Dying & Death in Law & Medicine

A FORENSIC PRIMER FOR HEALTH AND LEGAL PROFESSIONALS

Arthur S. Berger

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Medical Foreword by
David V. Schapira, M.B., Ch.B., F.R.C.P.(C)

Legal Foreword by
Judge Raphael Steinhardt

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Medical Foreword

The practice of medicine has become more sophisticated in the past three decades. Coinciding with, and as a result of, advanced technology, issues relating to informed consent, competence, the right to die, and specific advance directives have arisen. These issues, and the recently emerging importance of cost-effectiveness in medicine and the economic burden that is put on the patient and the family, are not addressed in medical schools. Arthur Berger's book on *Dying and Death in Law and Medicine* contains essential information that should be read by both medical students and physicians.

This book is essential reading for several reasons. The important topics discussed here are not consistently taught in medical schools, and therefore most practicing physicians are not familiar with or comfortable addressing these issues, which present themselves frequently in clinical practice. As physicians, we can no longer ignore the economic burden that results from the style of medicine we practice. We have to take into account that the majority of health-care spending occurs in the last few months of most patients' lives. We must learn to be comfortable addressing the medical and legal issues regarding the right to die and advance directives. We must also become comfortable allowing the patient to die with dignity and avoid heroic measures that often do not prolong survival or improve quality of life.

We must guide patients without being paternalistic or authoritarian, yet still allow the patient to participate in decision making relating to treatment and their feelings regarding death and dying. We have to be comfortable with issues relating to death and dying in order to communicate clearly and compassionately with patients when discussing their death. We must

also be aware that patients will deny and rationalize, and we have to be sensitive to how much information each particular patient wishes to receive.

The medical and legal issues that are addressed in this book cover all the ground I have described and more. Having been interested for many years in issues of informed consent, the right to die, cost-effectiveness in medicine, and patient and medical undergraduate and postgraduate education, I highly recommend that individuals entering or already practicing medicine read this book. It addresses a gamut of issues not normally discussed in one book, representing the issues every physician comes in contact with on a daily basis. If as physicians we can become informed and comfortable with the issues described in this book, we will practice medicine with greater sensitivity and compassion.

David V. Schapira, M.B., Ch.B., F.R.C.P. (C)
Chief, Cancer Prevention Program
H. Lee Moffitt Cancer Center and Research Institute
Professor of Medicine
University of South Florida College of Medicine

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Legal Foreword

My interest was piqued when I was asked to write a foreword to *Dying and Death in Law and Medicine* by Arthur S. Berger, from the standpoint of a jurist.

Mr. Berger has indeed opened the subject of dying and death to full view by laymen as well as the legal profession. True, those practitioners involved in this comparatively new field of endeavor have at their disposal information and guidelines above and beyond the sphere of what is outlined in this book. Nevertheless, it is a major reference source and a valuable contribution to all, and will assist immeasurably in coming to grips with this complex subject of dying and death.

What should be a simple natural act of dying is really not so simple. As a matter of fact, dying is very complex when one considers what is entailed. For one, do we have the right to a natural death, a death not fraught with life-sustaining systems that foster vegetation with no prospect of recovery? Do we owe protection under the law to health-care providers who aid in natural death when all avenues have been closed and peace should be brought to bear? How do we protect the rights of the patient? Additionally, Mr. Berger has addressed miscellaneous groupings of civil law, criminal law, statutes, case law, and all matters relevant to this subject matter.

Dying and death is the one common denominator. We are destined to follow this path with no deviation, for to live is to eventually die. But with guidelines as to how and when we die set within the framework of the legal system, one need not fear that one's expressed final wishes will not be followed. Nor does one have to fear termination of life will occur without proper oversight by the legal and medical professions. True, no system on earth is perfect—perfection is a utopian ideal that seldom reaches fru-

ition—but, with knowledge of all options available, reasonableness can be achieved.

Mr. Berger is to be commended. He has put the spotlight on a subject shrouded in darkness.

Judge Raphael Steinhardt
State of Florida
Eleventh Judicial Circuit
County Court of Dade County

Preface

Why this book? In the wake of advances in medical technology, the bright glare of publicity on right-to-die court decisions, the enactment of "natural death" and brain-death statutes, the emphasis on living wills, and the development of the organ transplantation program, there has ensued widespread public and professional concern over the legal and ethical issues raging around these subjects. This book meets the need for effective treatment of these subjects; its text and case studies will sensitize health-care professionals to the problems. The book aims to help the medical community understand the issues and increase its ability to deliver more appropriate patient care.

I came to write this book wearing several badges not normally associated with writers of medicolegal books. I serve on the ethics committee of a 750-bed county hospital. I am a lawyer who hopes to keep health-care professionals out of court and not in it. I also am a thanatologist. Thanatology approaches dying and death from a variety of avenues and includes everyone—physicians, nurses, psychologists, psychiatrists, sociologists, clergy, and philosophers—whose training or specialties lead them to examine or deal with these subjects. This book takes a new approach. It looks at dying and death through the eyes of the law; brings together unrelated case and statutory laws applicable to dying patients, the right to die, advance directives, brain death, and organ transplantation; and formulates them into a "law of dying and death."

Every utopia has been conceived without courts and lawyers. Since our society is very much the opposite of a utopia, it is slave to them. So we find that the most popular programs on television have been "Perry Mason" and "L.A. Law" and other "lawyer" shows. Their immense

popularity has gone far to stimulate our interest in and even make us more cognizant of the law. But although knowledge of the workings and tools of the legal system are important and can be useful to us, we remain relatively unsophisticated. I, therefore, have written this book for a second purpose: to help health professionals understand the legal system better and to learn the research tools they can use, if they wish, to examine pertinent case law and statutes. In this respect, this book differs from other medicolegal books as well.

This book also offers professional legal counsel subject matter of growing concern to the law. Medical decisions and issues pertaining to dying and death that once were the sole province of doctors, hospitals, patients, and families have become matters for increasing judicial and legislative attention. Since the Karen Ann Quinlan case in 1976, state supreme courts have intervened in such matters and in 1990, with the Nancy Cruzan case, the U.S. Supreme Court intervened. By 1991, more than forty states had enacted legislation dealing with advance directives; in that same year, the first federal statute to focus on these directives and the rights of adults to refuse life-sustaining treatment became effective.

This book should be useful to lawyers as a primer, also, because the "law of dying and death," like patent law, is generally absent from a law school curriculum except possibly as an aspect of constitutional law. My hope is that, since lawyers have received no formal education on this kind of law, those just becoming interested in these problems will find this book a valuable reference, giving them access to a considerable range of subjects and citations to authority beyond their limited areas of specialization.

Although this book is addressed to members of the medical and legal professions in their capacities as professionals, it is also addressed to them as people with private lives and private concerns. For in the drama of dying and death, the roles of physician, nurse, hospital administrator, or lawyer are only temporary. At any moment, a player can be asked to play a different role—the physician can become a patient, a lawyer can become a family member. Since we are all potential patients and family members, what this book has to say is of concern to us all.

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Death: Issues and the Law

1

Death Comes Alive

THE SHAPING OF HISTORY

What is history? For some, such as Ralph Waldo Emerson, history is humanity and the emphasis is on dominant personalities on whom events centered and by whom they were shaped. As Emerson said: "There is properly no History; only Biography" (1933:181).

Everywhere I look Emerson's view of history is borne out. When I examined world history, I found a Napoleon or Hitler shaping its eras of war and destruction, and when I took a glance at American history, there were Columbus, Ponce de Leon, Balboa, and Henry Hudson shaping its era of discovery; Alexander Hamilton, George Washington, and Thomas Jefferson its revolutionary and constitutional eras; Lincoln, Wilson, and Theodore and Franklin Roosevelt its political and economic eras. The history of literature in English centers on Chaucer, Shakespeare, Milton, Thoreau, Melville, Whitman, and Emerson himself; of philosophy on the speculative thought of Plato, Aristotle, Epicurus, Descartes, Spinoza, Leibniz, Locke, Kant, and Schopenhauer; of art, on Leonardo da Vinci, Michelangelo, Rubens, Rembrandt, Goya, Turner, and Holbein; of science, on Copernicus, Newton, and Einstein. The evidential corroboration for Emerson's belief is so persuasive that it led me to write a history of parapsychology in America centered on its dominant personalities, such as Joseph B. Rhine (Berger, 1988).

But Emerson's theory does not seem to apply to that era of recent history when America changed its attitude toward death. This achievement was not the work of any extraordinary individual or commanding figure but of two inconspicuous women. They would have lived and died in obscurity

but for tragic accidents that made them personifications of the miracles of medical technology. These miracles gave physicians the power to sustain life in situations where two decades earlier a patient would have died naturally. The life sustained, however, is in a senseless state and in a form few would consider worth living.

One of these women was twenty-two-year-old Karen Ann Quinlan who passed into a persistent vegetative state in 1976 after ingesting drugs and alcohol. The other was thirty-three-year-old Nancy Cruzan, whose only claim to fame was that she tried to help handicapped children before her auto accident in 1983, which left her in a persistent vegetative state. Their conditions were the same and their cases were identical: The parents of both women tried in vain to get their hospitals and physicians to terminate their child's life support. But there the similarity ends. A court in Karen's case authorized her parents to remove her respirator and allow her to die while the U.S. Supreme Court affirmed a state court's decision to refuse the removal of Nancy's tubal feeding and thus forced her to live.

THE KEY ISSUE

Until these cases made headlines, death—like AIDS, VD, and other social diseases—was a pornographic subject not discussed in polite Western society. Gorer observed that, whereas sex and copulation have become more and more mentionable, death has always remained unmentionable (Gorer, 1965). Kalish calls this silence the "horse on the dining room table syndrome" (Kalish, 1977:226). It seems that a group of friends were having an amiable dinner party when a horse walked in and sat on the center of the dining room table. But everyone went on talking as if the horse weren't there. Neither the host nor the guests mentioned the horse for fear of embarrassing each other. So, although the horse, like death, is always uppermost in everyone's mind, it is never talked about.

In Eastern religions—Buddhism, for example—one must be aware of death and meditate upon it in order to appreciate the impermanence of life. Avoidance and aversion were, however, Western attitudes—specifically, American attitudes. As Herman Feifel wrote, we see death "as the destroyer of the American vision—the right to life, liberty and the pursuit of happiness. Hence, death and dying invite our hostility and repudiation" (Feifel, 1977:5).

"The idea of death," said Ernest Becker, "the fear of it, haunts the human animal like nothing else; it is a mainspring of human activity" (Becker, 1973:ix). And society obliges us by affording us a large variety of social activities into which we can and do plunge frenetically in order to avoid

thinking about death. Hospitals and medical technology have facilitated the avoidance of death in other ways, too, by saving and extending lives and by postponing death for longer than ever before. Avoidance has also been made easier because few of us ever see death outside our television screens and the movies. Real death is concealed from us. Our family members no longer die at home but in health-care facilities. The care of the dying and the burial of the dead are given over to professionals. We have wanted to know nothing about these matters.

The beginning of a change in these negative attitudes was made with the publication of two important books: Herman Feifel's *The Meaning of Death* (1959) and Elisabeth Kübler-Ross's *On Death and Dying* (1969) in which the "death and dying lady" dealt with dying patients and their care. But the cases of *Quinlan* and *Cruzan* created a tidal wave of controversy over the "right to die" and brought public, scholarly, philosophical, medical, and legal concern to a peak. With general recognition by the American legal system of the "right to die" and "death with dignity," euthanasia and an acceptance of death seemed to be condoned by the courts. They brought home to many that, because of medical technology and unwanted medical treatment, life was more to be feared than death. They forced people to reconsider their concepts of death; people now had to distinguish between death as they had always known it and that strange form of death that comes when life is sustained in the physical body but does not exist in the brain.

The *Quinlan* and *Cruzan* cases compelled society to turn its face thoughtfully in the direction of death. They got many of us over the "horse on the dining room table syndrome" and induced an increasing number of us to think and talk about death. In this sense, death has come alive. We all—lay persons, educators, scholars, psychologists, health-care professionals, lawyers, clergy, social workers, funeral directors and more—have come to realize that dying and death are crucial problems we must face. We have come at last to the conviction that, in the final analysis, the problem of death is, as Feifel writes, "the key issue of life" (1977:xiii).

But there is, in fact, no one "key issue"; there are several distinct ones. Because these matters have been played up in the media, filled the pages of medical and legal journals, and occupied philosophers and ethicists in consequence of the *Quinlan* and *Cruzan* cases and others similar to them, death is able to penetrate the armor that American thought had worn to protect itself from the subject. Leaving some of these issues for treatment in Chapter 5, here we can identify the end of life, time of death and postdeath issues that have and continue to produce conflicts among health-care providers, patients, members of a patient's family, lawyers, clergy, and ethicists over what is "right," "wrong," or "legal."

END OF LIFE ISSUES

The dying process is related to but is distinguishable from death. We cannot experience death, but we can experience the dying process. Must that process be hard and bitter? Should patients be told that they are dying? How do we address deathbed fears? Should medical technology prolong lives even though patients have descended into the depths of helplessness and uselessness or have no cognitive functions? If competent patients do not want their lives prolonged, can medical treatment without which death will result be withdrawn or withheld upon request? Is artifical feeding without which a person will starve medical treatment that can be refused? What ethical issues are raised by a refusal of life-sustaining treatment? What are the concerns of health-care providers? Is a court the right forum for making decisions whether or not to terminate such treatment? How can litigation be avoided? If such medical treatment can be stopped, what are the legal bases for doing so? If such bases exist, is the legal entitlement to stop treatment an unfettered right? Does stoppage violate the sanctity of life and amount to murder? Or does it make one who withdraws treatment rejected by a patient and without which the patient will surely die guilty of aiding a suicide? What is the prospect of civil or criminal liability for physicians who withhold or withdraw life-sustaining treatment? If the patient is incompetent, who decides to stop life-sustaining treatment? If a third party can decide, what are the guidelines and criteria for deciding? To prevent suffering should a dying person be put to death by a doctor or family? Who has the right to decide? What are living wills and are they a satisfactory solution?

TIME-OF-DEATH ISSUES

Medical technology and the subject of death raise the question of when death occurs. What is the importance of a determination of death? What are the medical and legal definitions of death? What is "brain death"? What are the merits—and demerits—of the brain-death criterion?

POSTDEATH ISSUES

What developments have taken place in the program for transplantation of cadaveric organs? What are the functions of the United Network for Organ Sharing? What laws have been enacted in response to the organ transplantation program? What are the ethical problems with the program and what is their importance?

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