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LIVING WITH DEATH

A doctor's examination and diagnosis of a taboo subject hits a public nerve

by Bob Roehr

Death, like sex, is always on our minds. "It may not be on our conscious minds, but it takes nothing to bring it out. We hide our eyes," says Dr. Sherwin Nuland, putting a hand to his face and peering through splayed fingers. "But we really want to see it."

The surgeon and teacher at Yale University set out to write *How We Die: Reflections on Life's Final Chapter* "to demythologize the process of

pany a loved one to death." He laments that the experience, captured so brilliantly in poetry and prose by writers such as Paul Monette, has not been embraced much beyond the gay community, "because humanity needs it."

"When people are very close to a dying person, they come to a sense of resignation about the death, an understanding of the power of nature, and the inevitability of this conclusion.

"Every person that I have taken care of who was dying knew they were dying, even if they didn't talk about it," says Nuland with absolute certainty. "The worst thing it seems to me, the worst, is holding cards so close to the vest that nobody sees it. That communion at the end, that expression of what my life means to you or your life means to me never happens."

And changes are due in the traditional character of the role of the physician. "The kind of hope we tend to give a dying person is a false hope. We are going to find a treatment that will keep you alive for another six months. We can really cure this thing. That is terrible. The real thing that makes sense is the communion with the people who are dying, the serenity, the not being forced to try a last-chance treatment when the chance of its working is tiny, tiny, tiny. When you devastate the last weeks."

Nuland says, "We give a lot of lip service to

Books

dy by presenting its biological and clinical realities." He did that in a manner one reviewer described as "almost sadistic in [its] candor." And there was something more. As with all works of genius, the book asserted its own persona.

Stories began to bubble forth—enveloping, breathing life into cold data. Stories of Nuland as a medical student grasping a still-twitching heart, "a wet, jellylike bagful of hyperactive worms," in a futile attempt to countermand a heart attack. Of the decline and passing of his Bubbeh, his beloved grandmother. Of HIV's relentless assault on Ishmael Garcia's organs.

"What I ended up doing was opening up this enormous rich vein that was waiting to be cracked. I hadn't been aware of it, except in retrospect."

Public response to his book has been overwhelming: 400,000 copies in hardback, rave reviews everywhere, the prestigious National Book Award for nonfiction—all within the first year. The paperback edition, just out with an initial 100,000 copies, hit the *New York Times* bestseller list even before its official release date.

"We are on the verge of wanting an open discussion about death," says Nuland, explaining a reception he had not anticipated. He compares it to the landmark *Kinsey Report* of 1948, which unleashed a national discussion of sex. "This book in essence gave them permission to talk about death."

AIDS was key. Up until the early 1980s medical schools "were teaching our students that infectious disease, within 15 years, would be a thing of the past. It would be eradicated." AIDS destroyed "that entire gestalt, our entire approach to medicine."

Nuland says, "All of a sudden this generation which assumed that nobody died until they were in their 70s was forced to recognize it."

Death reasserted itself. Death which had been removed from the bedrooms and parlors of our grandparents and locked inside sterilized hospital walls. "Death with dignity," that myth which had flourished in isolation and ignorance, now came tumbling down. Death, like sex or homosexuality, which acquires much of its power to intimidate through our silence, our fear to speak the word.

"Death is, to use the cliché, part of life," says Nuland. AIDS has brought a large measure of this recognition to the gay community. Natural and created families have formed "to do something that has been lost in society, which is to accom-



families or patients themselves, but the fact is, families and patients always do what doctors want. I used to point out to people, with pride, that in 30 years of clinical practice I have never had a patient refuse my recommendation. And after I wrote this book I said to myself, 'Jesus Christ, what have I been doing, I've been brow-beating people, like all doctors do.'

"[A doctor] can be authoritarian in the sense of having better knowledge, but that doesn't mean that all of the aspects of judgment come from knowledge alone. They come from knowing the other

guy's values, they come from knowing what makes sense at this time in his life for him."

In his manuscript the author lauded "the whole AIDS community—the people who have it, the people who treat it, the support groups—for their thoughtful, humanistic care." But his editor said it was too much and excised a page and a half of homage.

"Death belongs to the dying and to those who love them," Nuland says. "Though it may be sullied by the incursive havoc of disease, it must not be permitted to be further disrupted by well-meaning exercises in futility.

"The greatest dignity to be found in death is the dignity of the life that preceded it.... Hope resides in the meaning of what our lives have been."

He adds, "By writing this book, I so familiarized myself with death that it is in no way the terra incognita it once was. Instead of me belonging to death, death now belongs to me."

How We Die: Reflections on Life's Final Chapter by Sherwin B. Nuland. Vintage Books, 1995; \$13.00, paperback.