Medical Care at the End of Life
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IN MEMORY OF MY FATHER,

Martin J. Kelly,

KILLED IN ACTION IN FRANCE, NOVEMBER 9, 1944

As of January 1, 2007, 13-digit ISBN numbers will replace
the current 10-digit system.
Paperback: 978-1-58901-112-0

Georgetown University Press, Washington, D.C.
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Library of Congress Cataloging-in-Publication Data
Kelly, David F.
Medical care at the end of life: a Catholic perspective / David F. Kelly.
p. cm.
Includes bibliographical references and index.
ISBN 1-58901-112-0 (pbk. : alk. paper)
1. Medical ethics—Religious aspects—Catholic Church. 2. Medical
care—Religious aspects—Catholic Church. 3. Medicine—Religious
aspects—Catholic Church. I. Title.
[DNLM: 1. Terminal Care—ethics. 2. Catholicism. WB 310
K295m 2006^]
R725.56.K46 2006
174.2—dc22
2006003017

Printed in the United States of America

This book is printed on acid-free paper meeting the requirements of the American

13 12 11 10 09 08 07 06 9 8 7 6 5 4 3 2
First printing
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I WISH first to acknowledge the essential role played by the St. Francis Health System, a multi-institutional system of hospitals and nursing homes owned and run by the Sisters of St. Francis of Millvale, Pennsylvania, and to the remarkable people who worked there prior to its closing for financial reasons in 2002. Without my work at St. Francis this book could not have been written. The people of St. Francis welcomed the discussion of ethics and welcomed me; they were patient as I tried to learn what real hospitals were about. I especially acknowledge John Hoyt, director of critical care medicine and chair of the ethics committee. It was he who hired me for the sabbatical I took at the hospital in 1989 and 1990 and then arranged for me to continue as a staff ethicist.

Duquesne University and its people have been equally important in supporting this book and the work that led up to it. The university gave me a sabbatical grant to write *Contemporary Catholic Health Care Ethics*, and while on sabbatical, I did most of the work for this book as well. I am thankful to the Duquesne administration, to Michael Slusser, chair of theology, and to present and past deans, provosts, and presidents. They have recognized that medical ethics needs both theory and practice and have been greatly supportive of Duquesne’s Health Care Ethics Center. I am grateful to Aaron Mackler, colleague in the Theology Department and associate director of the Health Care Ethics Center, who took over the administration of its graduate degree programs while I wrote. He also read the previous book and the major additions to this one, making suggestions for improvement.
INTRODUCTION

FOR the past thirty years I have written about medical ethics and taught the subject to physicians, nurses, social workers, hospital chaplains, undergraduates, and graduate students. During this time I have been active in American hospitals and nursing homes, helping patients and their families deal with the difficult and often painful issues regarding medical treatment at the end of life. As I have worked on hospital ethics committees, designed hospital and nursing home policy, and taken part in ethics consultations, I have also helped my own friends, colleagues, and family members work their way through these issues. In this book I write about what I have learned. My aim is to provide patients, their families, hospital chaplains, and the entire health care community with a useful resource for thinking about decisions that so many people, at some point in life, must face.

This, then, is a practical guidebook that describes in detail the American ethics and law about forgoing treatment. It draws on Roman Catholic medical ethics, since much of what has become American policy in the area was taken from Catholic sources, and it engages certain questions that are currently debated within Catholic medical ethics. But it is not intended only or even primarily for those interested in Catholic issues. It is a book about the ethics of end-of-life care in America.

Two recent events have focused attention, both within and without the field of Catholic bioethics, on this critical issue. In March 2004 Pope John Paul II delivered an allocution, also known as a
formal speech, concerning nutrition and hydration (John Paul II 2004). And then, more recently, came the case of Theresa Marie Schiavo, the Florida woman whose feeding tube was removed after years of political and legal dispute. I will discuss both of these events, given the profound implications they have had within Catholic bioethics and on the American medical and political landscape.

There are eight chapters in this book. The first five develop in detail the bases for what I call the “American consensus” on forgoing treatment. Chapter 1 introduces the three pillars, or bases, for the American approach to this area and presents the first of them: the widespread agreement that some life-sustaining treatment is ethically optional and may be withheld. Chapter 2 details the important distinction between actively killing dying people and allowing them to die, a distinction I call the second pillar. Chapters 3, 4, and 5 analyze in detail the third pillar, the important legal and ethical issues of who decides and how the decision is made, including issues concerning competent and incompetent patients as well as advance directives (living wills and durable powers of attorney for health care). I introduce the Schiavo legal case in this context.

Chapter 6 is about feeding tubes. I discuss and reject the proposals of some who, by requiring nutrition and hydration for permanently unconscious patients, would undermine the claim that treatment is optional if its burdens outweigh its benefits. Here I again note Schiavo and discuss at some length the 2004 papal allocution. In chapter 7 I reject arguments by those who would support the practice of euthanasia and physician-assisted suicide and would reject the claim that there is an important difference between killing and allowing to die. And in chapter 8, on medical futility, I confront claims by those who would reduce the authority of patients to make decisions about their treatment.

This book is not meant to be an exhaustive treatment of end-of-life matters. It is intended to highlight what I believe to be the most important issues at stake—issues that require clear thinking and some understanding of medical ethics and relevant legal cases. I can only hope that readers of this book will gain some useful knowledge, and some degree of comfort, from my efforts.
ABBREVIATIONS

CPR cardiopulmonary resuscitation
DNR do not resuscitate
DPA durable power of attorney
DRG diagnosis related group
ER emergency room
HMO health management organization
ICU intensive care unit
IRB Institutional Review Board
PAS physician-assisted suicide
PDE principle of double effect
PET positron emission topography
PSDA Patient Self-Determination Act
PVS persistent vegetative state
UDDA Uniform Definition of Death Act
USCC United States Catholic Conference
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From the 1960s to the 1980s, Americans were unable to reach a consensus on the morality of forgoing medical treatment. Scholars disagreed about many of the issues—this continues today, as we will see—the basic stance of U.S. law had not been determined, the medical profession was largely unsure of what to do, and hospital policies varied widely. To the degree that there was a general approach, it was usually that the physician decided what to do in each individual case, and often that decision was to insist on ongoing aggressive treatment even when there was little human benefit. In the 1960s and 1970s, the growing field of bioethics reacted against this approach, against what came to be called “medical paternalism” (Veatch 1973). This criticism and other factors resulted in a radical change, so that by the 1990s it was possible to speak, at least in some sense, of an American consensus. This consensus emerged from bioethical scholarship and showed itself in a number of significant court cases, starting with the Quinlan case in 1976 and continuing through the U.S. Supreme Court cases on physician-assisted suicide (PAS) in 1997; it was also the result of a number of important decisions reached by governmental committees and commissions. It is true, of course, that there has never been universal agreement on the issues, and today what consensus exists is under attack, especially from those who would legalize euthanasia and/or PAS and, to a lesser extent, those who would use “medical futility” to reduce the decision-
making authority of patients and surrogates and return it in some degree to physicians. The consensus is also under attack from those who claim that certain treatments, particularly medical nutrition and hydration (feeding tubes), are morally required even when their benefit to patients is slight or nonexistent, as in the case of patients in a persistent vegetative state. I will discuss all of these issues in detail in later chapters. Yet despite these areas of controversy, it is possible to speak of a consensus in U.S. law, medicine, and ethics about the legal and ethical rightness of forgoing life-sustaining treatment.

The Three Pillars of the Consensus

The best way to understand the current consensus is to see it as based on three pillars of support. The first pillar is the recognition that not all treatments that prolong biological life are beneficial to the patient. In the Catholic tradition, this concept is expressed in the distinction between ordinary and extraordinary means of preserving life, the topic of this chapter.

The second pillar is the agreement that there is a moral difference—and ought to be a legal difference—between killing (active euthanasia) and allowing to die. This will be the topic of chapters 2 and 7.

In the U.S. legal system, these two ethical bases have been combined with a basis in law, the legal concept of the right to autonomy, privacy, and liberty. This is the third pillar, which will be developed in chapters 3, 4, and 5. Taken together, these three pillars provide the foundation on which the present consensus concerning the moral and legal rightness of forgoing treatment has been built.

The first two of these pillars are well established within the Roman Catholic tradition, which had already developed, prior to the arrival of so-called American bioethics in the 1960s and 1970s, a detailed and complexly argued system of medical ethics. The only
other tradition, religious or secular, to have done this is Jewish medical ethics, and that tradition, for various reasons that need not concern us here, has had a lesser impact on American secular medical ethics and American law than has the Catholic tradition. Indeed, it is probable that the current consensus would have been impossible had these concepts not already been developed in Catholic moral theology.

**Ordinary and Extraordinary Treatment**

The first pillar on which the current consensus is based is the general agreement that not all medical treatment that prolongs biological life is of benefit to the patient. Thus some life-sustaining treatment can be forgone.

The ethical distinction between mandatory and optional treatment has been provided by the Catholic tradition in its centuries-old distinction between “ordinary” and “extraordinary” means of preserving life, terms often used even in secular conversation and policies. The distinction goes back at least to the sixteenth century, was included in the important work of Alphonse Liguori in the eighteenth century, and was emphasized and made popular by the teaching of Pope Pius XII in the 1950s (Paris 1986, 31–32; Pius XII 1958, 395–96). It is essential to recognize that this is a moral distinction, not a medical one, and it relies on theological and philosophical understandings of the meaning of human life of which the practical implications, if not the theological bases, have largely been accepted. It is mostly a question of human benefit versus human burden.

There is no need here to go into detail about the history of the distinction. It is important to note, however, that there have been two different approaches among the moralists who have proposed it (Shannon and Walter 1988, 638). The more restrictive approach looked only to the burdens of the treatment itself. A treatment was said to be extraordinary if it was painful, caused great hardship, or
was expensive. But the likely outcome, that is, the state of the patient after treatment, was not taken into consideration. The other approach, most often used today, weighs both the burdens and benefits of treatment. Here, even if the treatment itself may be inexpensive and not cause any great discomfort, it is extraordinary and therefore optional if the benefits it promises are slight or nonexistent when seen in the context of the patient’s overall condition. This second approach is the one used by Gerald Kelly, arguably the most important Catholic medical ethicist prior to the Second Vatican Council of 1962–65 (Kelly 1958, 129). His definition of extraordinary means, quoted by others (McFadden 1961, 227), is given clear approval in the Declaration on Euthanasia, an official document issued by the Vatican in 1980. The declaration states that “a correct judgment can be made regarding means, if the type of treatment, its degree of difficulty and danger, its expense, and the possibility of applying it are weighed against the results that can be expected, all this in the light of the sick person’s condition and resources of body and spirit” (Congregation for the Doctrine of the Faith 1998, 653). Precisely. The latest edition of the Ethical and Religious Directives for Catholic Health Care Services quotes this as its source in adopting the same approach (National Conference of Catholic Bishops 1995, Dirs. 56, 57). The catechism of the Catholic Church says in a similar vein, “Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate” (Catechism 1994, 2278, 549).

VITALISM

The distinction between morally ordinary and morally extraordinary means of preserving life proposes a reasonable middle ground between vitalism and subjectivism, two extreme positions that are sometimes advocated. The first of these, an absolute vitalism, permits no cessation of efforts to prolong life. This position claims that
life itself is the greatest possible value and it should be sustained at all costs.

A nurse once told me that she finally refused a physician’s fifty-second order for cardiopulmonary resuscitation (CPR) on the same patient within forty-eight hours. Here is vitalism in the worst possible sense of the term. Perhaps it was the doctor’s orders, or perhaps a surrogate was insisting that everything be done to keep the patient alive. Many hospital professionals have encountered situations in which a dying person’s relatives insist that everything be done to keep their loved one alive, perhaps out of guilt, from fear of being left alone, or from a belief that Jesus may perform a miracle. In this last case, I try to suggest, gently, that Jesus—or God—does not need ventilators and defibrillators for miracles, but I have met people who are sure they have an obligation to keep a dying loved one alive as long as possible in order to give God time. No theological explanation that God does not need more time, that the ventilator and the defibrillator have already been shown to be inadequate, and so on seems to help in these cases.

Catholic medical ethicists have never considered this kind of prolongation of dying as morally required or even as a particularly good option. Theologically, I believe that Catholics’ faith in the Resurrection has a good deal to do with this. The present life is to be treasured, but it is not all there is. Biological life need not be prolonged by extraordinary means.

Subjectivism

The other extreme position is a totally lax subjectivism that permits cessation of treatment, and even active killing, based only on the subjective choice of an individual. Here the idea that human life is of intrinsic value is rejected. Life is of value only if the individual gives value to it. I am convinced that there is too much of this in the United States, too much individualism, too much insistence on absolute subjective choice. I do not mean to suggest a preference
for a totalitarian or authoritarian system in which government ordains our values, but we are, after all, social beings. We owe help to others precisely because they are of value, even if for some reason they have lost a sense of this themselves. And U.S. law has not moved all the way to the subjectivist extreme. Attempted suicide, for example, though not a crime, is still a reason for insisting on treatment, even involuntary commitment. While this can in some cases be ill advised, even hurtful, it is good for us to maintain the sense that human life is valuable even if an individual rejects that value. Human life, while not of absolute value, is always intrinsically valuable. Indeed, U.S. law recognizes that the state has an interest in preserving life, an interest in avoiding subjectivism.

Roman Catholic tradition has rejected both vitalism and subjectivism. It has recognized both the sanctity of life (life is sacred) and the ethical import of at least some aspects of the quality of life (life need not be prolonged under all circumstances). That is, at some point a lack of the ability to carry out humanly meaningful purposes, which some would term a lack of quality of life, means that life can be let go. This does not mean, however, that a person's life loses its worth, that it ceases to be of intrinsic value. But it does mean that when, in an individual case, the benefits of continued living truly are outweighed by the burdens of the kind of life that is likely to result from life-sustaining treatment and/or by the burdens of the treatment itself, the treatment may be forgone. And Americans, as well as American law, have come to a consensus on this. There are times when enough is enough.

The distinction between ordinary and extraordinary means of preserving life, as I have noted, goes back several centuries. According to this tradition, one is not obliged to preserve one's life by using measures that are morally extraordinary. The terms "ordinary" and "extraordinary" are useful, and I am hesitant to abandon them even in the face of some recent criticism. Critics do have a point, however, when they argue that these words are open to misinterpretation if the distinction is understood as a medical one (Congregation for the Doctrine of the Faith 1998, 653). It is, rather,
a moral distinction, and there are no simple technical or statistical criteria for determining the difference. Means that are usually thought of as medically ordinary (no longer experimental, normal hospital procedures in some cases, not requiring Institutional Review Board protocol approval) may be morally extraordinary. Thus what would be an ordinary or reasonable means when used in caring for a person whose chance of renewed health is great would become extraordinary in the care of a patient who has little or no chance of recovery.

Other terms have been suggested and are in general use, but there is no pair that exactly replaces the nuances of “ordinary” and “extraordinary.” “Reasonable” and “unreasonable” work in some cases, but not in others. Unreasonable means that the treatment is irrational. This implies that it ought not be given, whereas extraordinary means that the patient may choose to reject the treatment, not that it must be rejected. The treatment is optional, not necessarily wrong. “Proportionate” and “disproportionate” suffer from the same problem, as well as from the difficulty of implying a methodology about which there is considerable disagreement. “Heroic” might work, but “nonheroic” is awkward, and these terms suffer from the same problem as do the more traditional “ordinary” and “extraordinary,” because they might imply that medical criteria determine the difference.

Some wish to avoid pair terms altogether and speak only of the right of autonomy, as this is guaranteed by U.S. law. But this is to restrict the issue to the legal aspects and the ethics of the law, ignoring what the Catholic tradition has properly included and what has been important in the American consensus, the moral rightness and wrongness of the decision itself. It is wrong to forgo ordinary means of preserving our lives, and there is a strong basis for this judgment. Briefly put, the dignity of human life means that we owe it to ourselves, to others, and in a very different way to God not to reject the gift of life. Because we have responsibilities to self, to others, and to God to take basic good care of ourselves, some treatments (morally ordinary) are obligatory whereas others (morally