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# Dilemmas of Dying

Policies and Procedures for  
Decisions Not to Treat

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Cynthia B. Wong  
Judith P. Swazey

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Proceedings of a 1979 Conference Sponsored by  
Medicine In the Public Interest, Inc.

Edited by

Cynthia B. Wong  
Judith P. Swazey



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# Preface

Chartered in 1973, Medicine In the Public Interest, Inc., referred to as MIPI, is a nonprofit corporation involved in studying current issues relating to medicine, science, and society in the United States. In light of the MIPI Board of Directors' long-standing interest in the medical, legal, and ethical issues surrounding the treatment of critically or terminally ill patients, the board decided, in spring 1978, to organize the Dilemmas of Dying Conference. While the Massachusetts Supreme Judicial Court's *Saikewicz* decision was a major impetus for the conference, the issues dealt with transcend the medical-legal particularities of any single state. How decisions are to be made concerning the treatment or nontreatment of critically or terminally ill patients, and by whom, involve questions of values, law, and medicine that need to be addressed not only by health professionals, but also by every segment of society.

Desiring a broad base of professional and public support for the conference, MIPI sought and received the cosponsorship of the Massachusetts Bar Association, the Massachusetts Hospital Association, the Massachusetts Medical Society, the Massachusetts Nurses Association, and WEEI Radio/CBS Boston. MIPI thanks these organizations for their cosponsorship and Eli Lilly Company for the contribution it made toward the preparation of this volume.

The members of the MIPI Board of Directors are also grateful to Dr. Judith P. Swazey, formerly a board member and now the Executive Director, for bringing this important topic to the board's attention, organizing the conference once it was approved, and arranging for publication of this volume. We also thank Mary Claire Adams, MIPI's Administrative Assistant, for arranging and running

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the conference, Cynthia B. Wong for her outstanding editorial work, and Joan LeVasseur for her patience and persistence in typing the several drafts of these proceedings.

Dana L. Farnsworth, M.D.,  
Honorary Chairman, Board  
of Directors, Medicine In the  
Public Interest, Inc.

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# Contributors

GEORGE J. ANNAS is Associate Professor of Law and Medicine, Department of Socio-Medical Sciences, Boston University School of Medicine. He received his J.D. from Harvard Law School 1970 and a M.P.H. from the Harvard School of Public Health in 1972, where he was awarded the first Joseph P. Kennedy Foundation Fellowship in Medical Ethics. Among his professional activities, Prof. Annas is Editor-in-Chief of *Medico-Legal News* and Vice-Chairman of the Massachusetts Board of Registration and Discipline in Medicine. His publications include *The Rights of Hospital Patients*, *Informed Consent to Human Experimentation*, and numerous papers in legal and health care publications.

LOUIS P. BERTONAZZI is a state senator in the Massachusetts Legislature and Adjunct Assistant Professor, Department of Socio-Medical Sciences, Boston University School of Medicine. Sen. Bertonazzi received a B.A. from Tufts University and a M.A. in education from Suffolk University in 1960. Among his many committee and commission assignments in health care and social services, he is Vice-Chairman of the Joint Legislative Committee on Health Care. His honors include the 1978 Annual Division Bronze Medal Award of the American Cancer Society and the 1976 Public Service Award of the Massachusetts Public Health Association.

ROBERT A. BURT is Professor of Law and Co-Chairman of the Program in Law and Medicine at Yale Law School. After earning a B.A. in jurisprudence from Oxford University as a Fulbright Scholar, he received his J.D. from Yale Law School in 1964. In recognition of his work in legal aspects of medicine, Prof. Burt has been elected a fellow of the Institute for Society, Ethics and the Life Sciences and a member of the National Academy of Sciences' Institute of Medicine. His publications include "Authorizing Death

for Anomalous Newborns," *Developing Constitutional Rights of, in, and for Children, Standards Relating to Abuse and Neglect, and Taking Care of Strangers: The Rule of Law in Doctor-Patient Relations*.

NEIL L. CHAYET is an attorney specializing in health law with the firm of Warner & Stackpole. He received his J.D. from Harvard Law School in 1963. Among his professional activities, Mr. Chayet is a lecturer in legal medicine at Harvard Medical School and a consultant in forensic psychiatry at Massachusetts General Hospital, a member of the Board of Directors, American Society of Law and Medicine, and a legal correspondent for CBS Radio, with a daily presentation on "Looking at the Law." He is the author of *Legal Implications of Emergency Care* and articles and chapters on such medical-legal topics as abortion, drug abuse, mental illness, and informed consent.

HARVEY W. FREISHTAT, a partner in Freishtat and Fried, a law firm specializing in health law, received his J.D. from Harvard Law School in 1972. Mr. Freishtat is a lecturer at The New England School of Law and a member of the Human Studies Committee of the Joslin Diabetes Foundation and the Massachusetts Mental Health Center. He was a major contributor to the volume *Certificate of Need: An Expanding Legislative Concept*, published by Medicine In the Public Interest, Inc., in 1978.

SALLY GADOW is Assistant Professor of Philosophy in the Division of Social Services and Humanities, Department of Community Health and Family Medicine, University of Florida College of Medicine. She received a M.S. in nursing from the University of California, San Francisco, in 1968 and a Ph.D. in philosophy from the University of Texas in 1975. In 1978-1979, she was a fellow in bioethics at the Joseph and Rose Kennedy Institute Center for Bioethics, Georgetown University. Her presentations and publications in health care ethics and the philosophy of medicine include "The Dialectic of Clinical Judgment," "Caring for the Dying: Advocacy or Paternalism?" and *Nursing: Images and Ideals: Opening Dialogue with the Humanities*.

LEONARD H. GLANTZ is Assistant Professor of Law and

Medicine, Department of Socio-Medical Sciences, Boston University School of Medicine. He received his J.D. from Boston University School of Law in 1973. Among his professional activities, Prof. Glantz is a consultant to the Boston University Center for Health Planning and to the National Center for Health Services Research and is the Associate Editor of *Medicolegal News*. His publications include *Informed Consent to Human Experimentation*, a forthcoming book on *The Rights of Health Care Providers*, and "Decisions Not to Treat: The Saikewicz Case and Its Aftermath."

ROBERT J. LEVINE is Professor of Medicine and Lecturer in Pharmacology, Yale University School of Medicine. He received his M.D. from the George Washington University School of Medicine in 1958. Among his diverse professional activities, Dr. Levine is Editor of *IRB: A Review of Human Subjects Research* and a member of the Board of Directors of Medicine In the Public Interest, Inc. He chaired the Department of Medicine's Committee on Policy for Do Not Resuscitate Decisions at Yale-New Haven Hospital and served on the Department of Pediatrics' Committee on Guidelines for Deciding Care of Critically Ill or Dying Patients. Dr. Levine's many publications include a series of papers for the National Commission for the Protection of Human Subjects, which he served as a special consultant from 1974-1978.

PAUL J. LIACOS, Associate Justice of the Massachusetts Supreme Judicial Court, is also Adjunct Professor of Law at Boston University School of Law. He received an LL.B. from Boston University School of Law in 1952 and an LL.M. from Harvard Law School in 1953. Justice Liacos is the author of numerous articles in legal journals and the *Handbook of Massachusetts Evidence*. In November 1977, he delivered the Supreme Judicial Court's opinion in *Superintendent of Belchertown State School v. Saikewicz*.

BRUCE L. MILLER is Associate Professor of Philosophy in the Department of Philosophy at Michigan State University, specializing in the philosophy of medicine and law. He received his Ph.D. in Philosophy from Case Western Reserve University in 1970. Prof. Miller's publications include "Open Texture and Judicial Decisions," "Integrating Ethics into the Medical Curriculum," and a report for The Council for Philosophical Studies on Professional



Responsibility in the Law. As a member of the Michigan House of Representatives' Task Force on Death and Dying, he participated in the drafting of that state's Medical Treatment Decision Act.

CATHERINE P. MURPHY is Assistant Professor at the School of Nursing, Boston University; she teaches classes on ethical issues in nursing and is project director of a Department of Health, Education, and Welfare Advanced Training Grant for the preparation of clinical specialists in medical-surgical nursing. She received her M.S. in nursing from Hunter College in 1968 and her Ed.D. from Teachers College, Columbia University, in 1976. Among her professional activities, Prof. Murphy is a member of the Advisory Committee for the Boston University Program in Medicine and Philosophy and of the Massachusetts State Nurses' Association Committee on Ethical Practice. Her publications include "The Moral Situation in Nursing" and a forthcoming volume, *Moral Problems in the Nurse-Patient Relationship*.

MARIANNE PROUT is Head of the Oncology Section at Boston City Hospital and is Assistant Professor in the Departments of Medicine and Socio-Medical Sciences at Boston University School of Medicine. She received her M.D. from Cornell University Medical College in 1971. In addition to publications in the oncology literature, Dr. Prout has developed teaching materials on the dying patient for the Socio-Medical Sciences course at Boston University School of Medicine and has inaugurated both home care and hospice programs for terminally ill cancer patients in inner-city Boston.

JOHN A. ROBERTSON is Associate Professor at the University of Wisconsin Law School and in the Program in Medical Ethics at the University of Wisconsin Medical School. After majoring in philosophy at Dartmouth College, he received his J.D. from Harvard Law School in 1968. Among his professional activities, Prof. Robertson served as a consultant to the National Commission for the Protection of Human Subjects from 1975-1978 and is on the editorial board of *IRB: A Review of Human Subjects Research*. His numerous publications include "Involuntary Euthanasia of Defective Newborns: A Legal Analysis," "Legal Issues in Non-Treatment of Defective Newborns," and *The Rights of the Critically Ill*.

BENSON B. ROE is Professor of Surgery and Co-Chief of Cardiothoracic Surgery at the School of Medicine, University of California, San Francisco. He received his M.D. from Harvard Medical School in 1943. Among his many professional activities, Dr. Roe is a member of the Ethics Committee of the University of California Medical Center, Vice-Chairman of the American Board of Thoracic Surgeons, and a member of the Cardiovascular Committee of the American College of Surgeons. He has written over 100 scientific and clinical articles, including many textbook chapters.

RUSSELL J. ROWELL was President of the Massachusetts Medical Society in 1978-1979 and is currently in private practice in Beverly, Massachusetts, where he is on the staff of Beverly Hospital and President of Beverly Anaesthesia Associates, Inc. He received his M.D. from Tufts University Medical School in 1946. Among his many professional activities, Dr. Rowell serves on the Board of Directors of the New England Academy of Medicine and the Bay State Health Care Foundation, is an executive of the Bay State Professional Standards Review Organization, and is Chairman of the Massachusetts Medical Society's Committee on Legislation.

JUDITH P. SWAZEY is Executive Director of Medicine In the Public Interest, Inc., and Adjunct Professor of Socio-Medical Sciences at Boston University School of Medicine. She received her Ph.D. in the History of Science from Harvard University in 1966. Among her professional activities, Prof. Swazey is a member of the National Academy of Sciences' Institute of Medicine, a fellow of the Institute of Society, Ethics and the Life Sciences, and a consultant to the Office of Technology Assessment, U.S. Congress. Her publications include *Human Aspects of Biomedical Innovation*, *The Courage to Fail: A Social View of Organ Transplants and Dialysis*, "To Treat or Not to Treat: The Search for Principled Decisions," and "Decisions Not to Treat: The Saikewicz Case and Its Aftermath."

I. DAVID TODRES is Director of the Pediatric Intensive Care Unit, Massachusetts General Hospital, a member of the hospital's Critical Care Committee, and Assistant Professor of Anesthesia (Pediatrics) at Harvard Medical School. He received his M.B., Ch.B., from the University of Cape Town, South Africa, in 1958. In 1975, Dr. Todres was the recipient of a National Endowment for the Humanities

Fellowship in Medical Ethics. His publications include "Pediatrics' Attitudes Affecting Decision-Making in Defective Newborns" and a forthcoming textbook, *Intensive Care of the Critically Ill Newborn and Child*.

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# Introduction

Judith P. Swazey, Ph.D.

The medicalization of society has brought the epoch of natural death to an end. Western man has lost the right to preside at his act of dying. Health, or the autonomous power to cope, has been expropriated down to the last breath.

Ivan Illich, *Medical Nemesis*

A dying man needs to die, as a sleeping man needs to sleep, and there comes a time when it is wrong as well as useless to resist. . . . That time has not yet come for me. But it will. It will come for all of us.

Stewart Alsop, *Stay of Execution*

Although death is an inevitable part of nature's life cycle, human beings through the ages have been absorbed with pondering the nature of their mortality. Today, particularly in American society, there is an increasing concern, not with the fact of death, but with the manner of dying. As I write, for example, a quick glance at some of the titles on my bookshelf suggests the flood of "death and dying" literature—popular, sociological, medical-legal, ethical, and

religious—that has poured forth in recent years: the *Concern for Dying* newsletter, sections on dying and death in various books on bioethics, and books, to name a few, such as *Euthanasia; Freedom to Die; The Dilemmas of Euthanasia; The Nurse as Caregiver to the Terminal Patient and His Family; Death, Dying, and the Biological Revolution; The Dying Patient; Awareness of Dying; Time for Dying; and On Death and Dying*. To works such as these, and others too numerous to mention, we can add as evidence of society's mounting interest in and concern with dying the production of plays, movies, and television shows about the dying patient; a profusion of academic courses on death and dying; training programs for health professionals; and the emergence of careers in "thanatology."<sup>1</sup>

There is no single, simple explanation for this outpouring, which seems to reflect a widespread view of dying as a process fraught with dilemmas for dying individuals, their families and caregivers, and society at large. If there was an event that touched off the past decade's mounting attention to the dying patient, it was the publication in 1969 of Dr. Elisabeth Kübler-Ross's now classic book, *On Death and Dying*. In retrospect, Dr. Kübler-Ross's book was both a causative agent, playing a major role in lifting the public and medical-professional taboo that had shrouded open discussion of dying and death for many decades in America, and a sign of the times, indicating that the dying process presented problems that needed to be acknowledged and addressed visibly.

To enumerate some of these problems briefly, we can begin with sheer numbers. There are some 2 million deaths annually in the United States, and an estimated 1 million persons, at any given time, live with the diagnosis of a terminal illness. These millions as well as the millions who are closely associated with them compose a large "constituency" concerned with the nature of dying in our society. Beyond numbers, advances in medical science and technology have brought about new patterns of morbidity and mortality. Most Americans now die a "slow death," at a later age, from chronic diseases. Over 60 percent of deaths in a given year now occur among persons 65 or older, and there is an increasing time span, an average of 30 months, between a terminal diagnosis and death. Another aspect of the contemporary pattern of dying and death is its location. Most persons today die in a hospital, with over 80 days of hospital care in the year preceding their deaths.

The hospital setting makes dying an increasingly costly process, framing economic, social, and ethical issues about how we ought to allocate health care resources for the terminally ill. In addition, as has been well documented, the nature of the modern hospital as a social system, quite apart from economic factors, all too often makes the time of dying lonely and dehumanized. It is a period of personal and interpersonal stress not only for the dying patient but for family and medical professionals as well.

Another aspect of the modern face of dying, and one most salient to the conference proceedings, is medicine's growing technological capability to sustain life, or depending on one's perspective, to prolong dying. As seen most dramatically in the armamentaria of newborn and adult intensive care units, the occurrence of death can be averted, sometimes indefinitely, by devices and procedures capable of maintaining vital functions.

These technologies have forced us to confront complex and controversial questions about the manner of dying and the event of death: questions about the sanctity of life and the quality of life; about the medical and nonmedical considerations that should enter into decisions on whether or how to treat various types of critical or terminal illnesses and those afflicted with them; about who ought to make such decisions; and about how they ought to be made. Although these questions are given urgency and immediacy by the technology of medicine, they transcend medicine, involving secular and religious values and laws. And the more we ponder them, the more they seem to be true dilemmas, for which no completely or universally satisfactory answers can be found.

As the foregoing suggests, the conference title was chosen deliberately, reflecting our recognition that the issues with which we would be dealing may never be fully resolved, and certainly not in a two-day forum. Our intent, rather, was to bring together a multidisciplinary faculty and participatory audience to explore intensively and attempt to clarify the substantive and procedural dilemmas associated with the care of dying patients. That the conference was held in Boston, as Dr. Farnsworth noted in his preface, was not an accident of time and geography, for the confusion and controversy in Massachusetts that followed in the wake of the *Saikewicz* decision was a major impetus for convoking Dilemmas of Dying.



We were privileged to have the Hon. Paul J. Liacos, author of the *Saikewicz* decision, deliver the keynote address. In his address, speaking publicly about the case for the first time, Justice Liacos reviews the background and content of the decision, discusses misunderstandings and controversies that have ensued since it was handed down in November 1977, and assesses the role of law in the value conflicts surrounding nontreatment decisions.

His address frames the range of medical, legal, social, economic, and ethical issues with which the conference faculty and audience grappled for two days in talks, faculty and audience interchanges, and workshops. Following the conference program, these proceedings are divided into three parts. With some overlap because of their interconnectedness, Parts I and II examine substantive issues in nontreatment decisions, and Part III deals with procedural issues. The chapters in these three parts tend to be informal, because the faculty members were asked to talk to the audience and to each other, rather than, as at most conferences, to read papers. After the presentations at each session, the faculty and audience engaged in often vigorous discussion periods, which are included in these proceedings as edited transcripts.

On a rainy Friday night, half the 200 participants returned for evening workshops—testimony both to their endurance and to their interest in the conference agenda. These workshops, which were not taped for the conference proceedings, dealt with issuing and implementing do not resuscitate orders, nontreatment decisions for critically ill newborns and adults, and judicial and legislative roles in nontreatment decisions. The workshops, their leaders and participants felt, provided a useful small-group format for sharing problems and concerns and for discussing, sometimes heatedly, the differing personal and professional perspectives of the health professionals, lawyers, legislators, judges, and philosophers who were present.

Following Justice Liacos's keynote address, Part I examines nontreatment decisions involving competent adult patients. Chapter 1, by Dr. Robert J. Levine, deals with a recurrently difficult and controversial nontreatment decision: the issuance of do not resuscitate orders. Dr. Levine's talk reviews the approach to deciding on and implementing a do not resuscitate order developed by a Yale-New Haven Hospital policy committee that he chaired. In its