coma, and I will die. I plan to make sure to say what needs to be said to the people I love, but if I don't, I imagine they will say it.

Afterlife? Nothing. But I've been wrong before at least once.

AIDS taught you...? Death is like so many other things: You think it could never happen to you or people like you, but it can -- and does.

Body disposal? I want my body to be photographed in a Versace heroin/luxe tube top-and-hot pants combo, appear in a fashion magazine and have 13-year-old girls nationwide envy its flat stomach.

Epitaph? Good friend. Good writer. Good lay.

Shawn Decker

Home: Charlottesville, Virginia
Age: 26. I have to lie to apply to *The Real World*, and that's a beautiful thing
Job: Underground musician and community activist
News: Check out www.positoid.com

Thoughts of death? Some days are consumed by the thought, and it's motivating because I'm a lazy artistic type who needs a good swift kick in the ass from the Reaper every so often.

Closest encounter? As a kid with hemophilia, I had a couple of close calls. When I was 5, I remember playing on my grandparents' porch, and the next thing I knew I was lying on the ground, and my side was hurting like I had been kicked by a mule. I was rushed to the hospital in an ambulance, and they found out that I had hepatitis B and my liver was failing. Needless to say, I went on to play again.

The most recent brush with death was in 1999. It was a slow fade, like watching *Meet Joe Black*. I kept losing weight and CD4 cells. I had just fallen in love, made a CD (which wasn't good enough to be a posthumous smash success), started on Marinol to get my appetite back and had a new doctor. After about five months of deterioration, I knew I had no choice but to start taking antiretroviral therapy.

Imagine it? When I was first diagnosed as a teen, I saw pain and dying young. That made me focus on the negativity of the daily grind that consumes the lives of most adults. I always thought I'd rather die young and happy than old and bitter. Now I may actually become an old geezer and slump over one day while talking with friends at the mall about the joys of Nintendo and what a great series *21 Jump Street* was. And I may *not* make it there, too. What I fear most is losing my wits.

Afterlife? I completely believe that my friends will be waiting for me. And all the cool strangers I never got to meet -- I'll get to share how they influenced my life too. It will be an opportunity to purge myself of all remaining negativity. And best of all, in between thumb-wrestling matches with Andre the Giant and Fight Club matches with Ryan White (hey, it's my heaven, we won't bleed there), I'll get to peek in on my friends who are still here. Maybe even meddle in their affairs once in a while. It'll be great, but I'm in no hurry to get there.

Best attitude? I embrace death as a rebirth. I learned so much about it as a child dealing with many hospital visits thanks to hemophilia. One person leaving this mortal coil affects the routine of countless others -- it has such a domino effect. The grieving process is normal, healthy, but it brings up a lot of issues for those who still have to start their day with a bagel and a cup of coffee.

AIDS taught you...? AIDS has taught me that a lot of people never think about their mortality. When I've been shut out as a result of my HIV status, it's because I'm a walking reminder that we're all going to be fertilizer someday. This makes some people cringe.

When I was first diagnosed, my initial thoughts were "How can I painlessly kill myself before it gets too bad?" That sounds harsh, but it's the way a 12-year-old's brain works. This provided me with a sense of comfort. As did *The Return of the Living Dead* movies -- their release magically coincided with my diagnosis.

Body disposal? I want my body to be donated to Hollywood, for use in action sequences. Actually, I'd prefer to be cremated. It's something I've never discussed with anyone -- it's good to

put it in print so my loved ones won't spend their money on a casket. I'd rather they take a vacation with that money and talk about all the cool, stupid, beautiful and insane things I did with my little positoid life.

Epitaph? A credible underground artist and AIDS educator who shamelessly tried to peek his head and cute dimple above ground every once in a while. The originator of the word *positoid*, and someone who thought life was pretty damn cool. And make sure you lock your door at night, I may be coming to eat your brains.

Research assistance by Phoebe Mackay

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