# Death in Hand

AIDS fired up the assisted-suicide debate -- until HIVers traded in the hemlock for HAART. But as combos fail, self-deliverance is back on the agenda.

September 1, 2001 By Bill Strubbe and Angelo Ragaza

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Rick was afraid the police might show up at his friend Aaron's house to stop Aaron from killing himself. "He had been ravaged for years by AIDS," Rick says. "He was the leader of our HIV support group, and he came to the group that day to say goodbye. But our facilitator felt she had to protect her license, so she called the cops." Rick hustled Aaron into his car and took off along a winding Northern California road. Aaron, who had taken anti-nausea pills to keep from throwing up, tried to down his lethal Seconal cocktail before it sloshed onto the seat. "I didn't know how much he actually managed to drink, and we were worried he might survive and be a vegetable," Rick says. "It seemed like it took days before he finally died."

But eventually Aaron did die. He'd done it right, and later the coroner named Aaron's cause of death as AIDS, not an overdose. "He might have figured out what had really happened," Rick says. "But I think a lot of doctors are sympathetic." Still haunted by the experience, Rick says he's not sure he'd make the same decision. One thing he is certain about: "It's incredible that we're not legally allowed to make this choice."

Incredible but true. Attempting or committing suicide is not illegal. But in all states -- except Oregon, where the Death With Dignity Act won by a slim margin in 1994 and survived a near-repeal by referendum three years later -- assisting a suicide is a crime, punishable by fines of up to $10,000 and five years in prison. By helping a friend, Rick risked arrest.

In the pre-HAART era, an AIDS diagnosis often had PWAs counting their days -- and sometimes choosing to slit wrists, down downers or self-inject air bubbles rather than suffering the inevitable ravages to come. AIDS fast became "the disease that 'most justifies' the right to die," says University of Sydney law prof Roger Magnusson, who has long studied AIDS-related assisted suicide. And other than some fearful disability-rights groups -- and those fun-loving fundies -- the majority increasingly viewed that death with dignity became empowered PWAs.

In LA, a cladestine network of HIVers stockpiled barbiturates. Membership skyrocketed in San Francisco's chapter of the world's oldest right-to-die organization, the Hemlock Society. State ballot initiatives legalizing physician-aded death appeared in several states. Even as Jack Kevorkian—a.k.a. Dr. Death—was imprisoned in 1999, the tide of America had turned. In CNN/USA Today Gallup poll that year, 61 percent of adults said that those who are terminally ill and in

severe pain should be allowed, with the help of a doctor, to end their lives.

But in the Lazarus-crowded AIDS community, the emphasis had shifted from death to survival. “The desire for assisted suicide has transformed in recent years because of HAART,” says Russel Ogden, a criminologist and author of the 1994 book Euthanasia: Assisted Suicide and AIDS. “The urgency had lifted.”

Fast-forward to 2001, and more and more HIVers at the end of their protease hope. With bodies and souls -- not to mention hearts and livers -- in decline, talk of self-deliverance has come back. For his upcoming book, Angels of Death: Exploring the Euthanasia Underground, Magnusson interviewed 49 AIDS docs in Sydney, Melbourne and San Francisco. One recalls the “horrendous, disfiguring” death of a friend with an undetectable viral load. He died rapidly, not of an “old AIDS” OI, but of a fungal infection that ripped through his sinuses and into his brain (see "The Way We Die Now“). Despite, and in some cases, because of HAART, Magnusson says, ”there is a significant reservoir of HIV infection to fuel patients’ demands to end life on their own terms."

The moral debate persists, of course, waged long and loud on Sunday morning talk shows and, more important, in hospital rooms where grieving families line up toe-to-toe over questions of playing God and slippery slopes. The most compelling arguments against assisted suicide have been framed by such disability-rights groups as Not Dead Yet. Leader Kevin Irvine, who has both hemophilia and HIV, fears that “legalizing self-deliverance will have devastating consequences on how people with non-HIV-related disabilities such as multiple sclerosis and muscular dystrophy are treated by the health care system.” These so-called right-to-life supporters argue that the bottom line is money. Legalized doc-aided suicide, they say, would offer HMOs the option of dropping pricey treatments and services in favor of minimal care and “compassionate” assistance in dying.

But the stigma of disability is as big a fear. “Many people still think it would be better to be dead than disabled,” Irvine says. And Marilyn Golden, of the California Disability Alliance, agrees. “This fear of disability typically underlies assisted suicide. Pain is not the main reason. It’s the indignity -- the inability to get out of bed or onto the toilet. But needing help is not undignified, and death is not better than dependency.”

Even docs who support assisted suicide admit that for them it’s a stressful, soul-searching process, the seeming antithesis to a career spent fighting to keep patients alive. This leaves many HIVers -- who are often used to doing it for themselves when it comes to making important treatment decisions -- to take matters into their own hands. But neither choosing, planning nor trying to end your life is as simple as following the instructions of the 1991 euthanasia bestseller, Final Exit, and downing a few pills.

“Fifty percent of AIDS patients who attempt self-deliverance fail,” says Faye Girsh, president of the Hemlock Society. “It’s pretty grim.” Girsh says that many botched suicides are the result of patients taking either too-few medications or the wrong kind, or falling unconscious before completing the fatal dose. (See "D.I.Y. Death")

Despite the American Medical Associations controversial stance condemning doc-aided

euthanasia, 53 percent of physicians in a 1995 study reported that they had helped hasten a PWA's death. "Many physicians say that they're opposed in principle, but if someone they love is terminally ill and in severe pain, they may act differently," Ogden says.

Girsh agrees. "Independent surveys have revealed that thousands of doctors quietly help people die when it is a repeated, desperate wish," she says.

As the debate over the issue has evolved, so has the terminology. Suicide begat euthanasia, followed by assisted death and, recently, among advocates, self-deliverance. Current champ: the choice to hasten death, which Susan Dunshee, director of Seattle AIDS Support Group, says "reminds people that these are dying people who simply want to bring the end sooner."

Wanting a "better way" after three lonely and desperate PWA friends chose to hasten death, Dunshee in 1993 founded Compassion in Dying, a Seattle-based death-assistance clearinghouse. Her group offers basic information, how-to consultation and the personal presence of another warm-blooded soul when the end draws nigh. Now with five affiliates, the group fielded hundreds of thousands of inquiries last year and managed about 325 cases, of which a tenth were AIDS related.

We only take on cases when we feel assured of the person's mental capacity, that there's no coercion and that this is a last resort," says Compassion in Dying's director, Barbara Coombs Lee. "We help optimize comfort care and make sure the client follows an effective protocol. But we do not provide the means or administer medication, so it's ethical and legal."

To protect patients and physicians, the Hemlock Society since 1986 has advocated for legislation with safeguards, including multiple independent confirmations of a terminal diagnosis, a mental health evaluation and a waiting period. In the 1997 landmark case Vacco v. Quill, the Supreme Court left it to states to wrestle with the moral and legal fine print. The passage of Oregon's Death With Dignity Act, modeled on Hemlock's safeguards, has spurred similar efforts in other states. So far, copycat initiatives have been voted down by thin margins in Washington, Maine and California. Two states, Hawaii and New York, have bills pending. Meanwhile, a backlash is underfoot, with anti-euthanasia legislation on slates in Alabama, North Carolina and Vermont.

Self-deliverance's ultimate benefit may be the sense of empowerment and control it confers, Dunshee says. Perhaps that's why, in the end, the vast majority of those who have a contingency plan for death never actually need to carry it out. "Many patients who, once they've gone through the protocol and gotten the meds, never do it," she says. "There is often enough relief in just knowing they have this option. It's no failure for someone to choose to die naturally."

Meantime, the right-to-die movement keeps pushing to make assisted suicide a legal and safe choice. "Death used to occur at home as a natural, family-centered event," Hemlock's Girsh says. "Now for most, it occurs alone, in a sterile hospital environment. We should place no restraints on someone's right to choose as they face life's most precious moment."

That's the way 72-year-old Sydney Morris sees it. "Life is precious, and I'm not looking forward to

ending it, and not waking up to hear some wonderful piece of music," the HIV positive playwright says, "see the pretty buns of the boy next door or taste a piece of chocolate cake." As a hospital volunteer in the 1980s, Morris saw hundreds of young men die "hard deaths with tubes and needles sticking out of them." Now with only one year to live, he's determined to escape the same gruesome exit. When the time comes, he plans to mix the 60 Seconals he has procured in vanilla pudding. "I joke about it," he says, "but I don't want a plastic bag over my head. I don't want the last words I see to be the name of a supermarket."

**A LONG-GOODBYE SHORT LIST**

*Books and websites for future self-deliverers and those who love them.*

**BOOKS**

***Last Wish***
by Betty Rollin
(Public Affairs Press, 1998)
A memoir about coming to terms with a terminally ill mother's decision to die.

Final Exit: The Practicalities of Self-Deliverance and Assisted Suicide for the Dying
by Derek Humphry
(Dell Publishing, 1997)
An updated edition of the classic, controversial how-to.

***A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life***
by Timothy E. Quill
(Johns Hopkins U. Press, 1996)
True stories about doctors, dying patients and physician-assisted death.

***Last Rights?: Assisted Suicide and Euthanasia Debated***
by Michael M. Uhlmann (Editor), Ethics and Public Policy Center
(Wm. B. Eerdmans Publishing Co., 1998)
Top theorists and activists go toe to toe.

***Lethal Judgments: Assisted Suicide and American Law***
by Melvin I. Urofsky
(University Press of Kansas, 2000)
An analysis of the landmark 1997 Supreme Court rulings, *Vacco v. Quill*.

***In the Arms of Others: A Cultural History of the Right-to-Die in America***
by Peter G. Filene
(Ivan R. Dee, Publisher, 1999)
Using Karen Ann Quinlan as a benchmark, a rundown of recent issues.

***A Chosen Death: The Dying Confront Assisted Suicide***
by Lonny Shavelson, MD
(Simon & Schuster, 1995)
A physician's account of patients who elected self-deliverance at the end.

**WEBSITES**

**Right-to-die groups:**

Compassion in Dying
www.compassionindying.org

**Death With Dignity**
www.deathwithdignity.org

**The Hemlock Society**
www.hemlock.org

**Anti-assisted suicide groups:**

Not Dead Yetwww.notdeadyet.org

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