Savage Grace

HIV, while slowly ravaging the body, gently nudges the spirit to life. But walking on the edge of life and death doesn't always lead to the same place. Spiritual quests can lead people with AIDS to self-affirming peace or strand them, alienated, in a no-man's land of the soul.

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The night I became infected with HIV, there was a thunderstorm in the valley where I lived. I drove around my ex-lover's block, steering past trees struck down by lightning, squinting through the rainy windshield, debating whether or not to knock on Bob's door for sex. I remember a feeling of danger -- enhanced by the weather, I'm sure, and the nasty thrill of seducing a person you no longer love. After we'd finished our violent, sloppy encounter, I walked back into the downpour feeling spent and exhilarated.

Six years later, when Bob got sick, we talked about what AIDS was like. "You're not going to believe me, but I've never been happier in my life."

I studied his face for irony. "But you might die," I said.

"Worse things could happen." Bob was serious. Clearly something had shifted in him since his diagnosis. He was softer now, more circumspect. The mentor relationship we'd had since I was 18, when he, a successful show business mogul, plucked me from juvenile delinquency and showed me how to clean up my act, was finally becoming a friendship between equals. Without the trappings of movie-star clients and limousines, my former hero could be seen for who he was, naked, accessible, human. AIDS had provided him with an exit from a fast-track life he had long grown weary of and permitted him to spend his days with the things he loved most: Elizabeth Schwarzkopf singing Richard Strauss' "The Four Last Songs" and the Navajo art of R.C. Gorman.

Satisfying the needs of his soul, Bob had also been spurred by illness to explore spirit. A diehard atheist, he'd begun to think about his relationship to God, to investigate wisdom literature, to ask questions about the nature of existence. While it's true that many of our lives have been shattered by HIV, it is also true that within this destruction, profound insights have led to a deepening of vision, purpose and faith. Knowing we may die very soon, we've been forced to look toward eternity; to come to treasure what we have; to realize, as a monk once wrote, that "if the cardinal's flight from bank to bank were less brief, it would also be less glorious."

Growth accelerates in this intensified climate. With nothing left to lose, risk takes on new meaning.

Changes that were daunting before an HIV diagnosis seem like nothing compared with the prospect of dying without having done them. With old values falling away, many of us have made what seem like erratic, extreme movements in search of happiness and spiritual meaning. One friend left his career as a Wall Street attorney to meditate and chop vegetables in a Zen monastery; another gave up a successful arts career to run grief support groups and to train to be a therapist. A drug addict got sober, then, finding out she was HIV positive, became a national spokesperson for women with the virus.

For me, the relationship between HIV and spiritual life has been equally fruitful and dramatic. It began on a trip to Jamaica in 1986. Having coffee with my best friend John in our hotel room, I discovered a purple spot on his foot that hadn't been there the day before. Five months later, panting behind an oxygen mask, John suffocated to death in a room overlooking an airshaft. Knowing that my own funeral could be next, I panicked for fear not only of dying, but also of dying completely ignorant of my inner life. Quitting my vacuous career in publishing, I followed a mystical friend to Germany, where I met my spiritual teacher, Mother Meera, then continued on to India, where I took up the long-avoided challenge of writing fiction. Suddenly, everything was urgent, nothing could wait and while this awareness of emergency created anxiety it also brought my life into focus.

Returning to New York City deeply changed but forced to earn a living, I gave up limousine chasing for the journalism of consciousness. Although I had long assumed I was HIV positive and acted accordingly, it was not until 1989 that I finally surrendered to my new lover's insistence that I take the blood test. I'll never forget the look of pity on the technician's face as he read my results. I assured him, in chronic care-talking fashion, that I was just fine. (I was more upset by my 24-year-old lover's positive test result than my own.) Then, as the news sank in, I discovered that the transition from a shadow of a doubt to confirmation was more significant than I'd anticipated; The leap, in essence, from dating to marriage. When this virus becomes a formal part of you, your identity shifts.

For me, this has been the ideal predicament: Carrying a potentially fatal bug (with its urgent message not to waste time) while remaining asymptomatic. I've often said that AIDS has actually saved my life, propelling me to change, encouraging me to confront what's difficult, urging my fascination with things divine. There is nothing Pollyanna-ish in this; it does not imply that I'd have chosen this virus or that I would not cure it tomorrow if I could. But there have been undeniable benefits to having the myth of immortality exploded. Like thousands of others living in this limbo, I've found depths and doors and potentials *in extremis* that I did not know existed before. Forced to look beyond the body for metaphysical meaning, I've learned that within the horror lies a tremendous mystery.

Still, it's hard to be grateful for suffering. My feelings about AIDS are more complex than gratitude can articulate. They exist in a realm beyond words, inspired by the awe at this fabulous pattern of death, grief and regeneration, at watching yourself and others transcend terrors you thought would kill you. This intimacy with suffering puts you in a state like the one described by Hindu teacher and AIDS pioneer Ma Jaya Bhagavati of being in "complete agony and complete ecstasy"

at the exact same moment.

Unfortunately, not everyone agrees about the honey in the rock. Due to my own transformative experience and those that I've witnessed around me since the appearance of AIDS, I came to my research expecting others to agree with my perspective. I was wrong. In fact, 13 years into an epidemic that is only getting worse, the concept of spirituality has come to have a surprisingly checkered reputation in the AIDS community. Speaking with people with AIDS and their lovers, therapists, doctors, ministers, authors and gurus, it often seemed repugnant to discuss God in the midst of affliction.

"It's hard to say anything good about AIDS," admits Karen Ziegler, a minister who works with the Metropolitan Community Church in Manhattan. "I just want it to be over." Instigating conversations about spirituality in the presence of suffering, I learned to risk vulgarity, to miss the point, to literalize what is by its nature subtle, personal and silent. As Joe Miller, a PWA living in New York, puts it: "Spirituality is like sex, the ones who really have it don't talk about it."

But then, the sheer magnitude of AIDS and all the attendant issues is enough to turn some former believers into skeptics. John McIlveen, who heads the volunteer division of the PWA Coalition in New York, is one of them. "My faith has dwindled during the AIDS crisis," admits this former Catholic. "It's left me more existential." A blue-eyed all-American of 33, McIlveen has not been infected but lives with an HIV positive lover. The shadow of death weighs heavily. "The serial loss is devastating. I've watched at least a dozen volunteers die in the past two years. I ask myself, if there is a God, why is this happening? This whole tragedy has made me cynical."

This cynicism has only been strengthened by certain faction of the New Age movement, whose saccharine philosophy is the second major obstacle to spirit among individuals groping with the gritty reality of AIDS. Responding to cries of helplessness and fatality following the first diagnoses in the early 1980s, the psychological pendulum swung to the opposite extreme in an effort to rally people away from victimhood toward the possibilities of self-healing and survival. Foremost among this group of advocates is Louise Hay, a Science of Mind minister whose books (including *You Can Heal Your Own Life*) have sold in the millions and whose name has become synonymous with pop notions of self-created reality and "taking responsibility" for illness.

Beginning in 1985, Hay (who refused to be interviewed for this piece) formed the first of many HIV healing circles across the country, urging the six men in her living room to drop their self-pity and take charge, using affirmations, visualizations, mirror work, teddy bears and other devices aimed at fostering self-love and its supposed correlate, spontaneous physical healing. Proffering what author Paul Monette dubs "*Readers Digest* psychology," with its simplistic think-happy-get-healthy message, Hay seemed to offer a sunny alternative to a slow and painful death. Those at risk and those already dying flocked to self-empowerment's ray of hope, following the injunction to uproot their evil death wish by becoming vigilantes of negativism.

This philosophy's dangerous fallout has struck many, including me. Working as a volunteer at New York's Cabrini Hospice, I was spoon-feeding a very sick patient once day when a member of the

New York Healing Circle came by for a visit. “I always knew he was a negative person,” this fellow said to me afterward in the hall, referring to the man in bed. Asked why I was wearing a mask in the room, I informed him that our patient had active TB. He laughed at my self-protective precaution. “But no one can give you anything you don’t want!” he scoffed.

Thus many infected and dying individuals, alienated by both the religious and New Age contingents, found themselves in no man’s land, compelled to create an approach to healing and spirituality forged from their own experience, meeting their own particular needs, incorporating their own unique gifts and drawing from the best of mainstream and alternative sources. “There are a million possibilities between death and denial,” says Sally Fisher, founder of the AIDS Mastery Workshop. “We just had to find them.”

Moving into this realm of possibility, the first thing that becomes obvious is the crucial role that solidarity, revolt and imagination have played in the AIDS movement. Hitting marginalized populations already high in survival skills and eager for their civil rights, the epidemic has acted as a social powder keg, unleashing astounding powers of resourcefulness and community support, an alembic in which activism and spirituality are distilled and linked.

Anger has been one tool that used skillfully has accelerated self-actualization as well as shifted the balance in social power. Many have turned to civil disobedience to protest medical, political and legal injustices and have found it to be a vehicle for both empowerment and the release of hostility bred from oppression. “Social consciousness is crucial to everyone in a beleaguered world,” Paul Monette told me, en route to deliver a scathing speech before the Library of Congress in Washington (Monette’s memoir, *Borrowed Time*, put AIDS on the literary map.) “By taking anger away from people, some forms of spirituality keep these people from becoming part of the political battle. Anger against injustice is the most significant emotion an adult can feel.”

Inspiring as anger may be, however, it is only one piece of the healing puzzle. “It may help change laws but if it helps their lovers dying in bed, I don’t know,” says death and dying pioneer Stephen Levine. “There’s a need to find something to sustain yourself in the face of death that goes deeper than rage,” says Sally Fisher.

Determined to be active martyrs instead of helpless victims, many PWAs are working hard to locate this middle path between rage and compassion. Their drive to transform personal suffering into public good is mythic in texture. According to Paul Bellman, a Manhattan internist whose practice is largely devoted to people living with HIV, “People with AIDS are the real heroes of our time, even more than those suffering from other diseases. Being young, many people with HIV embark on a kind of medical, psychological and spiritual quest to find better treatments and discover themselves. It becomes a hero’s journey.”

Ten years ago, Dean Rolston was a high-powered Wall Street attorney, art world maven and part-time Zen student, up to his eyebrows in New York City hysteria and longing for a break. An urbane man of 40, renowned for his remarkable wit and trademark head scarf, Rolston grew tired of elbowing the best and the brightest and used AIDS as an exit from a world he’d outgrown. “This

illness gave me permission to change," said Rolston, who ditched Manhattan for the serenity of the Green Gulch monastery outside San Francisco following his positive diagnosis in 1987.

This change of scenery had unexpected rewards, both spiritual and medical. Like an increasing number of PWAs, Rolston continued to outlive his physicians' prognoses for survival ("It's almost embarrassing," he once laughed), attributing his continued relatively good health to changes of life-style and priorities.

Living with AIDS, he claimed, had radically transformed his character. "You become more tender and expressive as you pierce the veil of ordinary reality and seek deeper things," said Rolston, who channeled his professional savvy into writing and curating art shows for charitable organizations, such as the San Francisco Zen Hospice. Often this tenderness led to unexpected spiritual insights. During a recent brush with death, Rolston had an experience of *satori* (enlightenment) that took him to "a completely different level of reality, a buoyancy lighter than air."

Although the experience of deepened spirituality is nearly universal among those touched by AIDS, many who call themselves atheists prefer to clothe their epiphanies in humanist terms. "My faith is in those I love and trust," says John McIlveen, who finds inspiration in "the charity of other people."

Many of us living with HIV and AIDS are making concerted efforts to integrate psychospiritual healing with the physical realities of immune deficiency. Called upon to reimagine a condition deemed incurable by the mainstream medical establishment (but, in the light of growing numbers of long-term survivors, perhaps not so), we rely upon physicians (as well as therapists) who are willing to support us in our struggle to cultivate hope during this twilight period of pessimism and uncertainty.

Yesterday I went for my three-month checkup. At the clinic, my doctor looks happy. He approves of my latest lab results; he is pleased by the numbers and ratios. My T-cells, whatever those are, seem to be normal. I'm not in immediate danger. I leave the office feeling smug, not quite grateful enough for continued good health as my friends get sicker. At home, an invitation has arrived announcing the baptism of my best friend Carole's granddaughter. Carole, whose rosary hangs by my desk, was an ardent Catholic who died of AIDS last year. Here was the granddaughter (named for her) she dreamt about but didn't live to see.

In an ironic passage, Aristotle defined luck as the moment the arrow hits the guy next to you. This is cold comfort, as the "worried well" and anyone dealing with survivor's guilt can testify. Indeed there is even a faction of seronegative extremists who actually claim they want HIV for solidarity. I've never been that crazy, but I do admit to feeling resigned sometimes: surreal, split off, already dead. So many have died, death is no longer a surprise. Sometimes it doesn't even hurt.

Once a father approached a Buddhist master and asked how he could possibly bear to live in a world where he could not protect his children from annihilation. The master picked up a crystal goblet. "I like this glass," he said. "It makes a lovely sound when you flick it and everything tastes

more delicious when poured from its delicate shape. But when a wind comes along and shatters it into a thousand pieces, I won't be surprised. You see, I know the glass is already broken."

Is this spirituality? Perhaps. Writing this story, I came to question the implications of that word more than I had before. It seems to imply some separateness, some privilege, some otherness that may not be useful. Is it spiritual or simply wise to admit you're already broken? Thanks to HIV, I have come to live with this fact completely. Every morning the routine's the same. I open my eyes, check my armpits for lumps, the sheets for perspiration. I search my body in the shower for purple lesions, then inspect my tongue in the mirror for signs of thrush. At first these rituals were disturbing. Now they simply keep me on my toes.

The funniest thing about it is that I've grown to love this way of life -- the intensity, clarity, poignancy -- the ability to see things at their value, to measure life, at last, by its true and terminal standard. I laugh louder these days and cry at nothing. I work until my fingers hurt and exercise my heart in love. The future is a fantasy and I think almost nothing about the past.

Of course AIDS is terrible -- a sentence to the guillotine. But terror can enlighten. Affliction has its gifts. Rainer Maria Rilke, who refused medication during his excruciating final illness, described this in a letter to a patroness. "It is true," wrote the poet, "that these mysteries are dreadful, and people have always drawn away from them. But where can we find anything sweet and glorious that would never wear this mask of the dreadful? Whoever does not, sometime or other, give his full and joyous consent to the dreadfulness of life, can never take possession of the unutterable abundance and power of our existence; can only walk on its edge, and one day, when the judgment is given, will have been neither alive nor dead."

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