

CONFRONTING DEATH

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CONFRONTING DEATH

Medical Ethics series

David H. Smith and Robert M. Veatch, Editors

To Alice Rhinesmith Schlundt 1944-1975

ACKNOWLEDGMENTS

I have incurred many debts in writing this work, mostly as a result of the generosity of numerous persons, institutions, and organizations. The actual writing of the book began, peculiarly enough, with chapter one. This occurred in the winter and spring of 1981, when I enjoyed a research leave from Miami University and the hospitality of the Center for Bioethics of the Joseph and Rose Kennedy Institute of Ethics at Georgetown University. But I did not conceive of "Death Mystiques: Denial, Acceptance, Rebellion" as a chapter in a book until later in that year when I was fortunate to participate in a National Endowment for the Humanities yearlong seminar on bioethics, directed by David Smith at Indiana University. There, with the encouragement of a very able and critically supportive group of Fellows and Director, I first began to suppose there was sufficient continuity and coherence in what I was thinking to write a book. Chapters four and ten were drafted during that academic year of 1981–82; chapter three was sketched.

In the summer of 1982, a Faculty Development Award from the Woodrow Wilson National Fellowship Foundation allowed me to spend most days trailing about Will Leder, an oncologist in private practice, as he made rounds through Christ and Deaconess Hospitals in Cincinnati. This enabled me to extend and vary my observation of clinical practice begun more than a year earlier on the Oncology Service of Georgetown University Hospital. Still later, in May and June of 1985, I received an Exxon Foundation Fellowship in Clinical Medical Ethics to participate, with nine other teachers, in a series of seminars conducted by the faculty of the Center for Ethics, Medicine, and Public Issues of the Baylor College of Medicine. Along with these seminars went extensive observation and interrogation of physicians and nurses at work in the many hospitals of the Texas Medical Center in Houston. In all these settings, I wrote no more than notes, and learned an enormous amount: from sensitive, caring physicians and nurses; from stimulating teachers; and from generous, often dying, patients.

In the summer of 1983, I hid in my office and wrote chapters two and three and did preliminary research for chapters five and six. This work was supported by a Summer Research Award from the Miami University Faculty Research Committee.

A conference I organized for September 1984 at the Marcum Conference Center of Miami University, on "Treatment Refusal and Suicide: Medical, Moral and Legal Issues," had a profound effect on two of the chapters. First of all, Dax Cowart came as keynote speaker, and that caused me to think through much of what is said about his situation in chapter nine. Sec-

ond, the conference ended with a panel discussion by David Jackson, David Smith, and Stuart Youngner that greatly stimulated my thinking on Joseph Saikewicz's case, discussed in chapter ten.

The largest part of the book—chapters five, six, seven, eight, and nine—was written in England, in the second half of 1986. A mostly research appointment for me as a Visiting Scholar to the Miami University European Center in Luxembourg, a leave of absence as Director of Butler County Planned Parenthood for Sue Momeyer, and absence with nominal approval from the Talawanda School System for Alison and Alexis, allowed us to make a home in London. There I spent most days in the Nuffield Library of the British Medical Association, where very knowledgeable and helpful librarians, and a magnificent setting, provided ideal conditions for thinking and writing. I did some of my work at the London School of Economics, where an affiliation as an Academic Visitor in the Department of Philosophy gave me ready access to computers for editing text.

A number of persons have read part or all of this work in manuscript and offered thoughtful, useful, and probably too often ignored suggestions for making changes. These include most especially Dax Cowart, Robert Burt, Sue Momeyer, David Smith, and Robert Veatch.

Among the deeper roots of this work is the experience I have had now for nearly twelve years at Miami University of teaching an interdisciplinary humanities course entitled "Confronting Death." This has been a consistently powerful and moving experience for me, and I have learned enormously from the colleagues I have been privileged to teach with and the students who have shared their experience and thinking. My co-teachers in this venture have been Roy Bowen Ward, religion; Roland Duerksen and Rebecca Lukens, English; Roger Knudson, psychology; and Terry Perlin, interdisciplinary studies. Among the students deserving of special mention are Chris Vinson, Ken McDiffet, and Kathy Boynton.

Earlier versions of chapters one, four, and ten appeared in the following publications, each of which has graciously granted republication permission: chapter one, in *Mosaic: A Journal for the Interdisciplinary Study of Literature*, February 1982; chapter four, in *Omega: The Journal of Death and Dying*, June 1985; chapter ten, in *Theoretical Medicine*, October 1983, and in *Bioethics Reporter*, September 1985.

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PREFACE

This is a book about the choices all of us must make in confronting death. Some few of these choices concern ourselves only; most directly and intimately involve others as well. Sometimes these choices are as fundamental as whether to go on with life at all; more often they have to do with our attitudes, feelings, and thoughts about life, its possible purposes and direction. Thus this is also a book about the values that inform the choices we make in life, during dying, and about death itself.

The reader is entitled to know the biases and commitments of an author on such matters as these. Most of mine, I hope, emerge clearly enough in the discussions on how people approach death and how they might best do so; on whether death should be regarded as a good thing, or immortality as desirable; on whether we ought to regard death as fearful or the fear of death as a worrisome inhibitor of giving good care to the dying, and so on. But it might still be useful to articulate at the outset some of my own most basic values that lead these discussions in the directions they take.

The questions taken up in this work are suffused with, immersed in, a long history of religious concern. No reflection on death, on meaning, on good and evil, on suicide and how to value life, on choices to resist death or submit to fate, can escape such a history. Nor would I want to ignore this dimension in discussing these topics. Nonetheless, I have done my best to shape and answer questions about such matters from a consistently secular point of view. This means that I have tried not to presuppose the need for or the truth of explicitly theological premises; further, that it has sometimes been desirable, even necessary, to assume the falsity of such claims; and finally, that on some occasions argument as to the falsity of theological premises is appropriate.

But while this is done unambiguously, it is not done without ambivalence. While I have little difficulty in rejecting fundamental religious claims—that there is a God, that individual human beings might survive the destruction of their bodies, that life without religious faith is meaningless, and the like—I do not dissent from some of the normative conclusions frequently thought to follow from such premises. That is, the religious traditions whose theologies I unambiguously reject have also used these fundamental beliefs to draw some normative conclusions and imply some values that I find far less problematical. Among these are an emphasis upon the value of each individual human life; the importance of caring for persons, especially impaired and vulnerable persons; and the need for drawing one's circle of moral concern considerably wider than one's own self-interest.

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A reflective reader will have more difficulty discerning what I accept and advocate, as distinct from what I reject and argue against. This will not be your failure. The difficulty is largely mine. To put the matter rather crudely, if we can call the theological commitments sketched above a kind of "religious communitarianism," then its predominant alternative, in our culture and in our times, is a kind of "secular individualism." And it is the "individualism," rather than "secular," which I regard with the greatest ambivalence.

"Individualism" means many different things, but at the core of its central uses it denotes a moral commitment to regarding individual human lives as requiring respect, and individual liberty, often cast as "personal autonomy," as among the highest values. The first part of this coupling is for me the least troublesome: indeed, without the centrality of respect for individual life I do not think morality even possible. The second part is problematical, for it is not at all clear to me that respecting persons necessarily means valuing their freedom and self-determination above all other interests, either of theirs or of larger communities.

I thus find myself frequently attempting to tread a narrow path between two extremes: on the one hand is the ideology that values maintenance and nurturing of human life over all else, and frequently finds itself expressed in absolutist and religious terms as "the sanctity of life"; on the other hand is the ideology that supposes that only self-determination and individual liberty are adequate for defining the value of any particular life, and which itself is expressed in relativistic and libertarian terms. In attempting to thread my way between these views, I alternately tilt one direction or the other. Thus on the issue of whether death is always an evil for one who dies, I argue that it is. Nonetheless, I argue as well that it is one's right to make a wide range of choices for death, and that such a right cannot be legitimately restricted for any but the most compelling reasons.

Some draw from the view that human life is precious and of paramount value the implication that all forms of human life ought to be preserved as far as possible for as long as possible. This means that all choices for death—from abortion to suicide, from terminating life-prolonging treatment for those who wish such termination to surrogate decisions to end such treatment made on behalf of terminally ill persons incapable of making their wishes known—are morally indefensible. In the other camp, the most enthusiastic "individualists" are prone to suppose that life is valuable only so long as it is *valued*; hence, if the person whose life it is ceases, for whatever reason, to value life, there is little reason to think that person's choice to end life is morally problematical.

I share the view that human life is precious and of paramount importance, that each life has a value that may well exceed the valuing of it by oneself or by others. I think further, however, that human life is fraught with pain and suffering, that while human aspirations are virtually unlim-

ited, our capacities for fulfillment are severely restricted, and that, all things considered, human life is pervasively tragic. Consequently, I do not believe there is any moral imperative to prolong all human life to the maximum degree possible. Other values—including, but not limited to, rights of self-determination—have a role to play in when death should be chosen. Frequently enough, there is not merely moral permissibility for hastening the end of life; doing so may well be obligatory.

In endorsing a broad range of morally legitimate choices for death, I am at pains to distance myself from those who take a rather benign view of dying and death, those who, in chapter one, I accuse of "romanticizing death." I find nothing appealing about death. There may be something good to be said for some sorts of dying—not much, but something, and then only *relative* to other ways of dying; there is still less to recommend death. The best that can be said for death, I argue, is that on some occasions certain forms of life would be worse than being dead. This still makes death an evil—in the requisite sense that for the one who dies the loss of life of any sort is a substantial, significant loss.

Another belief I hold, but do not much support in what follows, is that much of what justifies specially valuing human life—a view often thought to be blatantly "speciest"—is that in all of known nature human beings are unique. More than any other creature, human beings are self-defined, and to the degree that they are self-defined, they are also self-creating. Less than any other creature, we are determined by our biological natures. These unique capacities of human beings, expressed in the whole history of humankind through the creation of society, civilization, culture, knowledge, art, music, science, philosophy, ad gloriam, warrant placing especially high value on human life. Neither rationality nor consciousness alone suffices to make human life unique, but the achievements of rationality and consciousness make human beings something to be especially prized.

I think one way human beings are self-creating is in our tendency to push against that which limits our aspirations for creative achievement. Nothing more surely or universally restricts our transcendence of limits than death itself. Thus, insofar as self-creation and the attainment of our collective struggle for progress are good things, death is a bad thing. Further, resistance to death has much to recommend it, and so I find considerable merit in that approach to death called "rebellion."

Readers not sharing my perspectives will, I hope, still find merit in this work. One way in which this might be done is in working one's way through the analyses and arguments supporting the positions taken and those criticized. For outside these introductory remarks, I have struggled to support my views with argument, to take more the route of reasoned argument than profession of faith. I stop short of claiming Truth supported by Universal Reason for my positions, since such could be claimed with neither good conscience nor a straight face. But I believe

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that most of what follows will be found at least interesting and frequently provocative by those who dissent.

A more profound value that I hope will be achieved in this work is that it make a contribution to each of our efforts to attain the Socratic ideal of living the examined life. Someone has said that "death, like the sun, cannot be looked at steadily." To this we might add the observation that no more than can earthly things be seen without the illumination of the sun can life be understood without reflection on death. It is not for naught that generations of philosophers did their thinking at desks on which a human skull sat.

"Confronting death" is something of a fraud. No confrontation of death is distinct from a confrontation with life, and no reflection on death can escape contemplation of what it is about life that we value, what it is that makes life worthwhile—when it is so—and what sorts of relations we choose to have with other persons. Hence, reflection on death is an inescapable component of our struggle to lead an examined life. If what follows makes a contribution to this effort on the part of readers, it will have been worthwhile.

A final note on reading the text might be useful. I have tried to construct the book in such a way that each chapter can stand alone, yet at the same time each successive chapter constitutes a building block in an extended argument. Thus it is possible to read chapters selectively and out of order—sometimes even not at all. But to grasp the full thrust of where the arguments in each chapter are leading, it is best to read them all in order.

For example, chapter three, "If Immortality Were Possible, Would It Be Good?" is characterized as a "thought experiment" on the desirability of endless life. It can be read alone and out of context, or it can be skipped by the less philosophically inclined, or it can be read as the exploration of an implication of the thesis in chapter two that to die is always to suffer a significant harm. The same might be said of chapter four, "Fearing Death and Caring for the Dying," except that here it is the more abstrusely inclined who might be tempted to pass on this exercise in applied philosophy. Only chapter eight is essentially unintelligible if not read after chapter seven.

However any individual may choose to read this work, it is advisable to begin with the Introduction and Overview to acquire a sense of what follows. And before plunging into the concerns of Part II, "Choosing Death," I recommend perusing the brief Introduction to Part II that marks the transition from Part I to Part II and summarizes the concerns of chapters seven through ten.

INTRODUCTION AND OVERVIEW

There are a limited number of categories into which human approaches to death might fit. If we begin with a focus on subjective responses to one's own death, as I do, then I think these categories are best labeled denial, acceptance, and rebellion. The burden of chapter one is to clarify and analyze these approaches, characterized as "death mystiques," and to assess each for adequacy in meeting human needs. Contrary to conventional wisdom, I find the acceptance of death the most problematical, although there is not a great deal to be said for death denial. Rebellion, correctly understood, seems to me the most subtle and complex of human responses to the prospect of subjective annihilation, and it is the one I recommend, inasmuch as any can be recommended.

In defending rebellion, I do not intend to leave the impression that such is always and only the appropriate response to death, one's own or another's. But I do believe it to be legitimate, even morally defensible, as an enduring and continuing response to a wide range of dying and deaths. Rebellion is not merely a stage through which "mature" persons pass on their way to a more desirable set of attitudes toward death. But then neither is denial always so. Nor, for that matter, is acceptance what we all must strive to attain in our inevitable confrontations with death.

Each of these is an altogether appropriate, mature, and, if you like, moral response to some deaths in some circumstances at some times. In saying this I am not endorsing an open-ended relativism. I argue, in chapter one and throughout, that some approaches to death are clearly preferable to others. Much, however, turns on the particulars of each individual case; much also depends on those deep and abiding value commitments we make. Among these values, I believe, is an emphasis upon the importance of sustaining autonomous human lives.

The claim that rebellion is generally the most appropriate response to real or impending death would be greatly buttressed if it could be shown that death is always a significant personal loss to a person—even to persons whose living is terribly burdensome, even to persons with greatly diminished autonomy. Thus in chapter two I argue that, for the person who dies, death is always a significant loss, if only of the possibility for further life, and is therefore in this sense an "evil."

Now it might be supposed that if, as I have argued, death is always an evil, then it follows that deathlessness (or some form of immortality) must always be a good. Chapter three is a thought experiment on precisely this latter proposition. Crucial to assessing whether immortality would be a good thing are two concerns: first, what sort of "immortality" is being considered; second, exactly which and how many persons

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are we to suppose are immortal. My assessment of these questions leads to the conclusion that only endless, healthy, non-aging bodily existence is a plausible and potentially desirable form of immortality, but that with such immortality it makes all the difference whether a single individual survives death, or whether everyone does, or whether only some select elite continues. For an embodied immortal, it is not at all evident that any of these would provide circumstances in which endless life would be desirable.

Following this highly speculative thought experiment, I consider a much more practical implication of the argument that death is an evil. If to die is always to suffer a significant loss, then it seems to follow that to fear death would be altogether rational. This is an implication that I think is far more certain to follow than claims to the desirability of immortality. But some authors have contended that fearing death is an undesirable state, a less than rational response to annihilation, and a considerable disadvantage to those who bear any responsibility for caring for dying persons.

This last claim is one I examine at length. I argue that its force derives almost entirely from two errors. The first of these is a misconception about the nature and origins of human fears of death, the second a conceptual confusion that occurs when death anxiety is collapsed into the fear of death, and the fear of death is conflated with death denial. Once we get our meanings clear, however, the truth of the matter seems to me quite the reverse: unless one is acutely aware and sensitive to her or his own inescapable and rational fear of death, there is little prospect for being able to offer the best possible care to terminally ill persons.

If chapter three is a philosophical musing on logical possibilities and their desirability as far as the prospects for immortality are concerned, chapter four is an exercise in using philosophical analyses to clarify meaning and to offer direction on eminently practical matters. This is a duality that runs throughout the text: some discussions incline more to pure philosophical analyses—specifically, conceptual clarification—others are much more in the vein of applied philosophy, wherein clear understandings derived from such analyses are applied to problematical situations and argument is advanced to justify a specific action or attitude.

Chapters five and six incorporate both these tasks roughly equally. There is an enormous amount of conceptual muddle about such notions as "natural death" and "good death," and all the other phrases frequently used with them. Among these are such phrases as "death with dignity," "a right to die," "a right to die with dignity," and, to combine several of these already unclear notions into one perhaps irremediably confusing phrase, "a right to die a good and natural death with dignity." And yet for all the confusion engendered and questions begged by such language, there is much that is important and true that the use of these phrases, however ill-formed, is attempting to reach.

Thus I begin by considering what might be meant by asserting that

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"A person has a right to a natural death with dignity." There are at least five distinct assertions contained here. The first of these is the claim that dying persons have a right to die with dignity rather than being treated as objects (diseases). Further, one who asserts "a right to die with dignity" may be advancing an ideal that everyone should aspire to, viz., that each of us should strive to maintain a sense of our own self-worth even as life wanes within us. Third, it might be that one intends to offer a guide to medical practice: "artificial means" of prolonging the lives of terminally ill patients are to be avoided. Fourth, to claim that a person has "a right to a natural death with dignity" may be to suggest that as a matter of public policy, legislation should be enacted to empower dying persons to exercise greater control over the circumstances of their death for example, through funding hospices or legitimating "living wills." Finally, one who asserts "a right to a natural death with dignity" may be covertly advancing an argument for the "naturalness" of death and the desirability of each person coming to "accept" death for herself or himself.

In all five variations of the assertion that there is "a right to a natural death with dignity," the meaning of "natural" is central. I argue that when "natural" is carefully analyzed, one will discover enormous ambiguity in the term. In fact, there are six distinctly different relevant meanings of "natural" that must be sorted out: scientific, statistical, anthropological, conventional, theological, and evaluative.

After these have been sorted out, it is then possible to examine the equation of "natural death" with "good death" (or "natural dying" with "good dying"). In the end, I argue that equating "good dying" with "natural dying" and "good death" with "natural death" engenders only confusion or begs the important questions. I recommend we dispense with such discourse altogether and get on with directly attempting to comprehend how dying can be good.

Chapter six does this. Three paradigms of good dying are investigated: sudden death, "appropriate" death, and death with dignity. For reasons I hope will be convincing, only death with dignity emerges as a worthy ideal of good dying. Why this is so turns on both insuperable difficulties alleged to attach to its competitors, and on an analysis of human dignity. This analysis uncovers some very fundamental human goods and values, including consciousness, rationality, self-determination, bodily integrity and self-esteem. To preserve these is to enhance human dignity, and to preserve these in the course of dying is to make possible death with dignity. Because such fundamental human goods are tied up with dignity, dying with dignity emerges as a most admirable ideal.

With such an analysis in hand, we are well positioned to assess whether the discourse of death with dignity is adequate to do all it has been called upon to do. That is, can this analysis of dignified dying be used to support the assertion of a right to die with dignity, to articulate an ideal of good dying, to guide medical practice, to shape public policy and legislation, and to advance an argument for accepting death? For

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the most part, I believe it will, and I attempt to show this with respect to three different phenomena: the claim that there is a right to die with dignity, the problem of dying with dignity while being cared for by the practitioners of modern medicine, and the belief that dying with dignity is an ideal all should strive to attain.

This much completes Part I of Confronting Death, for we have explored at some length a number of vital connections between death, good, and evil. The transition from Part I to Part II marks a number of changes. In the largest sense, it might be viewed as a transition from the private to the public, or from personal values and choices to public morality and policy. Part II, "Choosing Death," focuses on moral arguments in the public domain, on issues and cases that move well beyond the boundaries of private choices. Moreover, if Part I is viewed as making an extended case for resistance to death, for protesting its intrusion into vital human lives, then Part II is an exploration of when choosing death is a prudent, morally permissible, or even wise course.

Choosing to die is, when made for oneself by oneself, always in some sense suicide. (I do not use "suicide" pejoratively.) Choosing death for others has many names, ranging from murder to euthanasia to self-defense, and so on. I am more interested here in variations on choices for one's own death than I am in choices to bring about the deaths of others. Accordingly, chapters seven and eight concern suicide and the question of whether there is anything like a fundamental human right to bring about an end to one's own life. Chapter nine is an extended case study of the plight of a young man who has compelling reason to choose death but finds himself coerced into not doing so. Finally, chapter ten explores one narrow slice of the vast domain of choosing death for others, viz., those situations in which there is morally sufficient reason to do so for persons whose best interests may well reside in such a choice but who cannot themselves so choose due to irredeemable incapacity.

By the time we get to such issues as this, we will have moved very far into considerations of public policy and legal deliberations. Indeed, chapter ten investigates more than half a dozen cases that are widely known precisely because they went to courts of law for resolution, including those of Karen Ann Quinlan, Brother Joseph Fox, Joseph Saikewicz, Edna Marie Leach, Mary Hier, and others. Some of the criticisms of court decisions offered are harsh, but much is at stake in these (frequently inappropriate) legal deliberations, including both individual lives and large issues of public policy.

A more detailed account of the contents of Part II can be found in the "Introduction to Part II." I hope this introduction and overview makes clear the structure of the work, especially the logic of its development. Further, there is every author's hope that the reader's appetite for finding out whether the author's stated intentions will be successfully realized is sufficiently whetted to proceed with reading the book.

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