

AGENDA FOR IMPROVING END-OF-LIFE CARE

Review of *LAST RIGHTS: RESCUING THE END OF LIFE FROM THE MEDICAL SYSTEM*

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We professionals working in the trenches are often too involved to take a broad overview of an issue.

A journalist, however, tells stories, marshals statistics, observes trends, and identifies the changes needed. Journalist David Shenk described coping with the profound consequences of increased life expectancy in *THE FORGETTING: ALZHEIMER'S: PORTRAIT OF AN EPIDEMIC*, Doubleday, 2001. In a similar manner, Stephen P. Kiernan portrays the big picture of how many elderly people die in dysfunctional ways in *LAST RIGHTS: RESCUING THE END OF LIFE FROM THE MEDICAL SYSTEM*, St. Martin's Press, 2006.

Assigned in 2002 to investigate a physician reprimanded for administering death-inducing sedatives and paralytics to kill a patient, Kiernan soon learned that the matter was very complex. The patient's lungs had collapsed, and she had been placed on a ventilator against her written wishes by an on-call physician. The reprimanded physician took her off the ventilator and challenged Kiernan, before he would be interviewed, to read journal articles by Timothy Quill, M. D.; Andrew Billings, M. D., and Sherwin Nuland, M. D., experts in the care of people who are dying. After reading the articles, Kiernan devoted several years of research and interviews to discover how America's dysfunctional medical system denies death and what could be done to improve it.

Kiernan tells stories about how the lives of several people play either passive or active roles living their lives before their deaths. He is especially poignant in describing what he learned from the passive role his Father played in his death from a ruptured aneurysm, in which his "family demanded more care, more interventions, more heroism," and of the active role his Mother played in her life before her death from terminal cancer, in which she refused extraordinary treatment and organized the days before her death.

"There was a process, for me and my family, an education through these two deaths," Kiernan wrote. "We discovered that the manner of a death has meaning, reverberating long after the person has died. In my father's illness, I can instantly conjure feelings of helplessness at seeing his dignity stripped away [and] a sense of complicity in his suffering. . . .

". . . Even now I can picture his sore eyes in the Falmouth hospital, his cracked lips. I hope he never regained consciousness sufficiently to realize that his hands were strapped down. In all, I feel an anguish quite apart from the sense of loss. This was a powerful man who shaped so much of his life. Yet his dying did not go well. And no repair of that is possible.

"By contrast," said Kiernan, "my mother's dying process was marked by rewards and accomplishments [as her] waning of life occurred on her terms. She attended important occasions. She left things in order, which was important to her. She made

preparations from the financial to the spiritual. She had a chance to exercise medical control, when offered the choice of that surgery [she decided not to do it]. She relished that her final care was inexpensive. She made peace with her children and played one last matriarchal role for her grandchildren.

”My mother also left an image that remains in my mind forever, but it is not one of weakness or powerlessness or defeat. It is as feisty as her determined Irish temper: In the end, her jaw was struck straight out.”

The earliest story recounted by Kiernan is about Jack, a 52-year-old who died of a heart attack in 1976 suddenly at his home while shoveling snow. Kiernan explains that a generation ago in 1976, deaths occurred suddenly “with the speed and severity of a guillotine blade.” Now however, death comes from “sicknesses that take their lives by degrees.” Heart attacks as the largest cause of death have been replaced by chronic obstructive pulmonary disease, congestive heart failure, diabetes that leads to kidney failure, osteoporosis that results in falls, Alzheimer’s and other dementias, stroke, and cancer. Lives ended at home for 75 percent of deaths in 1920, but in 1994, 75 percent died in hospitals or other institutions.

How did this shift happen? Kiernan points out numerous statistics about Americans demanded “better delivery of the medical capacity . . . regardless of cost,” in the quest for “longer and healthier lives.” If Jack were to have had his heart attack in 2006, his wife could dial 911, which did not exist in 1976. Although 1500 emergency medical technicians (EMT’s) were certified originally in 1971, they were not distributed throughout the county by 1976. By late 2003, however, about 900,000 EMT’s in 54,339 ambulances and several hundred air medical transports would be ready to respond anywhere in the country. Portable defibrillators could be used to get Jack’s heart going again. Kiernan cites statistics that “In 2002 alone 2,057 heart transplants, 93,000 heart-valve replacements, and 515,000 cardiac bypass procedures” were successfully performed in America’s quest for saving heart attack patients.

Further contributing to greater life expectancy were such social policy phenomena as life guarding courses offered by the Red Cross, safety standards from the National Traffic and Motor Vehicle Safety Act, investigations of air crashes by the Federal Aviation Administration, and food supply standards under the Wholesale Meat and Poultry Acts. Kiernan further credits consumer and employee lawsuits for improving products and workplace safety.

Yet with all of this death-defying activity, “there may be a great deal wrong with using intensive medicine,” understates Kiernan, “on a person whose death is certain and near.” Especially as he points out that a study indicated that half of American patients who die in hospitals suffer “moderate or severe pain at least half of the time” during their final days. Moreover, 38 percent of patients who die in the hospital spent ten or more days in intensive care or on a ventilator. In fact, 44.9 percent of deaths occurred after life support was withdrawn or withheld. Kiernan says, “In essence, people in that situation were eager to die.”

It is not much better in nursing homes according to the studies that Kiernan reports where over twenty percent of Americans end their lives. “Strapped down, hungry, dirty, humiliated—that is the experience of American elders.

Palliative and hospice care offer the best remedy for improving quality of care, but they are resisted by the medical establishment. Kiernan cites studies that such care is much more cost effective than intensive medical intervention with all of the attendant lab results and imaging tests. This will take “decades” states Kiernan for the medical system to embrace the “tenets of palliative care and thereby realize the potential savings.”

Interwoven amongst the statistics and the argument on how the medical system must change and how other countries have better priorities, Kiernan tells his stories based upon interviews -- some disappointing in which the medical system of inertia ignored patients’ wishes reducing patients’ to passive suffering and some vividly rewarding in how purposeful and active lives could be before deaths occur.

Kiernan sets out an agenda for change involving several actors. The Federal Government should set policy and direct funding towards palliative care. State governments should regulate physicians such as the California law requiring training in pain management and then disciplining physicians when pain alleviation standards are not followed. States also should facilitate communication of advance directives so that patients’ wishes would better be followed. Litigation such as Kathryn Tucker’s *Bergman* case in California could force more change in the system, states Kiernan.

The medical community should require more training in death and dying rather than discounting and dismissing care for the terminally ill, according to Kiernan. The Joint Commission on Accreditation of Healthcare Organizations should follow through on its initiative in 2000 to encourage palliative care and pain management rather than back off. Kiernan says that the medical system needs to sustain its focus on the patient as a person when that person is near death rather than “a manifestation of illness.”

Finally, Kiernan says that the American Public’s “isolating sorrow and emotions” from witnessing our unsatisfactory ways of dying will become a “juggernaut” once directed to positive change. The American Cancer Society, the American Heart Association, American Lung Association, AARP, and business groups will likely demand that the medical system reform end-of-life care. Lawyers in the American Bar Association [and NAELA] could emphasize more aggressively assisting clients with clear healthcare directives and enforcement of them. Patients, says Kiernan, should “insist on dignified end-of-life care,” prepare their own healthcare directives and have their agents enforce them, and reflect upon and communicate how they want to shape their end-of-life experiences.

In concluding his exposé and hopeful, practical descriptions of how the system could work better, Kiernan reports four lessons he learned as he recognized that he became personally involved in what was to be a broad policy review of the too-often

disorganized, deficient, and disastrous ways many people are cared for before they die. Readers should read the book to appreciate his lessons, summarized as follows: first, we are “at all times bearing our mortality around with us inside;” second, “death teaches us compassion;” third, “helping someone who is dying, even if just by providing brief entertainment, is one of the most gratifying experiences imaginable;” and four, “the most important time in your life is not the moment of your death but the time as it approaches.”

As a lawyer who actively assists clients in dealing with these life and death issues every day with planning, drafting, and advocating, I join with palliative care guru, Ira Byock, M.D., who wrote about *Last Rights*, that “this is one book that America must read!” NAELA members will find it to be both a resource and a call to action in better serving their clients.