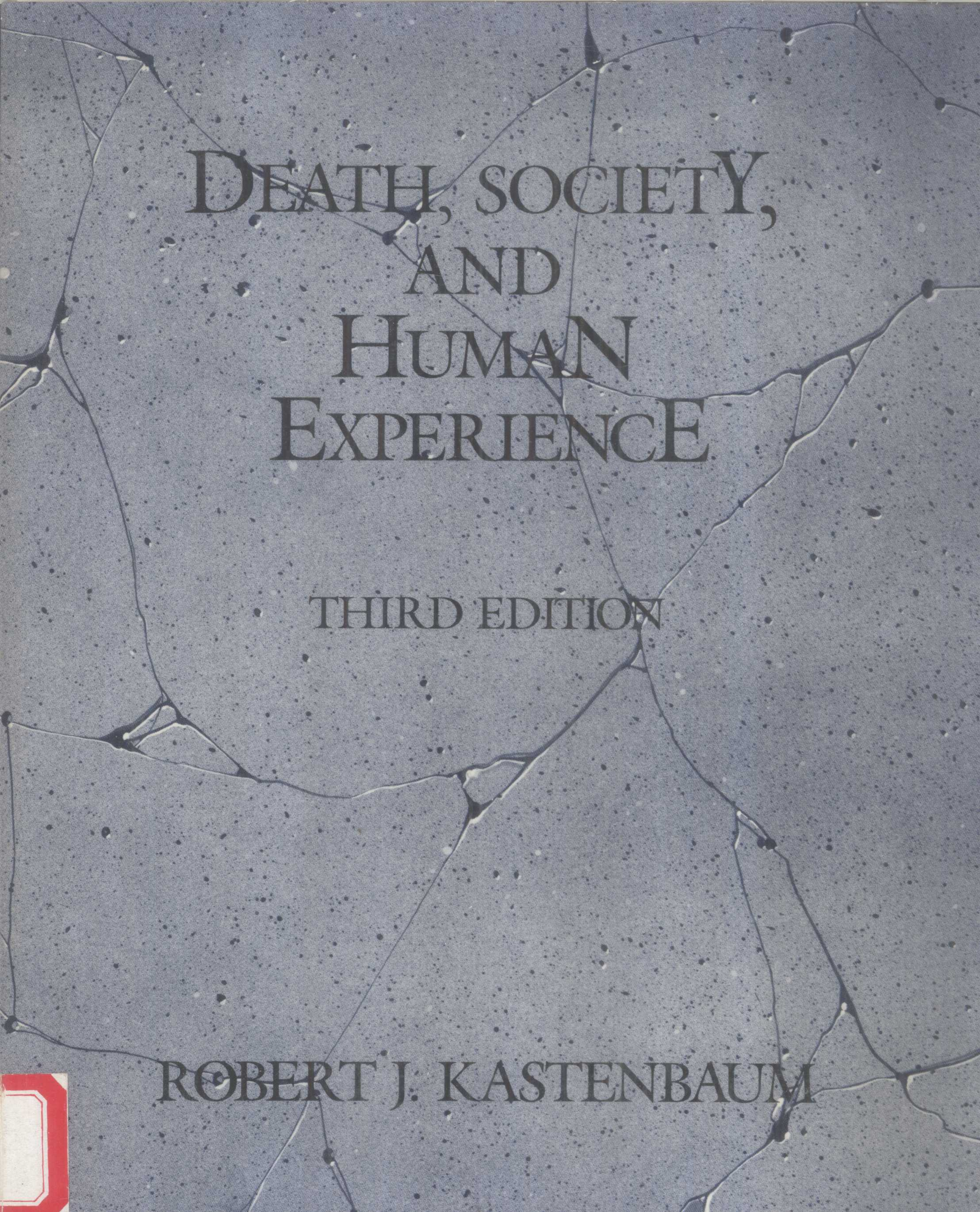

DEATH, SOCIETY, AND HUMAN EXPERIENCE

THIRD EDITION

ROBERT J. KASTENBAUM

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PREFACE

Sometimes you just listen.

*The subject is denial. A young man in the second row recalls one of his experiences in Vietnam. He speaks softly, but nobody misses a word. He and his buddy had been on guard duty. A quiet night—so far. Suddenly the routine mortar barrage began. The first round sounded close. He turned to speak to his buddy. "Only his boots were left, and they were steaming. A minute ago he was there, and then... only his boots." The student remembered his immediate reaction: "I said to myself, 'It can be dangerous here.' It's amazing to think about it now, but I went about for a couple of weeks before it struck me that my buddy was dead. I guess that's some kind of denial, huh?"

*The subject is funerals. A woman has returned to class after a week's absence. The sudden death of her father had brought family members together from around the nation. Along with consoling each other, there was also the responsibility of making funeral arrangements. The conservative funeral director in the conversative little town rejected one of the family's requests. "He insisted that Dad wear a suit and a tie. We knew that Dad wouldn't want that. He used to joke that he wouldn't be caught dead in a suit and a tie!" Family members agreed among themselves that Dad would have preferred to be buried in his red jogger's outfit with his favorite bolo tie. The funeral director wouldn't hear of such an impropriety and put pressure on the family to withdraw the request. "But we didn't cave in. I had learned enough about death and funerals that I felt strong in insisting that our Dad still belonged to us, and that our rights were more important than the funeral director's stuffy old habits." It was the funeral director who capitulated. Later the funeral director apologized to the family for his resistance and said that he had learned something valuable from this experience.

*The subject is suicide. A new and angry voice is heard in class. It belongs to a woman who has attended every session but never said a word. "I hear everybody feeling sorry for people who kill themselves. They have it easy. It's all over for them. Do you ever think about their children?" Her own father had committed suicide more than 40 years ago. "They all said it wasn't suicide, but we all knew it was. I kept wondering what I did wrong, or what Mother did wrong that my father should kill himself. I spent years being scared, being guilty, being angry. And the being angry is still there, as you can hear!"

A class on death, society, and human experience provides an exceptional opportunity for students and instructor alike. Generalities become specifics as strangers become part of each other's lives. Perhaps it is not so surprising that many students later report that this has been the most compelling and valuable academic experience they have ever had. The topic is certainly both powerful and of universal provenance. When a course focusing on death proves useful, it is through the contributions of the students themselves, the instructor, and the readings, videos, and other materials provided. Each of these components offers something distinctive and valuable. The instructor's knowledge and teaching skills and the personal experiences of everybody in the classroom together comprise the foundation for significant learning. The quality, scope, and pertinence of the readings, however, also have an important role. It is time, then, to say something about what the third edition of *Death, Society, and Human Experience* tries to accomplish and how it differs from previous editions.

GOALS

1. *This book is intended to provide accurate and up-to-date knowledge on a wide variety of death-related topics.* The importance of such knowledge can be illustrated by a few very brief examples:

   Hospice has moved rapidly from vision to reality. But what is the status of the hospice movement today, and how well is it fulfilling its promise?

   Grief is a searingly personal experience. But developments in many public sectors of society can affect the expression of grief. How, for example, does something as remote as union-management negotiations influence the way that survivors respond to their loss?

   Defining death has emerged as a significant issue for lawmakers, attorneys, nurses, physicians, clergy, and family. What are the alternatives? And what happens as society attempts to devise sound legislative acts and arrive at wise judicial decisions?

   Death anxiety and *denial* have become key concepts, often encountered in attempts to explain why we think, feel, and behave as we do. But how well do these concepts really explain what death means to us? What conclusions are justified by the available evidence, and what cautions must be kept in mind?

2. *This book is intended to provide guidance to caregivers, whether professionals, volunteers, or family members.* Among the many examples:

   Suicide continues to take a significant toll both on those who end their lives and on the survivors who are left with a sense of loss, guilt, anger, regret, and confusion. There are some guidelines, however, that can help reduce the probability of a lethal suicide attempt.

   Funerals are often criticized these days. It is not unusual for people to feel that they do not want to participate in a funeral process. Nevertheless, there are important functions served by the funeral process, if not always in the most appropriate and useful way. An improved understanding of the funeral process can help in making the decisions that will be most beneficial to those involved.

   Protecting children from death is a strong and easily understandable impulse among parents and teachers. The protection we can offer is never sufficient, however, and we can provide more emotional security to our children with a better command of the facts and acquaintance with guidelines derived from intensive direct experiences.

3. *This book is intended to help the reader develop a more comprehensive understanding of the complex relationships between the life and death of individuals on the one hand and the large-scale sociocultural process on the other.* A few such examples can be mentioned briefly:

   Productivity and profit motives are powerful forces in the United States and many other industrialized nations. Although in some ways the operation of these motives enhances and protects life, in other ways the risk to lives is greatly increased, as examples from the coal and uranium mining industries demonstrate.

   Rights of the individual are highly valued in American society. Precisely how far these rights extend and how much claim society can place on the individual are questions that become of life-and-death urgency in some situations, as expressed, for example, in the views of the Hemlock Society, and in court decisions regarding both terminally ill and disabled-but-not-dying individuals.

   Meanings of death have always emerged from the particular needs, values, and circumstances of a culture. Contemporary views of death represent our response to contemporary circumstances, but also our relationship to history. Examining the continuities and the differences between the meanings of death today and those in the past of humankind can provide a valuable perspective on our own situation.

NEW FOR THE THIRD EDITION

A number of important changes have been made for the third edition of *Death, Society, and Human Experience*. Some of these changes were prompted by new research findings and new developments in caring for people in death-related situations. Other changes were suggested by students, instructors, and professional reviewers who detected areas in which additional coverage would be useful.

Among the changes—all improvements, I believe—are the following:

1. A completely new opening chapter examines in detail a *natural death act* typical of those enacted or being considered by state legislatures across the nation. This provides an excellent opportunity to discuss "brain death" and related definitional problems as well as the larger issue of what can and what perhaps cannot be achieved by legislative interventions. It also provides an introduction to the complexities and perplexities of the "death system" in action.
2. A completely new chapter is devoted to *the funeral process*. This chapter is a systematic examination of the functions of the entire funeral process, ranging from immediate post-death activities to the personal, interpersonal, and symbolic events that may continue long after the funeral. One main theme is "From Dead Body to Living Memory"; another is "Balancing the Claims of the Living and the Dead."
3. Another new chapter has been created to encompass *attitudes toward death*. Some previous material remains because of its undiminished relevance, but I have added a substantial review of the research literature on death anxiety and denial. The concluding section on "Anxiety, Denial, and Acceptance" should be especially useful.
4. There is still another new chapter: "Death Education, Counseling, and Ethics." A historical introduction is followed by an examination of what should be expected of death education. Limitations and potential problems in death education as well as its achievements and contributions are explored. A major section on counseling and the counselors examines both the personal characteristics and the professional activities of those who attempt to help people in the midst of life-and-death crises. A major section on ethical issues includes but goes beyond the landmark case of the late Karen Ann Quinlan. We consider several other actual situations in which difficult ethical and practical decisions have been required, including questions associated with euthanasia.
5. Important new information is presented on the hospice movement. Three important changes have occurred in the short interval since publication of the second edition: the rapid proliferation of hospice programs, the enactment of Medicare regulations that provide reimbursements for hospice care under certain circumstances, and the completion of by far the most extensive evaluation study ever attempted. As a member of the National Hospice Demonstration Study's research team I have been able to share some of the most relevant findings (others are still being analyzed as of this writing).
6. Three features of the previous editions have been found particularly useful: case studies and examples; thought exercises and self-examinations; and guidelines for coping with death-related situations. I was asked to provide more material of all three

types and was pleased to do so.

7. I have reorganized the book in a way that I believe will fit better into most instructors' semester plan. There are now 13 chapters, allowing for a chapter-a-week assignments if so desired. Historical and cultural material previously distributed among three chapters have been condensed into the current Chapter 2. The two chapters examining *the death system* not only have considerable new material, but are organized to promote more effectively the integration of the theoretical with the applied. "Dying" and "The Hospice Approach to Terminal Care" now come earlier in the text. Although encompassed in two rather than three chapters, the coverage has not been reduced, and new material has been introduced at a number of points. There is some reorganization of material within chapters (for example, the discussion of suicide) that will be apparent to those familiar with earlier editions. These reorganizations were motivated by my recognition that there were more effective ways to sequence the materials from the student's viewpoint.

Significant new research and scholarly contributions are included throughout the book; for example, Sabom's provocative study of people reporting near-death experiences and the examination by McIntosh and his colleagues of the vulnerability of Native Americans to suicide. I have refrained from introducing material that is "new" in the sense of having been published recently but that actually adds little to what was previously known.

MORE PERSONALLY...

I am grateful to all those who have offered suggestions for creating this edition; many of these recommendations have been accepted and acted upon. For all the students who have continued to share their thoughts and feelings with me—even with tears on their cheeks or rage at unbearable fate in their eyes—my appreciation is boundless.

I have a habit of wanting to apologize in advance to those readers who have a strong need to find THE ANSWERS. This apology might begin by saying that I can draw upon a large reservoir of experience and research from many sources: psychology, nursing, medicine, sociology, philosophy, anthropology, religion, history, and what have I forgotten? I can draw as well upon a quarter of a century of my own clinical and research efforts. The apology might continue by admitting that none of these suffice. For THE ANSWERS, I am afraid we will still have to depend upon either our deepest caverns of faith (somehow immune to the shocks and calamities that any moment can thrust upon us) or to enlightened common sense. But this is my last such apology. I must tell you that I would be providing no service if I presented the uncertain as certain, the dangerous as docile, the complex as simple.

Death is fresh in my mind as I write these final words (the preface is almost always written last, as you might have guessed). The anxiety and then the loss could only have been intensified had physicians told me well-intentioned lies, had nurses rattled off pious "words of inspiration," or had I recited to myself any of the cliches that have attached themselves to the study of death and the care of the life-threatened. They didn't and I didn't and Cynthia died anyway. Answers taken off the shelf wouldn't have helped me at all. I wonder who they would help. Confronting death is just too serious a situation for reliance upon fast-food type answers. Some truth helps, and as much love as there is within and between us. I think you will find in this book what limited truth there is at the moment and, in the oddly contorted way that a textbook must do such things, perhaps a little love as well.

Robert J. Kastenbaum

CONTENTS

chapter I WHAT IS DEATH?

Familiarity breeds contempt, according to the old saying. Psychological research, however, suggests that familiarity breeds *habituation*, the tendency to ignore what has become commonplace.[5] The habituation response can create difficulties in situations that should be examined alertly rather than taken for granted. The word *death* is so familiar and will be used so often in this book that one might be tempted to believe that its meaning has already been firmly estblished. It is often assumed that death exists as an absolute fact. Death is certain if anything is certain. People may have different attitudes, but surely death itself stands well apart from individual and social custom. Or does it?

Our understanding of death in all its aspects is never completely dissociated from the habits, language, needs, and values of the human community. Accordingly, this chapter converts the familiar word *death* into the starting point of inquiry. What is death? We cannot afford to adopt an easy and unquestioning attitude toward death because each premature conclusion and every unchallenged assumption has the potential for increasing error, vulnerability, and suffering.

This chapter begins by examining in some detail SB 1155: Natural Death Act, which is only one of the many possible examples of Western society's current effort to modify its orientation toward death. This measure was first introduced into the State of Arizona legislative process in 1984. It was intended to provide a foundation in law for the principles expressed by the Living Will (see box, p. 2). Although it is an influential document, the Living Will nevertheless has no binding legal power to call upon. SB 1155 was given serious consideration and eventually could well become law after further discussion and amendment. Other states have considered and some have enacted similar pieces of legislation.

Circumstances of death have long been the subject of church doctrine, royal edict, and civil law. Who gets what from the estate of the deceased has been one of the questions most frequently addressed by statute. Today the legislature and the courts are becoming increasingly active in the regulation of death-related issues. In almost every instance our assumptions about the nature and meaning of death are put to the test. Through an examination of SB 1155 it is clear that our conceptions of death do not exist in an abstract sphere of their own. Individual experiences and social forces continually exert influence on what we mean, or think we mean, by the word *death*.

A NATURAL DEATH ACT

Basic Provisions

The intent and guiding assumptions of SB 1155 are spelled out as follows[13]:

A. The legislature finds all competent adult persons have the right to control the decisions relating to their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn when a terminal condition exists.

B. The legislature further finds that modern medical technology has made possible the artificial prolongation of human life beyond its natural limits.

C. The legislature further finds that the artificial prolongation of the life of a person with a terminal condition may cause loss of individual

THE LIVING WILL

To my family, my physician, my lawyer, my clergyman
To any medical facility in whose care I happen to be
To any individual who may become responsible for my health, welfare, or affairs

Death is as much a reality as birth, growth, maturity and old age—it is the one certainty of life. If the time comes when I, ________________________, can no longer take part in decisions for my own future, let this statement stand as an expression of my wishes while I am still of sound mind.

If the situation should arise in which there is no reasonable expectation of my recovery from physical or mental disability, I request that I be allowed to die and not be kept alive by artificial means or "heroic measures." I do not fear death itself as much as the indignities of deterioration, dependence, and hopeless pain. I therefore ask that medication be mercifully administered to me to alleviate suffering even though this may hasten the moment of death.

This request is made after careful consideration. I hope you who care for me will feel morally bound to follow its mandate. I recognize that this appears to place a heavy responsibility on you, but it is with the intention of relieving you of such responsibility and of placing it on myself in accordance with my strong convictions that this statement is made.

Signed ________________________________

Date ________________________________

Witness ______________________________ Witness ______________________________

Copies of this request have been given to ________________________________

____

> dignity and secure only a precarious and burdensome existence, while providing nothing medically necessary or beneficial to the patient.
>
> D. In order that the dignity, privacy, and sanctity of persons with terminal conditions may be respected even after they are no longer able to participate actively in decisions concerning themselves, the legislature hereby declares that the law of this state shall recognize the right of a competent adult to make an oral or written declaration instructing his physician to withhold or withdraw life-prolonging procedures or to designate another to make the terminal decision for him if the adult is diagnosed as suffering from a terminal condition.

Many key words and phrases appear in this opening section, among them: "all competent adults," "right to control the decisions," "withheld or withdrawn," "a terminal condition," "artificial prolongation," "natural limits," "individual dignity," "precarious and burdensome existence," "privacy," and "sanctity." Each of these terms is subject not only to interpretation but also to dispute. Some of the difficulties inherent in these terms will be examined later. Two considerations are most relevant at the moment:

1. Human life is conceived as having a "natural limit." Does this not imply that death also has its place and, moreover, its claim? Does trespassing beyond the natural limit of life violate an obligation to death? At the least, this term suggests that the individual's claim to life does not extend beyond a certain (albeit uncertain) point.
2. The legislative measure describes itself as a "natural death act." This suggests that (1) death can take more than one form—natural or unnatural—and (2) it is in society's interests to foster the former type and avoid the latter.

This legislative language contradicts two other forms in which the idea of death has been constructed. Death has often been seen as the enemy, humankind's most dangerous and persistent foe. Some of the most ancient documents bequeathed from early civilizations already characterize death as the enemy supreme, and much the same attitude is found inculcated in 20th century medicine. But the typical natural death act (of which SB 1155 is simply one example) stakes out a zone in which death can function in a law-abiding manner. Death is no longer a stark adversary but rather an enfranchised, interested party with the legitimate right to collect on claims. The physician is expected to yield to these claims under conditions specified and protected by law.

The other assumption implicitly rejected by SB 1155 is that "death is death, no matter what." Whether we depart this life young or old, after long illness or sudden accident, peacefully or in anguish, the outcome is the same. This view is not represented by SB 1155. Instead, the legislation seems to take the position that *how* we die is somehow connected to the quality of the death itself. SB 1155 might have addressed "natural dying," but, in company with similar measures, has chosen to speak instead of "natural *death*." What is the difference between *dying* and *death*? There are, indeed, important differences, even if they are obscured or confused by the language we select.

Specific Provisions

A closer look at some of SB 1155's more specific provisions will give you more to think about. (In some instances lengthy legislative prose has been condensed, with care taken to remain faithful to the substance and intent of the original.)

A. Any competent adult may, at any time, make a written declaration directing the withholding or withdrawal of life prolonging procedures if the adult has a terminal condition in the future. A written declaration shall be signed by the declarant in the presence of two subscribing witnesses. An oral declaration may be made by a competent adult in the presence of a physician and two witnesses by any nonwritten means of communication at any time after the adult has been diagnosed as having a terminal condition.

B. A declaration made in accordance with this chapter is presumed to have been made voluntarily.

C. It is the responsibility of the declarant to furnish the physician with a duplicate of the declaration. Any other person may notify the physician and furnish a duplicate if the declarant is comatose or otherwise incapable of doing so. A declaration is void if the declarant is a patient in a nursing care institution unless witnessed by the spouse or adult child, by two witnesses or by the judicially appointed guardian or committee.

D. *The declaration* (in its essentials): If at any time I should have a terminal condition and my attending physician has determined that there can be no reasonable expectation of my recovery from such condition and if the application of life prolonging procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to comfort me or to alleviate pain or dehydration.

E. The *declaration becomes obligatory* only after two physicians have stated in writing that, to the best of their professional judgment, the declarant is suffering from a terminal condition. It is *not obligatory* if a result of self-induced or self-inflicted illness, injury or disease. Furthermore, it is not obligatory to withhold or withdraw life prolonging procedures if the person or persons involved have a *conscientious objection* to such action.

F. It will not be considered a suicide for any purpose if life prolonging procedures are withheld or withdrawn in accordance with the provisions of this law. There can be no criminal prosecution of physicians or other qualified personnel who act in accordance with these provisions, nor shall they be deemed to have engaged in unprofessional conduct.

G. There are also provisions for withholding or withdrawing life prolonging procedures when an adult patient suffering from a terminal condition is comatose, incompetent or otherwise physically or mentally incapable of communication and has not made a declaration. (This provision does not apply to pregnant women.) Those who must be involved in the consultation and agreement are specified.

H. A declaration may be revoked at any time by the declarant.

Meanings of Death Implied by this Legislation

All these provisions imply that there is a clear definition of death. Such a definition, however, is not to be found in the legislation itself. Perhaps wisely, the lawmakers have refrained from furnishing an explicit definition of death. There are certainly problems enough in determining, for example, what constitutes "artificial" prolongation of life, how "competency" is to be defined, and precisely what is meant by "dignity" and "sanctity." A discussion of just a few of these difficulties is necessary before the implicit definition of death itself can be examined.

Artificiality

Fluids, medication, and a low level of nutrition can be provided through an intravenous drip (IV). In this procedure a needle is inserted into a vein connected with a raised plastic container of fluid whose rate of flow can be regulated by a control device. This could be regarded as an artificial method of treatment because we do not usually or naturally support our bodies through such means.

Suppose that the continued survival of two accident victims depends on IV support. This method, being the same for both people, would seem to be as artificial for one as for the other. There are differences in their condition, however. One has a chance to recover and go on to live for many years. The other is given no chance to recover any significant degree of function. There are similarities and differences: the lives of both people are being prolonged (artificially), yet their long-term prognoses are far from identical. The accident victim who pulls through with the help of IV support will have had his life prolonged by the same method that is criticized in the proposed legislation. There are a great many techniques employed in modern health care that could be considered artificial. Widespread use and acceptance of a technique tend to make it appear more natural as time goes on. The introduction of both sterile technique and anesthesia met with considerable opposition as being not only artificial but also as wrong-headed and immoral. The same procedure, then, may strike us as more or less artificial at different times. Furthermore, we seem to have little objection to artificial life-prolonging techniques when they lead to significant recovery and survival. The IV drip is a conservative example. Total replacement of an infant's blood is a more radical procedure, but one that usually escapes criticism because it can mean the difference between early death and a normal life span for a person born with destructive antibodies resulting from mother-child RH-factor incompatability.

The proposed legislation tries to protect a person's right to a natural death by making it possible to withhold or withdraw artificial techniques. Nevertheless, serious question can be raised as to whether it is the artificiality of the technique that really concerns us or something else that is not clear. Already a difficult situation exists: the questionable use of the term *artificial* as applied to life-prolonging techniques and the lack of a positive definition for *natural death*.

All Competent Adults

The right to make a binding decision in favor of natural death is given by SB 1155 to "any competent adult." In an earlier time such a privilege might have been restricted to white men who own property. People held in slavery were not entitled to determine either their own lives or deaths. To whom a death "belongs" has been a matter regulated by social custom, although customs change. An individual who is not granted a full franchise in society loses options with respect to death as well as life. Strange though it may seem, natural death tends to be a privilege for those who have acquired a certain measure of social standing.

Consider one of many possible examples. The burial places of native Americans are held to be sacred. Spirits of the ancestors are believed still to be a presence, still a resource for the living. It is likely that a Hopi, Navajo, or Ute natural death act would attempt to ensure the proper status of the dead, just as SB 1155 works so hard on the status of the terminally ill. Nevertheless, the burial places and remains of native Americans have been repeatedly violated by agencies and individuals representing the dominant establishment.[7] The Navajo conception of both life and death differs appreciably from that of the American culture at large. The proposed act of legislation ignores much that is central to the Navajo and other native Americans who reside in Arizona and keep their own traditions. For *natural death* to have any significance the Navajo would require that the sacred lands remain inviolate and the spirits of the ancestors respected in all regards. Although the civil rights of individual Navajo's as competent adults may be protected, as a people with a distinct set of beliefs and way of life their voice is generally ignored. The core beliefs of competent adults, then, may not be represented in a natural death act, while practices that escape regulation in SB 1155 (e.g., desecretion of graves and sacred land) do continued violence to the perceived status of the dead.

What about children? Why doesn't a child whose own life is nearing a premature end have the right to express a preference for what should and should not be done? Why doesn't a person under the age of eighteen have the right to participate in discussion between family and physician about the treatment of a comatose and dying parent? The easy answer is that a formidable body of law has accumulated through the years that created a sharp distinction between rights of adults and minors. It could be very difficult to modify this distinction in the already complex and controversial realm of terminal care. Are minors really that different from adults in their ability to comprehend and respond to major life crises? Is there perhaps a better way to handle the situation? Few lawmakers seem eager to deal with these more difficult questions. So it remains that the proposed law does not hold that children have a right to control their own death or participate in decisions about other people who may be very close to them. Natural death, then, does not require enfranchised participation from the person most intimately involved even if that individual is intelligent and alert. Instead, the implication is that natural death involves a social transaction that can be negotiated by those enfranchised to do so.

Other questions also remain. How competent must a person be to make what kind of decision? What standards are necessary to ensure that the judgment of competency is made fairly and accurately? There is nothing simple about the important details involved in ensuring that a natural death act has its intended results. Moreover, the lack of a clear and positive definition of death interferes with legislative attempts at regulation.

Dignity and Sanctity

Both dignity and sanctity have appealing connotations, and neither is defined in SB 1155. There is no denying that these key words help to convey the general intent of SB 1155, to protect something of value under difficult circumstances. Neither term was scrutinized before being incorporated in the text, nor was it judged that definitions were needed. The principal supporter of the measure now recognizes that these well-intentioned terms are subject to a variety of interpretations.[3] It is possible, for example, that comforting as well as life-prolonging measures might be withdrawn because an outsider is upset by these techniques. ("How terrible! What a loss of dignity! What a violation of sanctity!") Yet the person undergoing the treatment might not be experiencing a loss of dignity. Unfamiliar, even bizarre apparatus might be enabling a person to breathe more comfortably, buying time to see loved ones and complete important business. On the other hand, the patient might not be experiencing anything at all. It is only in the eye of the beholder that dignity is being violated.

Family and professional caregivers do have significant rights in the care of the terminally ill (Chapter 6). This right is not at issue here. What is of concern is the possibility that people will fail to discriminate between what violates their own sense of dignity and what the dying patient is actually experiencing. Terms such as *dignity* and *sanctity*, when enshrined in law, can also serve as the pretext for actions that are not necessarily in the best interest of the patient. People can use these terms to justify their own values and biases. As a former hospital administrator, I know of numerous situations in which a decision to withhold treatment would have been cloaked in concern for dignity and sanctity when the demonstrable motive was to save money or hasten patient turnover.

Only three of the key terms included in SB 1155 have been discussed—enough, perhaps, to indicate that there are many difficulties involved in trying to formulate clear, workable, and sound legislation in the realm of terminal care. These difficulties are intensified by the understandable hesitation on the part of lawmakers to commit themselves to a precise definition of death. Recognizing as you now do some of the medical and social implications, you can look at several approaches to the title question: what is death?

BIOMEDICAL APPROACHES TO THE DEFINITION OF DEATH

Death is "certified" thousands of times every day by physicians. In this practical usage the question shifts from "What is death?" to "Under what conditions should a person be considered dead?" It is a distinction worth attention. The physician's determination meets society's need for verifying that one of its members has been lost. The concept of *nonreversible cessation of life processes* provides a general criterion for classifying a person as dead. This functional criterion, however, does not necessarily represent a positive and comprehensive definition of death. Note that death is treated here primarily as the absence of life. This is a satisfactory definition for some people, yet others have a more complex view that is not addressed by the physician's ritual. Death may be conceived variously as a transition, a splitting of spirit from body, or some otherwise altered state of being. To the physician, *dead* means the body no longer supports or can support life processes. To many people, however, *death* implies something that continues or begins when the last breath is released. Even the most confident certification of death, then, does not necessarily represent a complete definition. This means that after the biomedical approach has been explored, some of the major philosophical, religious, and social conceptions of death also must be considered.

Traditional Determination of Death

Recent developments in biomedical science have created new pressures on decision makers and produced new criteria for the determination of death. Not everything is new, however. Physicians have already had a set of criteria to employ and have sometimes been faced with difficult circumstances.

The most commonly relied on indices of death have been lack of respiration; lack of pulse (or heartbeat); and failure to respond to stimuli such as light, movement, and pain. Lowered body temperature and stiffness were other characteristics expected to appear after a period, followed still later by bloating and signs of decomposition. A competent physician did not generally have reason to miss the more advanced equipment available today. Simple tests, carefully performed, usually would make it clear whether or not life had fled. In many instances the physician or family could also take the time to wait before burial arrangements were made, thereby allowing more opportunity for a possible spontaneous revival of function.

Nevertheless, life-threatening errors could be made. Victims of drowning[12] and lightning,[19] for example, would sometimes be taken for dead, when in fact their vital functions had only been suspended. Those who suffered a stroke, epileptic seizure, or diabetic coma might also be pronounced dead instead of receiving treatment. The same fate could befall a person gifted in the once popular art of hysterical fainting.[6] More than a century and a half ago a Transylvanian physician carefully pointed out how almost all the signs of death could be mistaken in particular instances—his own uncle had narrowly escaped just such an error.[15]

The prudent physician, as well as the informed public, had sufficient opportunity to learn that the possibility of survival could still exist under the appearance of death. How often this situation actually existed is impossible to determine, but enough such circumstances arose for a tradition to establish itself—a tradition of second-guessing the physician, seeking protection against premature determinations, and looking for ways to revive the apparently dead. Indeed, the fear of being buried alive held much the same morbid fascination for people of the 19th century as does the fear of being kept indefinitely in a vegetative state somewhere between life and death today. Mark Twain[16] reported with appalled fascination on his visit to a municipal "dead house" in Munich:

> Around a finger of each of these fifty still forms, both great and small, was a ring; and from the ring a wire led to the ceiling, and thence to a bell in a watch-room yonder, where, day and night, a watchman sits always alert and ready to spring to the aid of any of that pallid company who, waking out of death, shall make a movement—for any, even the slightest movement will twitch the wire and ring that fearful bell. I imagined myself a death-sentinel drowsing there alone, far in the dragging watches of some wailing, gusty night, and having in a twinkling all my body stricken to quivering jelly by the sudden clamor of that awful summons! (p. 189)

This tradition of concern remains with us today, taking new forms such as the cryonic movement that attempts to preserve dead bodies at lowered temperatures for subsequent rejuvenation.[10] Furthermore, those who contend against the latest biomedical approaches to determining death may well be reflecting anxiety that has been floating around society for a great many years. Although the municipal death watch has vanished, its place is gradually being taken by medicolegal regulations buttressed by the technique of electroencephalography (EEG). The challenge to both concept and method will now be exemplified.

Ways of "Being Dead"

The question "When is a person dead?" has gained increasing practical significance in the past twenty years. This is a direct consequence of advances in clinical medicine. A patient who would have lapsed into coma and died in a short period can now be maintained by a life-support system for months or even years. Traditional approaches to defining death no longer seem adequate. The heartbeat, the respiratory system exchanging its gases, and reflex responses may also occur.

We hestitate to say "dead." We also hesitate to say "alive." The body retains some of its functions, but the *person* appears to have departed. There is no speech, no clear signs of understanding, no complex actions. Theoretically, even one such instance should challenge casual, overly familiar conceptions of death. How can we say a person is dead when the chest rises and falls and deep reflexes can be elicited? Yet how can we say the person is not dead when there are no words or actions indicative of a functioning human being. Our capacity to ignore confusing and vexing problems might have continued to triumph. The increasing frequency of such instances, however, does not permit the luxury of inattention. Practical decisions must be made. Following are a few of them, each dependent on a firm definition of death:

1. Family members and the attending physician agree that the life-support system should be withdrawn because the patient is unresponsive and has no apparent chance to recover. Would "pulling the plug" constitute murder? Or is the *person* already dead? And, if you cannot murder the dead, is it nevertheless a crime of some sort because vegetative functions could have continued indefinitely?
2. Another patient is also comatose and unresponsive, but vegetative processes continue even in the absence of an elaborate life-support system. (An IV is in place, but there is no device to keep respiration going artificially.) Elsewhere in the hospital an organ transplant team is urgently seeking a kidney that might keep somebody else alive for many years. Ruling that the comatose patient is dead could liberate the kidney. The

needed organ should be removed immediately if the other patient is to have a chance at survival. The operation will probably be fatal for the comatose patient. Is this murder? Or a new type of life-taking crime? Or a valuable procedure that might help one person and cannot harm another because he or she is actually dead?

3. The vegetative functioning of a comatose, nonresponsive woman is being maintained by elaborate life-prolonging procedures. If a person in such a condition should be considered dead, then this woman is dead. However, there is a living fetus within. Without intervention the fetus will not survive. Would this constitute the death of a person? And what does it mean if society acts to keep a "dead" person "alive" long enough to improve the chances for the survival of an immature being whose claims to personhood are disputed within this same society? Would delivering the fetus safely result in a "second death" of the mother?

   This leads to still another question. Clearly, the mother had been a person. This person seems to have died in some sense of the term. This death of a person may now be followed by the death of what still remained. How do these two types of death compare with the feared death of a fetus who, according to some members of society, was never a person in the first place?

Just how many deaths or ways of being dead can there be? Several possibilities have already been identified, all of which occur today:

- The *person* is dead. (He or she does not respond, communicate, or show any other characteristics associated with a distinctly human being.) Nevertheless, vegetative processes continue because of an elaborate life-support system.
- The same condition just described exists; however, vegetative processes continue without an elaborate life-support system.
- All vegetative functioning has ceased. (The body is dead.)
- The same condition just described exists; however, the dead organism had never been a person in the usual sense of the term.

Either the similarities or the differences among these conditions could be emphasized. How vital is the distinction between cessation of bodily processes and loss of the person as a person? What difference, if any, is there between the "deadness" of a body that continues to function on a vegetative level with or without an elaborate life-support system? Should the previous nature of the organism have anything to do with the present situation (who or what it was that no longer lives)?

These are some of the questions that confront health care professionals, legislators, and legal experts today. Philosophical and religious issues break to the surface in concrete situations, and important practical decisions must be made. The next section examines how the medical and legal communitites have attempted to respond to these problems that are both philosophical and practical. (See also Chapter 12 for further examination of the problems raised here.)

Brain Death and the Harvard Criteria

The medical world was ready for the concept of brain death by 1959, when the French neurophysiologists Mollaret and Boulon[8] reported their pioneering study of comatose patients whose breathing was being maintained by respiratory apparatus. Some of these patients were found to be "beyond coma": no electrophysiological activity could be detected from the brain (reflexes were also absent). Postmortem examinations eventually were performed on these patients. The investigators discovered extensive destruction of brain tissue consistent with the premortem evaluation of electrophysiological activity. The term *respirator brain* soon appeared. There was now some evidence to support the position that some patients connected to respiratory machines had lost their brain function—irreversibly—and therefore should be considered dead.

Another influential development occurred about a decade later (1968), when a committee composed of Harvard Medical School faculty issued its opinion.[1] Much of current policy and practice are derived from the *Harvard criteria* for determination of a permanently nonfunctioning (or dead) brain. Note that the first three criteria (given below) would have come as no surprise to physicians of an earlier generation. It is the last two criteria, dependent on 20th century technology, that introduce a new consideration.

The Harvard Criteria

1. *Unreceptive and unresponsive.* No awareness is shown for external stimuli or inner need. The unresponsiveness is complete even under the application of stimuli that ordinarily would be extremely painful.
2. *No movements and no breathing.* There is a complete absence of spontaneous respiration and all other spontaneous muscular movement.
3. *No reflexes.* The usual reflexes that can be elicited in a neurophysiological examination are absent (e.g., when a light is shined in the eye, the pupil does not constrict).
4. *A flat EEG.* Electrodes attached to the scalp elicit a printout of electrical activity from the living brain. These are popularly known as *brain waves*. The respirator brain does not provide the usual pattern of peaks and valleys. Instead the moving automatic stylus records essentially a flat line. This is taken to demonstrate the lack of electrophysiological activity.
5. *No circulation to or within the brain.* Without the oxygen and nutrition provided to the brain by its blood supply, functioning will soon terminate. (Precisely how long the brain can retain its *viability*, the ability to survive, without circulation is a matter of much current investigation and varies somewhat with conditions.)

In many instances the first three criteria (the traditional ones) seem to be adequate. The Harvard report was not intended to require the use of the EEG in all cases, only those in which some question remains. This is fortunate because EEG testing is not always feasible, and procedures for testing cerebral blood flow also require special provisions that may be difficult to arrange. The Harvard report was intended chiefly for application in problem situations in which the traditional criteria may not be enough. It was recommended that in such situations all the tests required for all the criteria be repeated about 24 hours later. In other words, the absence of all processes associated with life should be reconfirmed before the conclusion is reached that brain death has occurred.

The Harvard report provides useful guidelines and has found widespread application. However, the definition of death and all its ramifications have remained a continuing source of concern. The situation was considered urgent enough to stimulate the activity of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. This prestigious group produced its own monograph in 1981, *Defining Death*.[11] Reviewing the Harvard criteria after more than a decade of application, the Commission concluded:

> The "Harvard criteria" have been found to be quite reliable. Indeed, no case has yet been found that met these criteria and regained any brain functions despite continuation of respirator support. Criticisms of the criteria have been of five kinds. First, the phase, "irreversible coma" is misleading as applied to the cases at hand. "Coma" is a condition of a living person, and a body without any brain functions is dead and and thus *beyond* any coma. Second, the writers of these criteria did not realize that the spinal cord reflexes actually persist or return quite commonly after the brain has completely and permanently ceased functioning. Third, "unreceptivity" is not amenable to testing in an unresponsive body without consciousness. Next, the need adequately to test brainstem reflexes, espe-