Chapter 1

1. The most common symbol of condolence in the greeting-card studies was flowers: They appeared on 80 percent of the specimens McGee analyzed. Live flowers also serve as a common vehicle for conveying sympathies when words seem inadequate. Funeral parlors typically overflow with flowers, and the American Society of Florists estimates that between 20 percent to 25 percent of business nationwide can be attributed to what is euphemistically called “sympathy sales” (personal communication).

2. Unfortunately, explains one cryonics advocate, individuals who were suspended when the technology was new left the responsibility for covering the annual maintenance fee (required for cooling and storage) in the hands of surviving family members, many of whom tired of keeping up with the payments after a few years. As a result, storage facilities have been forced to foreclose on the estates of about half of those who have been suspended to date. The bodies of these individuals have since been thawed out and disposed of in a more traditional fashion.

Chapter 2

1. Some believe that Halloween was conceived, at least in part, as a way to familiarize children in this country with the idea of death.

2. Americans deny taxes in the sense that they continue to subscribe to the myth of the free lunch. It seems that liberals and conservatives alike have a nearly insatiable appetite for public programs that benefit them directly. Yet no one seems very willing to pay the tab, which is why America sets the low-end standard for tax burden among the industrial nations of the world. Our enormous public debt—currently well over $4 trillion and growing at a rate of about $7,000 per second, every second, minute, hour, and day of the year—is clear evidence of that phenomenon.

3. “Low-ingredient” offerings (low fat, sodium, sugar, cholesterol, etc.), “light-food” products (e.g., light beer, wine, popcorn, ice cream, and even cat and dog food), and “ingredient-free” product lines (sugar-free, caffeine-free, alcohol-free, cholesterol-free, sulfide-free, etc.) are ubiquitous in the modern American grocery store. New eating trends—the search for that food that will enhance our immortality—are also part of the food fad craze. Fiber, oat bran, fish, chicken, pasta, wine (much to the delight of many), and vegetarian regimens have all been touted as culinary routes to a long and healthy life in recent
years. Interest in organic growing methods (no use of pesticides or herbicides), herbal teas (purported to have significant medicinal benefits), home-canned produce, and “all-natural” foods (whatever that means) of every description have also been marketed as means to similar ends.

4. The water diet, the liquid diet, the Atkins diet, the Scarsdale diet, the Stillman diet, the high-protein diet, the high-carbohydrate diet, and the grapefruit diet are just a few examples. Various food manufacturers offer ready-to-microwave entrées for people who do not have time to prepare their own dietetically correct meals. Diet powders and pills are another option for those who are a bit more desperate for results.

5. Having the meals prepared for pickup or delivery—provided in conjunction with in-house counseling—is a popular option that has helped the diet business blossom in the last two decades from a minor enterprise into a major industry with $33 billion in annual sales. Americans have spent about $2 billion of that total patronizing a variety of dieting programs that offer weight-reduction services, even though these businesses have been subject to federal investigation for advertising programs that have no proven, long-term effect. According to some university-based researchers, the diet plans pushed by these retailers may even be dangerous. At best, researchers agree that the long-term success rates for the 7.9 million people who have enrolled in such programs is astoundingly low (E. Rosenthal, 1992).

The ever-popular self-help groups also stand ready to pitch in. Some adults even patronize weight-loss hypnotists, and others repair to residential fat farms. Even husky kids have an option along these lines: the summer camp for overweight children.

6. Some, obsessed with their figures and unable to achieve the results they desire through dieting and exercise, end up with anorexia nervosa, the deliberate self-starvation that arises from an obsession with food that leads to unhealthy and potentially life-threatening weight loss. Bulimia, involving recurrent episodes of binge eating followed by purging through use of diuretics, laxatives, and/or self-induced vomiting, is another such disorder. Figures vary, but it is generally thought that anorexia afflicts approximately 1 percent of Americans and that as many as 8 percent of American women are bulimic. According to psychologist Christine Ganis, approximately 85 percent of those who suffer from these sorts of eating disorders are either in the normal weight range or underweight already (cited in Jacobsen, 1992).

7. Meanwhile, tanning parlors have proliferated in the last decade or so. Many Americans patronize these salons in an attempt to add a golden glow to their pale bodies, despite increasing evidence about the link between skin cancer and ultraviolet radiation.

8. Also, by 1969, when Neil Armstrong took that first big step for mankind, Americans had conveniently forgotten the catastrophic rocket failures that marked the first few years of the race into space, incidents that flew in the face of American ingenuity. That all helps explain why when technological tragedy struck again with the Challenger disaster in 1986, Americans reacted with shock and confusion: “How could this have happened? Our rockets are not supposed to blow up.”

9. There is also the issue of the tens of thousands of Iraqi children who have died since the war for lack of pure water. That story did not get very much play either: Why should it when “surgical” air strikes on water purification plants by Stealth bombers are good by definition, according to scientistic American thinking.
Chapter 3

1. Janus, the Roman god of comings and goings, is a figure with two faces, one looking left and one looking right. It was common for the Janus figure to be located near doorways, the mark of both an entrance and an exit. We invoke Janus here to describe the two-faced nature of medical technology. On the one hand, it feeds into scientism and thereby fuels the forces of restraint. On the other hand, technology is responsible for creating medical scenarios where right-to-die activism comes into play.

2. Tomography (from the Greek *tomas,* "a cut," and the Greek *graphein,* "to write") creates three-dimensional pictures oriented along the body's axis, running from head to toe. Patients are injected with a dye that is sensed by the scanner, which produces relatively detailed images of the body in slices, like rings of a cut-up pineapple.

3. Using the same principle that is applied in submarine sonar, ultrasound is now used for imaging various body parts. Probably the most popular use today is for monitoring fetal development. Somewhere between 30 percent and 50 percent of all pregnant women in the United States have at least one ultrasound during gestation, and ultrasounds are required of women in Great Britain and Germany.

4. MRIs detect the chemical composition of structures within the body by introducing that body to an electromagnetic field, then scanning for any resulting electromagnetic resonance emanating from body tissues. The principle is parallel to that in play when a tuning fork is struck, then brought within close proximity of a second tuning fork. If the two forks are of the same size, the first fork's vibrations will induce the second to begin humming in resonance. So it is with the MRI: If one is attempting to detect the presence of hydrogen in the body's tissues, the MRI can be set to generate a magnetic field that will excite or resonate with hydrogen nuclei. Then, a radio frequency sensor detects resonances in the body and traces them out as a visual image of where the hydrogen is located in the body.

5. Scopes and instruments are inserted through small openings in the leg. Then, with the patient under local anesthesia, the equipment is threaded up through a blood vessel to the heart, two to three feet away, where the major arteries can be assayed and unclogged using inflatable balloons.

6. Cupping involved placing partially evacuated cups on the skin near areas of affliction in order to draw blood toward or through the skin and out of the body. The average adult body holds about five quarts of blood.

7. Kidneys are transplanted five times more often than all other organs combined.

8. Indeed, to the dismay of most ethicists, a lucrative black market for kidneys has emerged in the Third World on the heels of organ-transplant advances. Prices vary, depending on the condition of the donor and the desperation of the potential recipient, but $5,000 is not out of line as a price for a kidney today.

9. Defibrillators are designed to restore a steady, rhythmic heartbeat in a person suffering a heart attack by discharging a large DC current through metal paddles placed on the individual's chest.

10. Elaine Esposito, the longest-surviving PVS patient to date, never recovered consciousness after receiving anesthesia on August 6, 1941. She finally died on the Sunday after Thanksgiving in 1978, 37 years and 111 days later (President's Commission, 1983, p. 177).
11. The few patients that have recovered consciousness after prolonged periods of unconsciousness were severely disabled. The degree of permanent damage varies, but most are unable to speak or see, and many suffer from permanent distortion of the limbs and paralysis.

12. It is interesting to note that when doctors began treating infants with spina bifida aggressively, the number of recorded “stillbirths” dropped drastically (Rothman, 1991, p. 191).

13. After the fact, the Florida Supreme Court decided to hear the case after all and in November 1992 issued its ruling. That decision affirmed the lower court’s ruling that prevented physicians from declaring baby Campo legally dead for purposes of transplanting its organs. That ruling was upheld, according to the court, on the grounds that there was not enough proof that such donations saved lives to rationalize making a radical departure from the standard brain-death criteria (“Florida Court Rejects,” 1992).

14. The viability of organs for donation deteriorates rapidly after a body expires, making it important to harvest them as close to the time of death as possible.

15. Americans spend about $2,651 per person annually in public funding of medical services for the over-sixty-five age group. Spending on those under sixty-five amounts to only about one-tenth of that amount—about $265 per person annually (Hahn and Lefkowitz, 1992).

16. This is a relatively small number, considering that Americans spend over $800 billion annually on health care, but $5 billion is still more than twice the amount spent on all public maternity and child-health programs in the United States combined (N. Clark, 1992).

17. Some critics find it especially hard to rationalize spending so much to avoid death in the seriously ill and elderly when so little attention—relative to that in other developed countries—is paid to preventing death (and treating the lesser serious illnesses) of those who are still very much alive, especially the young. The United States ranks tenth out of ten Western countries in the percentage of preschool children with full polio, diphtheria-tetanus-pertussis (DPT), and measles immunizations (Shapiro, 1992, p. 21). The U.S. infant mortality rates top those in any other developed country (Shapiro, 1992, p. 18). The United States also leads the way in the percentage of infants born at low birth weight (Shapiro, 1992, p. 19). The fact is that this country devotes less than 5 percent of health-care spending to prevention efforts in any given year, while spending billions on those who, from a medical standpoint, are lost causes.

18. Only about 580,000 individuals were eighty-five or older in 1950, but that number swelled to 3.1 million in 1990 and is expected to expand another 70 percent to 5.3 million by the year 2005.

19. This pattern of resource allocation in Great Britain is common to most other European countries, as well (Jennet, cited in Bronzino, Smith, and Wade, 1990, p. 252).

20. That works out to about $800 billion annually, or about $2,500 for every second of every minute of every hour of every day of the year. On an annual, per-capita basis, that is about $2,700 for every man, woman, and child in the country.

Chapter 4

1. The first Nobel Prize laureate, Wilhelm Conrad Roentgen, discovered the X ray in November 1895 when he “viewed with stunned amazement the bones in his hand with the crude device he had fashioned” (Bronzino, Smith, and Wade, 1990, p. 417).
2. This was done partly out of necessity. Catholic and Jewish doctors were regularly discriminated against in Protestant and secular institutions, and so the only route of advancement open to them was through their own denominational hospital system.

3. Two hundred seventy community hospitals were closed in just the ten-year period from 1977 to 1987, a rate of about twenty-five closings per year (Rolde, 1992, p. 55).


5. The transportation revolution had an impact, as well. The improvement of roads and the proliferation of automobiles made it easier to go to an office or hospital for care.

6. Although Westerners accept the orthodoxy of specialization and compartmentalization as the ideal, it is by no means clear that the attitude is well founded. Eastern medical orthodoxy continues to embrace a more holistic approach, and, at least in some cases, this alternative seems better able to produce the desired effects that one has come to expect of modern medical practice.

7. The future of the general practice in the United States looks even gloomier: Only 18 percent of current medical school students surveyed say they are planning to go on to generalist graduate training ("Overspecialized Doctors," 1992). The remaining 82 percent will choose from among twenty-five specialties and fifty-six subspecialties, thirty-five of which have been recognized in only the past five years ("Overspecialized Doctors," 1992). In contrast, over half of all Canadian doctors continue in the general practice of medicine.

8. Not surprisingly, the overwhelming percentage of malpractice lawsuits filed in the United States are filed against specialists. Of course, there are more specialists than generalists, and specialists are more apt to apply riskier technologies and deal with more problematic cases. But part of the reason for the disproportionate number of suits filed against specialists surely has to do with the social distance—and commensurate lack of trust—between specialist and patient.

9. According to Starr (1982), specialists and subspecialists tend to treat their patients as organisms suffering from a collection of special and subspecial problems rather than as people suffering from general maladies, and that tends to distance the clinicians from the clients in human terms. Moreover, as specialists and subspecialists learn more about microscopic body parts and processes, their knowledge and language becomes more foreign to the average patient. Physicians and patients grow more distant as the information gap widens and as the language of interaction become more objective and technical. Patients, especially in the research setting, may tend to lose their humanity in the eyes of highly trained specialists by being objectifiable as "clinical material."

10. Some have even suggested that those who choose to go into the health-care fields are a self-selected group of individuals who have a heightened sense of denial as a common denominator (W. Smith, 1985, pp. 284–285). These individuals choose to become experts on health care, so the argument goes, out of a deep-seated need to gain some measure of immortality by acquiring the kind of knowledge that would help pave that path (Schulz and Adelman, 1980, p. 134).

11. One survey of medical publications in the years 1960–1971 failed to turn up even one article documenting instruction concerning death and dying for medical students, and Bugen (1979) suggests that the situation has not improved much in the intervening years.

12. Nursing schools have done a bit better along these lines. According to William Smith, "Most professional literature related to the psychosocial care of the dying is written by
nurses. The dichotomy between nursing and medicine is striking in this regard" (W. Smith, 1985, p. 284; also see Charmaz, 1980, p. 236).

13. According to Schulz and Aderman (1980, p. 142), the dying patient is a deviant in the medical subculture, and as a result, dying patients elicit aversive attitudes from caretakers. Less charitably, Schoenfeld (1978, p. 53) suggests that physicians avoid the dying because dying patients “simply will not feed the doctor’s narcissism by responding and getting well. Their care is demanding, frustrating, and far from helpful to the medical magician’s self-esteem.”

14. As Walter Smith (1985, p. 286) notes, “The contemporary practice of medicine is seriously compromised by the herculean demands made on physicians, nurses, and other allied health professionals. The volume of work required of these persons, coupled with the urgency, gravity, and intensity of the demands of medical intervention, seriously affect their ability to manage equally well all the important dimensions of effective patient care. Providing medical care is an emotionally complex task. The profession places great strain on its members in terms of personal investment, effort, and energy as well as commitment of time.”

15. Some claimed that the unvarnished truth would be too much for their patients. That truth is described as “a death sentence,” “torture,” or “hitting the patients with a baseball bat.” Expressions of concern about the psychological damage that could ensue from such revelations were common, even though there was no empirical evidence to support the claim (indeed, there may be evidence to the contrary). Others cited “therapeutic privilege” as a reason for exempting themselves from the requirements of informed consent when caring for terminally ill patients (President’s Commission, 1983, pp. 52–53).

16. One study conducted in 1953 revealed that over two-thirds of the 442 Philadelphia physicians sampled never disclosed diagnoses of terminal cancer (DeSpelder and Strickland, 1992; see also Oken, 1961). A 1960 national study of physicians revealed that 84 percent withheld information from patients about their incurable cancers at least some of the time, with 22 percent admitting that they withheld such information all of the time. In three other studies, conducted between 1953 and 1961, it was reported that 69 percent to 90 percent of physicians routinely failed to inform cancer patients of their diagnoses.

17. According to Raymond Carey and Emil Posavac’s (1980, p. 145) study of physician attitudes in the late 1970s, 29 percent of physicians and fully 45 percent of nurses agreed that the physician should give complete and honest information regarding the terminal condition without waiting for the patient to ask. In addition, 42 percent of physicians and 43 percent of nurses agreed that doctors should go ahead and reveal terminal condition information if a patient asks (see also Carey and Posavac, 1978–1979, and Rea, Greenspoon, and Spinka, 1975, both cited in Charmaz, 1980, p. 137). These are only self-reported attitudes, however, that may or may not have much to do with actual behavior.

18. Such fears are not necessarily unfounded. A third of all physicians, half of all surgeons, and three quarters of all obstetrician/gynecologists will be sued at least once in their professional careers (Shapiro, 1992, pp. 28–29). Physicians in the United States are five times more likely to be sued than physicians in either the United Kingdom or Canada.

19. Malpractice suits represent not so much a lack of faith in doctors as, in the first instance, an abiding faith in both doctors and technology—a faith shared with doctors, fueled by a physician’s aggressive treatment impulses. Malpractice suits are not so much a manifestation of faithlessness as they are a manifestation of a faith—scientism, magnified by the technological imperative—that has been broken.
20. One motivation we have not examined very deeply is avarice. Some suggest that certain physicians may overtreat their patients out of simple greed. To be sure, there is not much money to be made in death: Sustaining lives is much more lucrative for all parties in a position to bill and receive payment for their services. But greed alone is not enough to account for doctors overtreating patients in medically futile situations. It is only one reason for some to choose to sustain life, rather than help to manage death, in accordance with the technological imperative (see Pellegrino, 1991).

21. One only need look at the relatively dramatic changes that have taken place in childbirth in recent years to find evidence of this trend toward demedicalization. Fifty years ago, during the early days of medicalization, doctors participating in home deliveries were threatened with the loss of hospital privileges, and midwives in some states (California, for one) were prosecuted for practicing medicine without a license (Starr, 1982, p. 392). Home deliveries have not returned, but most hospitals now offer the next best thing: birthing rooms with homey decor, rocking chairs, and comfortable beds that can be adjusted for the delivery. There is also a resurgent interest in midwifery. And prospective parents are no longer kept in the dark about what to expect. Instead, the father- and mother-to-be take classes on natural childbirth, as a team. Preadmittance tours of the hospital are offered in many communities, and when the delivery time comes, the father is welcomed in the delivery theater, no longer relegated to nervous pacing in the waiting room.

22. Not as much progress has been made at the end of life, but advances are evident, with the hospice movement providing the most conspicuous changes. Not only have residential hospices been set up, many areas now offer hospice care in the home. And many large hospitals provide a special hospice area, where dying patients can get the medical attention they need while enjoying relaxed bureaucratic rules involving visitation, diet, and decor.

23. At the same time, patients or their surrogate decisionmakers who try to break with the physician-autonomy mold typically have a rough go of it. The story of Norman Paradis (1992) is illustrative. Paradis, director of emergency medicine research at New York University-Bellevue Hospital, and his brother, an attorney, found themselves with no control whatsoever over treatment decisions for their incompetent, terminally ill father (himself a physician for nearly fifty years). Despite clear instructions to the contrary, the physicians attending the elder Paradis continued for weeks to perform invasive diagnostic procedures and therapies. As Norman Paradis lamented, in closing his story, “If a doctor and a lawyer could not get decent care for a doctor, what chance does the public have?”

24. The Joint Commission on Accreditation for Hospital Organizations is a nonprofit credentialing organization contracted by the federal government to certify hospitals as worthy of reimbursement under Medicare and Medicaid.

25. For example, in New York, the state legislature essentially passed the technological imperative into law with passage of an act that requires that all patients be resuscitated in the absence of a DNR order to the contrary (Joint Commission, 1987, p. 90).

26. Anesthesiologists present one important exception to DNR policies that tend to empower patients with the right to decide their own medical fate. This group of specialists see resuscitation as part of their “standard of care” in dealing with the necessary and anticipated cardiorespiratory effects of anesthesia. For that reason, they typically will decline to honor the DNR in the operating room. With the backing of their national professional association, anesthesiologists prefer not to honor the DNR because the drugs they administer may be directly responsible for precipitating the arrest. In addition, since they have the
knowledge and skill to execute the resuscitation in the heavily monitored, controlled, and well-equipped environs of the operating room, the chances of successful resuscitation are relatively high (American Hospital Association, 1992, pp. 1–5).

27. In one study done at Duke University, researchers followed 146 CPR patients from 1988 through 1991 and found that only about half (84 patients, or 58 percent) were successfully resuscitated, and only 5 percent (7 patients) got well enough to leave the hospital. Subsequently, these patients were responsible for over $1 million in health-care expenditures, which amounts to about $150,000 per discharged patient (“Common Use of CPR,” 1993).

28. Still, the fact that 41 percent of the ethics committees that existed in 1983 were located in New Jersey suggests that the Quinlan decision had at least something to do with the proliferation of such bodies.

29. Advance directives were conceived of as state laws that would allow for both the execution of a living will (stating a patient’s treatment preferences if terminally ill) and healthcare proxy laws (giving others the right to make decisions for the patient when the patient becomes incompetent).

30. Several other recommendations were made, as well. The commission exhorted the medical profession to do everything possible to renew respect for the concept of informed consent. According to the commission’s report, the patient (or legal proxy) should have both the right to the latest, most comprehensive information regarding the medical situation of the patient and the right to refuse treatment. Finally, the commission boldly raised the resource-scarcity issue and recommended that it would be inappropriate to expend resources on “lost causes” if such expenditures would preclude the use of those resources in another case with a better prognosis.

31. Data from various studies also suggest that female physicians are apt to spend more time with patients than their male counterparts (Angier, 1992). In one study, male physicians were found to spend ten minutes or more with a patient less than half the time, whereas female physicians were found to spend more than ten minutes with two-thirds of their patients. Candace West, a sociologist specializing in this area, found that male physicians interrupted their patients twice as often as patients interrupted them. If the patient was a woman, male physicians were much more likely to interrupt than if the patient was a man.

32. Dubler (1993, p. 25) argues that hospital counsels regularly exaggerate this fear out of all proportion to case-law realities.

33. There are other reasons why advance directives may not be honored. Sometimes, patients dying at home go into arrest, and despite the patient’s expressed wishes, the family panics and calls 911. Emergency medical personnel, not wanting to waste time in a crisis situation, are likely to go ahead and initiate resuscitation, waiting to sort out advance directives after the fact. And sometimes, advance directives simply are not available even under more controlled conditions in a hospital if, during a medical crisis, a treatment/no treatment decision has to be made without delay.

Chapter 5

1. The homeopathic philosophy flourished in Europe in the late eighteenth century and early nineteenth century. And the popularity of homeopathy has remained high there, especially in France, according to the National Center for Homeopathy, with 32 percent of
family physicians adhering to this approach and with homeopathic prescriptions covered by the national health-care system.

2. Relaxation techniques, chiropractic massage, imagery, and spiritual healing were among the common therapies tried. Herbal medicine and folk remedies, biofeedback, hypnosis, and self-help groups were also mentioned (Haney, 1993).

3. The National Welfare Rights Organization is dedicated to promoting and advocating the rights of the poor in the areas of health, education, and welfare.

4. Increasingly sophisticated attempts to measure and report on quality of care have continued through the 1980s. The Health Care Financing Administration began issuing Medicare mortality analyses for selected hospitals across the country in 1986, and other state agencies have followed suit by publishing reports on the status and quality of institutionally based medical care within their respective jurisdictions. New York State’s Department of Health and Pennsylvania’s Health Care Cost Containment Council have both begun collecting and reporting data on health-care charges and mortality rates for individual physicians and hospitals in selected treatment categories, and other states are expected to do so in the future. Although it is difficult to measure the impact of such reports, banner headlines about higher-than-expected mortality rates—with individual physicians and hospitals identified by name (at least in Pennsylvania)—cannot help but cause further erosion of public confidence in the medical profession.

5. Women, according to Hippocratic writings, were governed by their womb and were therefore incapable of logic and reason. In addition, spiritual deficiencies were supposed to have laid them open to temptation by the devil. During the Middle Ages, intellectual deficiencies were added to the list of flaws presumed to plague the female character. And twentieth-century critics argued that women were simply too physically frail, insufficiently dedicated, and temperamentally ill suited to the study and practice of medicine. When women did survive the gauntlet of medical education to become certified to practice, they were discredited for overemphasizing sympathy over science (The Boston Women’s Health Book Collective, 1984, p. 592).

6. The Dalkon Shield was an intrauterine device (IUD) marketed by A. H. Robbins and prescribed by American physicians from 1971 to 1974. This contraceptive device was implicated in many cases of pelvic inflammatory disorder (PID) and miscarriages that led to at least seventeen documented deaths. The Dalkon Shield was taken off the market in 1974, but devices already sold were not recalled, so that, in the early 1980s, it was estimated that 50,000 American women still had them in place (with another 500,000 women using the device in other countries).

7. Even though the number of women using the pill peaked at ten million in 1973, it is still the most widely used reversible contraceptive both in the United States and worldwide (The Boston Women’s Health Book Collective, 1984, p. 237).

8. Not only did the pill help spawn a sexual revolution, it also facilitated a revolution in the labor force, as more women found it possible to enter the work force when they were more in control of their own reproductive mechanisms. This was an empowering experience in itself for the experience women have gained in the workplace has helped them become more confident of their abilities and more comfortable in dealing with—and challenging—authority figures.

9. Estimates of sex abuse in the general physician population run as high as 5 to 10 percent. In one survey of health-care professionals in California, published in a 1973 edition of the American Journal of Psychiatry, 36 percent of psychiatrists and 46 percent of psycholo-
gists reported having sex with at least one of their patients (cited in The Boston Women’s Health Book Collective, 1984, pp. 562-563). Such breaches of confidence, often magnified out of proportion by the media, served to put women on guard.

10. This was a position that made delivery more difficult and painful for the mother, but it was (and in many places still is) used because the more natural position—with upper body more vertical and the vagina tipped downward—forces medical personnel to crouch.

11. Approximately 90 percent of first-time mothers delivering in major U.S. hospitals undergo episiotomies (Davis-Floyd, 1992, p. 168). Physicians continue to argue that this procedure prevents damage to the baby’s head, vaginal tearing, and other internal damage, even though there is little clinical evidence to support those claims (The Boston Women’s Health Book Collective, 1984, p. 383; also Michaelson, 1988, p. 13).

12. The cesarean rate is significantly higher in profit-making hospitals and with women covered by private health insurance (“U.S. Says 349,000 Caesareans,” 1993).


14. Studies by the federal Center for Disease Control suggest that the chances of death during childbirth are two to four times greater for women delivering by cesarean than for women delivering vaginally, and the National Institute of Health suggests that somewhere between 33 percent and 75 percent of cesareans are not necessary (cited in The Boston Women’s Health Book Collective, 1984, p. 385). Approximately 30 percent of these cesareans are performed on women who have already had them, even though there is little hard evidence to indicate such a course of action.

15. Not surprisingly, perhaps, hysterectomies occur far less frequently under prepaid plans, such as HMOs, than under more traditional fee-for-service insurance plans like Blue Shield (The Boston Women’s Health Book Collective, 1984, p. 511). Some go so far as to suggest that the number of hysterectomies has gone up as the birth rate has declined because obstetrician/gynecologists have scrambled to maintain the cash flow of their practices. (Fees run $3,000 to $6,000 per operation, adding up to about $5 billion worth of operations annually in the United States).

16. There was a medical committee to review experiments with human subjects (essentially everything that was done within the hospital), but it was rarely consulted. Instead, professionals were left to regulate themselves. As one institute director put it, “The usual patient [wants] to avoid the necessity of grappling with painful facts related to his own welfare. He prefers (and in a real sense he has no other choice) to depend on the overriding faith that the physician and institution will safeguard his interests above any other consideration” (cited in Rothman, 1991, p. 58).

17. The very fact that researchers would defend the practices Beecher questioned and explicitly reject the notion that ethical protocols could even be developed, much less be of any use, speaks volumes about the potential for dissonance between the medical research community and the general public during this period.

18. We should note that the very coverage by the popular press of articles (like Beecher’s) that had appeared in professional medical journals was somewhat unique at the time, which is one reason why, to that point, medical researchers had been able to report their questionable research protocols in the medical journals without prompting much second-guessing. But the ethic of consumerism, the blossoming rights culture, and the general distrust of authority figures made both the reporting of and the response to articles about the abuse of the public trust by medical researchers almost inevitable.
19. Given this mood, the public understandably moved beyond criticism of research protocols and began to question the very motives of medical researchers. In the past, the disciples of Hippocrates were accorded almost saintly status. They were assumed a priori to be acting in the best interests of their patients. But now, a more complex and realistic set of motivations seemed to emerge. The profit motive (from the marketing of new drugs and technologies), glory, academic prizes, lucrative research grants, career advancement (all the spoils of successful research projects), and power (regarding the lives and deaths of patients in their care) were added to the purely humanitarian motives that were assumed to drive the medical researcher's behavior.

Chapter 6

1. According to Lofland (1978, p. 87), the happy-death movement deserves to be called a movement because, as with the women's rights movement and the ecology movement, it creates new patterns of thinking about the world on a mass scale. The movement phenomenon does not necessarily require an organized, entirely conscious effort on the part of some dedicated core of participants. Rather, such movements represent a "sprawling, diverse, multi-structured, diffuse assemblage of persons" who act "independently and as part of organizations, engaging in a multiplicity of largely uncoordinated activities and in possession of varying degrees of 'consciousness' relative to their participation in the movement" (Lofland, 1978, pp. 75-76).

2. Indeed, Fletcher's work is widely acknowledged as the first modern work on medical ethics to be issued outside the stream of writings by Catholic theologians (Glick, 1992, p. 59).

3. College classrooms provided an important venue for increasing Americans' exposure to death. That exposure is also crucial to right-to-die activism because many who take a course in death and dying will become inoculated, to varying degrees, with social stigmas and cultural taboos relating to death. These students will have read about, talked about, and written about death in ways their parents would not have dreamed of. Many of these students may well go on to inoculate their own progeny, creating yet another level of geometric growth in sensitivity to death and dying as a natural part of living. In the end, what goes on in U.S. institutions of higher education has the potential for far-reaching effects, well outside the purely academic realm.

4. It is probably safe to say that the seminal works on death published between the mid-1950s and the mid-1970s were more important for what they led to than what they accomplished in and of themselves. This is because, in addition to securing their own positions in academe, their authors encouraged others to work in the area of death. Fletcher, Gorer, Feifel, Kübler-Ross, Becker, Templer, Weisman, and their colleagues set a course for others to follow and provided the intellectual foundation—new theoretical frameworks, new concepts, and old methodologies applied in new ways—on which others could build. From there, the increase in publications, the proliferation of college courses, and the expansion of the general interest in death issues became something of an inevitability.

5. In fact, litigation in the United States accounts for fully 2.5 percent of the gross domestic product (GDP), a rate that puts this country in a category of its own. Belgium, France, and Austria tie for second place with only 0.6 percent of GDP devoted to litigation (Shapiro, 1992, p. 136).
6. Surely, the emergence of the rights culture, fueled by the enduring nature of American individualism, can help explain this litigiousness. In addition, the explosion in the lawyer population (today, there are 310 lawyers for every 100,000 Americans) has been partly responsible for increases in legal activity. In Great Britain, the percentage of attorneys in the population is less than half what it is in the States (Shapiro, 1992, p. 136). The related shift toward activism on the part of the courts also plays a major role in the increased legal activity.

7. Clearly, decisions about this sort of care were being made routinely without formal court review. Indeed, the Supreme Court of New Jersey recited at some length the testimony of a physician witness indicating that problems such as these had “long existed and ordinarily had been handled without the involvement of people or social institutions other than the patient's family, physicians, and possibly hospital administrators. The witness endorsed the practice, which he termed 'judicious neglect’” (President's Commission, 1983, p. 155).

8. Since that time, the number of articles published in the medical literature in a given year has never dropped below 30 and has climbed steadily since 1984 to nearly 175 in 1990 alone. Material on publications presented here is derived from the analysis by Glick (1992, pp. 53–91).

9. Part of the devotion to the right to die in the scholarly and popular literature, beginning in 1976, can be attributed to passage of the nation's first living-will law that same year: California's Natural Death Act. Aside from being the first such law, however, there is nothing particularly radical or controversial about the California NDA. Indeed, it was and continues to be a very conservative and restrictive measure that, unlike Quinlan, does little to advance the right to die in a substantive way (see Chapter 8 for more details on the NDA). In contrast, the Quinlan decision involved an identifiable set of actors and represented a marked departure from past thinking on the right to die (see Chapter 7 for more details on Quinlan). Passage of the NDA was important and noteworthy, but the Quinlan decision represented the real turning point for the happy-death movement.

10. To be sure, the courts had been involved in medical cases before Quinlan, but inevitably, doctors were found without fault as long as they could demonstrate that they had acted in good faith and in accordance with “accepted medical practice.” Accepted medical practice was the carte blanche that always had been invoked to defend physician autonomy, and generally speaking, this defense had carried the day to that point. But when lawyers for Quinlan's physicians attempted the same tack, they were rebuffed. The physicians' lawyers also advanced another common pre-Quinlan argument about the Hippocratic commitment to do no harm. This rationale, too, was found wanting by the New Jersey court in the face of overriding family interests.

11. The Patient Self-Determination Act, sometimes referred to as providing the medical equivalent of Miranda rights, took effect on December 1, 1991. It requires that all hospitals receiving reimbursement from Medicare or Medicaid inform incoming patients about their rights to make advance directives (e.g., living wills and durable powers of attorney) about health-care decisions, including the decision to accept or refuse life-sustaining treatments. Hospitals can design their own method of informing patients about advance directives, and they need only inform patients of their rights under state law. But they must broach the subject in a timely manner and provide guidance along the way to those who wish to execute instructions about what therapies, if any, they would prefer to refuse and under what conditions.
12. For some patients, questions about advance directives will be dismissed as just more bureaucratic probing in an already belabored admissions process. For others, however, information about the right to refuse medical treatment, provided pursuant to the PSDA, may be an empowering dose of reality. We suspect that, as time passes and as more Americans cycle through the hospital, more individuals will become informed about and comfortable with their rights to make advance directives, thanks to the impact of the PSDA.

13. Busalacchi was talking with physicians at the Hennepin County Medical Center, the Minnesota institution that went to court to stop medical treatments for Helga Wanglie; see Chapter 3.

14. Both were young women from Missouri, both were victims of automobile accidents, and both were diagnosed to be in a persistent vegetative state. At one point, they were both treated in the same Missouri institution.


16. Members of the new group thought it important to drop the “E” word—euthanasia—due to its negative connotations.

17. Humphry divorced Wickett several years later in a messy and well-publicized split after she was found to have terminal breast cancer. Wickett took her own life—using techniques espoused by the Hemlock Society—in the solitude of the Oregon backcountry. Given Humphry’s high profile, that story, too, made headlines.

18. Humphry’s book also advises that patients devise a backup plan, such as tying a plastic bag around the head—should the ingested drugs be vomited up before they have the intended effect.

19. His comments were made in response to questions submitted to him by Dr. Bruon Haid, a Catholic himself and chief of anesthesia at the University of Innsbruck surgical clinic (Reiser, 1977, p. 47).

20. Significantly, the positions of these two organizations are the only full-text statements by such groups that the authors of the Presidential Commission report chose to provide in their 500-page treatise on forgoing life-sustaining treatments.

21. The Catholic position seems to have softened on the issue of pain management, as well. In the past, Catholic elites discouraged the extensive use of sedating drugs for at least two reasons. First, pain and suffering were thought to be useful vehicles of redemption. And second, sedating patients too extensively might bring on unconsciousness, robbing the patient of the opportunity to mentally and religiously prepare for death. Pope Paul’s 1980 statement on the subject represented a more accepting view regarding the use of sedatives to manage pain, even if such use brought on unconsciousness, and possibly even depressed vital bodily functions to the point where death was hastened (Glick, 1992, p. 61).

22. The Catholic Health Association, the national service organization comprising Catholic hospitals and long-term care facilities, was very supportive of the PSDA concept, lobbying for and testifying in favor of its passage during hearings before the Senate Finance Committee’s Subcommittee on Medicare and Long Term Care (Catholic Health Association, 1991).

23. There is really only one important distinction to be made between assisted suicide and mercy killing. With assisted suicide, the dying principal takes an active part in the death and is only assisted by a second party. With mercy killing, the second party takes on primary responsibility for causing the death of the principal. Both assisted suicide and
mercy killing are considered “active euthanasia” because individuals take an active role in precipitating death. By way of contrast, “passive euthanasia” involves allowing an individual to die: Medical treatments may be withheld or withdrawn, after which “nature” is allowed to take its course.

24. In May 1992, after Proposition 119 went down to defeat, the United Methodist church, representing nine million Methodists nationwide, went partway down the trail cut by its Northwest Conference. It approved a resolution that, though not endorsing any specific assisted-suicide legislation, expressed a general sense of understanding regarding the plight of persons in a medically hopeless situation. “When the natural process of dying is extended by application of medical technology, the emotional, economic, and relational consequences for self and others may lead a responsible person seriously to question whether continued living is faithful stewardship of the gift of life. Churches need to provide preparation in dealing with these complex issues” (United Methodist church, 1992, p. 144).

25. Kevorkian had been writing for decades about what he calls “medicide,” a word he invented to describe orchestrating the deaths both of condemned criminals (in earlier writings) and of those wishing to end their lives because of some overwhelming physical ailment (a more recent interest). The aim of medicide, according to Kevorkian, is to advance a wholly new specialty: obitiatry (pronounced “oh-bit-eye-a-tree,” another Kevorkian term). This new category of medicine would involve the conducting of live human experimentation (under deep and irreversible anesthesia) and the harvesting of organs and tissues.

26. This line of thinking holds that the Pythagoreans, who were vehemently opposed to abortion, falsely attributed their oath to Hippocrates in hopes that recruiting the father of medicine as the author post mortem would lend credibility to their views on this and other controversial subjects. (The Hippocratic Oath does forbid doctors from conducting abortions.) The fact that Hippocrates was a common name at the time, coupled with the lack of copyright law, meant that few eyebrows were raised when the Pythagoreans first began promulgating an oath under that name, several score years after Hippocrates’ death.

27. Some draw a parallel between human and animal life here. There are ethical norms in society, argue proponents of assisted suicide, with regard to putting animals “to sleep” when they are in great pain or near the end of life. Few would argue about the propriety or even the expediency of putting animals out of their misery in such situations. But if it is inhumane, and maybe even illegal, to make animals suffer needlessly, how can a failure to provide humans with moral and legal protections against end-of-life suffering be considered ethical or humane? What happens to humanity, argue those who advance the assisted-suicide alternative, when humans are doing the suffering?

28. As Kevorkian notes, just as with “back-alley abortions,” if the suicide is done improperly, in haste, or sloppily, a person can end up in a substantially worse condition than before the attempt was made.

29. Although the activities of the two doctors have many similarities, there is at least one primary and important difference between them: Quill readily admits to being ethically challenged by the prospect of assisted suicide, whereas Kevorkian seems cocksure. For many, Kevorkian seems to lack an appropriate sense of discomfort with the entire idea of assisted suicide; he seems not to appreciate the departure from standard practice that publicly acknowledged assisted-suicide represents. In short, Kevorkian seems ideologically wed to a purpose whose ends many might agree with but whose means become problematic for the potential for abuse is nightmarish.
Chapter 7

1. Material for Chapters 7 and 8 is drawn, in part, from an article entitled “The Right to Die: State Courts Lead the Way Where State Legislatures Fear to Tread” (Hoefler and Kamoie, 1992).

2. The privacy cases commonly referred to by the courts included: *Einstadt v. Baird* (affirming the right of access to contraceptives by unmarried persons, including minors, 405 U.S. 438 [1972]), *Loving v. Virginia* (affirming the right to interracial marriage; 388 U.S. 1 [1967]), *Pierce v. Society of Sisters* (affirming the right to attend private school; 286 U.S. 510 [1925]), and *Meyer v. Nebraska* (affirming the right to learn a foreign language, 262 U.S. 390 [1923]). It is beyond the scope of this inquiry to discuss the specific privacy questions raised in each case. It is sufficient for present purposes simply to note that these cases were significant for dealing with the privacy interest in an increasingly broad area of life activity (Borst, 1985, p. 905).

3. Commenting on the extension of the privacy right to right-to-die cases, Vincent Borst suggests that “abortion decisions can be viewed, therefore, as a reaffirmation of the principle that the constitutional right to privacy protects an individual's autonomy in making decisions which involve intimate matters. No decision is more intimate than to terminate one's own life” (Borst, 1985, pp. 905–906).

4. *Cruzan* was the first right-to-die case of its sort to be heard by the Supreme Court. Thus, the justices could not possibly have held that the right of privacy encompassed the right to refuse treatment.

5. Extending his line of reasoning, Rehnquist argued that, on the one hand, erroneous decisions to maintain life are correctable or can be negated in a number of ways: discovery of new evidence regarding the patient's intent, medical advances that would alleviate the patient's condition, or the unexpected death of the individual, despite the continuance of life-sustaining treatments, for example. On the other hand, an erroneous decision to withdraw treatment is not susceptible to correction. Therefore, it is not unreasonable for the state to require petitioners to satisfy elevated evidentiary standards before allowing the withdrawal of life support.

6. The significance of *Saikewicz* in this regard should not be overemphasized. The Massachusetts court later modified (although it never explicitly rejected) this policy. And significantly, it has been rejected by all states that have raised the issue, save for an Ohio appellate court (Glick, 1992, p. 147).

7. We should note that items (1) and (3) seem to borrow from the best-interest standard, and item (2) derives from the substituted-judgment standard. It is not uncommon for courts to mix and match the two as they see fit, in finding their way to the decision they have in mind.

8. Generally speaking, according to the National Center for State Courts (1992, p. 177), a “coma is a sleep-like (eyes closed) unarousable condition resulting from impairment of brain stem functions.” The most profound coma is described as “brain death,” in which the coma is both irreversible and severe to the point that there are no brain-stem functions whatsoever. Unlike those in a coma, individuals in a PVS have their eyes open, even though their neocortical functions have ceased. It is not uncommon for someone in a coma (eyes closed) to “evolve” into an eyes-open PVS. In both cases, patients can be considered to be “neocortally dead” because their brain stems—the center of all thinking and sensory activity—is permanently and irreversibly damaged. However, under the currently accepted def-
inition of legal death, these individuals are still alive because their brain stems, controlling involuntary motor functions and internal organ functions, continue to operate. Patients in either of these conditions have ceased to have any sensory, thinking existence, but they continue to live on—at least in the legal sense of the word—in either an eyes-open (PVS), or eyes-closed (coma) state. As a matter of fact, these patients cannot even be described as terminally ill, even though there is absolutely no medical reason to hope for recovery in most cases. This is the case because they may be maintained, with proper medical care, for years and even decades (the longest recorded survival being thirty-seven years [Meisel, 1989, p. 139]; for more on PVS and brain death, see our Chapter 3).

9. To this point, the only possible exception is the decision in Couture v. Couture (48 Ohio App. 3d 208, 549 N.E.2d 571 [1989]; see National Center for State Courts, 1992, p. 168).

10. The National Center for State Courts (NCSC, 1992) lists 105 state and federal cases addressing the initiation, maintenance, and removal of life-sustaining treatment, beginning with Quinlan in 1976 and carrying through Busalacchi in 1992. Our analysis, based on data contained within that report, suggests that the prototypical right-to-die case involves family members who are asking permission to withdraw ANH from an incompetent principal somewhere in his or her seventies.

11. Many of these incompetent individuals were characterized as being in a persistent vegetative state (41 cases out of 108), even though that specific term was not always used (other terms included chronic vegetative state and semicomatose). Patients were considered to be fully comatose in another 12 instances and brain dead in another 6. This brings the total of those who were essentially in a persistent vegetative state to well over half the total of 108.

12. Artificial respiration came in a close second as the procedure most likely to be involved in court cases, at 35 percent (38 out of 108 cases). Refusing surgery (mostly amputations) was cited as the central issue in 14 cases, and refusing therapy (e.g., hemodialysis and chemotherapy) was an issue in 6 other instances. In 5 other situations, the removal of "life-support procedures" was referred to in general terms. (The total does not add up to 108 because some cases involved more than a single procedure.)

13. As noted, Massachusetts wanted final decisionmaking in right-to-die cases to rest with the courts, whereas New Jersey advocated the use of ethics committees, thinking the court would become the final arbiter only in cases with extenuating circumstances or irresolvable disagreements. For its part, the New York court raised the evidentiary standard for right-to-die cases set by Quinlan by requiring that guardians produce "clear and convinc-
ing evidence” that terminating life support was consistent with a principal’s desires. New Jersey had adopted the more lenient standard, in which guardians had only to demonstrate that the termination of life could reasonably be expected to be the wish of the principal.

14. New Jersey has its *Quinlan*, *Colyer*, and *Conroy* decisions; Massachusetts is cited for authoring the *Spring*, *Saikewicz*, and *Hier* decisions; New York has its *Eichner*, *Storar*, and *Klein* decisions; and California rounds out the group with decisions in the *Barber*, *Bouvia*, and *Donaldson* cases.

15. In addition to its two right-to-die precedents, the New Jersey court has been noted for a variety of rights-based rulings, including (1) its ruling that the local system of school finance unconstitutionally discriminated against children in poor districts, (2) its attack on zoning ordinances designed to exclude low-income housing, and (3) its strengthening of protections against illegal searches and seizures by rejecting the “good faith” exception.

Chapter 8

1. The statutory information we assembled for analysis here constitutes a “snapshot” of right-to-die law in the fifty states as it existed during the time the of our research (beginning in the summer of 1991 and ending in the spring of 1992). Admittedly, many states have amended their laws since that time, making some of the details of our analysis a bit outdated. At the same time, we feel the general theme of the analysis holds up quite well: The state courts have led and continue to lead the way on right-to-die policymaking, and the state legislatures struggle to resist but ultimately converge with the consensus position carved out by the state courts.

2. Durable powers of attorney for health-care provisions give the principal a way to empower a second party with the right to make health-care decisions for the principal when he or she becomes incompetent. These new kinds of provisions have been required because regular powers of attorney are not typically applicable in right-to-die situations for two reasons. First, powers of attorney traditionally become void when the principal becomes incompetent; making powers of attorney “durable” resolves this defect. Second, traditional powers of attorney have been thought to cover only estate and fiduciary matters, making it necessary to pass perfecting legislation in which the coverage of the power of attorney is specifically extended to health-care decisionmaking.

3. Glick (1992) notes that the *Quinlan* decision did not directly motivate the California legislature to act for the issue had been on the decision agenda in that state for several years. What *Quinlan* did was provide right-to-die advocates with a window of opportunity, which helped them finally push the bill over the top.

4. The state law in Washington provides a good, typical example (see Washington Natural Death Act [1979]).

5. In an effort to distinguish acts associated with allowing terminal patients to die from the acts suggested by the controversial terms *mercy killing* and *euthanasia*, the Alaska statute goes so far as to coin a new term—*mercy dying*—to describe what the statute condones.

6. In a departure from this norm, California requires living wills to be reauthorized every five years and reexecuted within four months after an individual is declared terminally ill. In another minor departure from the norm, Georgia requires reauthorization every seven years.

7. The Patient Self-Determination Act of 1991 represents a significant development along these lines at the federal level. The PSDA—somewhat like the Nevada law that pre-
dated it—requires hospitals, hospices, nursing homes, HMOs, and other health-care facilities receiving reimbursement under either Medicare or Medicaid to provide written information to patients upon admission regarding the extent of their legal rights (in accordance with their respective state laws) to refuse medical treatment should they become incapacitated. Hospitals must also note the patient’s preferences on his or her medical records. The act also requires the Department of Health and Human Services to conduct a nationwide campaign to educate the public about right-to-die legal options.

8. In apparently the only “wrongful life” case heard to date, an Ohio court dismissed all charges against St. Francis-St. George Hospital, where Edgar Winter, an eighty-four-year-old heart patient, was resuscitated after a heart attack, against his wishes (“Wrongful Life Suit,” 1991).

9. Residents of Mississippi should take note of their state’s one exception to the liability shield: Physicians involved in removing a patient’s organs for purposes of transplantation are prohibited from participating in the withdrawal of life support from that patient.

10. Some public officials, including U.S. Representative Pat Schroeder (D-Colorado), suggest that it would make good economic sense to give premium discounts to those who were willing to sign advance directives. Though the ethical arguments against such a move may seem prohibitive at this time, this is an option that no doubt will receive more attention in the future, unless spiraling health-care costs can be brought under control some other way.

11. To be sure, some degree of variation among the state laws is no evidence of their weakness as a whole. Indeed, those arguing from a “states’ rights” or “new federalism” perspective would celebrate what diversity exists, while demurring at the prospect that state laws should be measured against some national standard for living-will legislation. At the same time, there may be some fundamental aspects of the right to die, grounded both in common law, and in the U.S. Constitution, that would supersede legislative prerogatives. It is the degree to which the state laws impinge on rights with those kinds of foundations that may, indeed, be taken as a measure of the state legislatures’ deficiency as a whole in dealing with the right-to-die issue.

12. Use of the terms conservative and liberal is not meant to necessarily suggest that these categories of linguistic construction represent positions endorsed by individuals of those respective ideological persuasions.

13. The named individual(s) must be willing and competent to make decisions for the incompetent patient. Otherwise, decision-making authority devolves to the next class listed.

14. The Uniform Law Commissioners provide guidance on only two important issues, stating that (1) a failure to reach consensus does not authorize the next class in line to decide and (2) the proxy decision cannot conflict with the previously expressed intentions of the individual (National Conference of Commissioners on Uniform State Laws, 1989, pp. 12–13). Even when the states have modeled their laws after the URTIA, however, it is not always clear that these two understandings have been adopted.

15. This is significant because of a recent New York case, even though pregnancy was not an issue. In that case, Murray Elbaum had requested that the feeding tube in his comatose wife’s stomach be removed, arguing that his wife had asked him repeatedly not to keep her alive if she should become comatose. The New York court, operating under the strict “clear and convincing” test charted in Eichner and Storar, refused Elbaum’s request on the grounds that his wife’s private pleas to her husband did not satisfy the required evidentiary
standard. After losing his case, Elbaum refused to continue paying for his wife's care, but an appellate division of the state supreme court eventually ordered him to do so: a sum amounting to $100,000 by the time the decision was rendered (Belkin, 1992).

16. In the Washington, D.C., opinion, the more significant of the two given the advanced stage of Carder's pregnancy (twenty-six weeks), the judges stated that "respect for patient autonomy compels us to accede to the decisions of a pregnant patient whenever possible" (cited in Greenhouse, 1990).

17. Incubator is a generally pejorative, shorthand term used by women's rights advocates to describe the nature of pregnancy exclusion provisions—provisions they see as reducing women to the status of an incubator if they are prohibited from exercising the right to die when pregnant.

18. The law was co-sponsored by several female legislators. And, if the New Jersey court is any indication, there is a tradition of liberal policy mediation in the state. At the same time, New Jersey has a relatively high percentage of Catholics. And with a 90 percent male membership, New Jersey has one of the most male-dominated legislatures in the country. Why, then, did the New Jersey legislature do what it did? One lobbyist for the state's Catholic Conference gave the impression that the conference in particular, and the pro-life movement in general, simply ran out of steam in a state that has traditionally taken relatively liberal stands on such issues (personal interview).

19. Using regression-analysis techniques, Glick (1992, pp. 182–184) finds just the opposite relationship: The more recent the passage of the bill or amendment, the more likely it is that ANH will be excluded as a procedure that can be withheld or withdrawn. We suspect, however, that the low number of states on which the analysis was based made the regression overly sensitive to a few exceptional cases. Regression is problematic as a method of comparative state analysis even when all fifty states are involved. When the number of states drops below fifty, results become even more questionable. In this case, nine states had no living-will laws in force when Glick did his analysis, and nineteen others did not mention ANH one way or another. Two more states equivocated on the issue, leaving a total sample of twenty states on which to run an analysis. Five of the six states to pass laws in the last three years have included ANH as a procedure that can be withheld or withdrawn, and two other states have amended their laws to allow for ANH withdrawal since Glick's analysis was conducted. The sensitivity of Glick's original analysis to a few atypical cases, combined with developments that have taken place since that analysis, help explain the divergence of conclusions on the ANH issue between Glick's analysis and ours.

20. The National Conference of Commissioners on Uniform State Laws (NCCUSL) is an interstate legislative body consisting of two representatives appointed by the governor from each state. Its stated mission involves drafting model pieces of legislation for all states to adopt. The NCCUSL is a well placed, well connected, and widely respected body, and as such, it is a source of legislative policy diffusion in a league of its own.

21. The commissioners updated the URTIA in 1989, and that, too, had a substantial impact on legislation across the country: The revised code was adopted, essentially in toto, in Alaska, Iowa, Maine, Missouri, Montana, and Oklahoma.

22. These groups issue interstate analyses of legislative initiatives and act as information clearinghouses for other issues. Such organizations also publish newsletters and magazines that facilitate the exchange of ideas and increase awareness of legislative developments. In addition, they hold conferences where legislators can exchange ideas face to face.
23. David Fairbanks (1980, p. 104) described the same phenomenon in 1980. He conducted policy innovation research on a range of issues that, like the right to die, have a distinctively moral (as opposed to economic) dimension to them and found that “most efforts to regulate morality are based on religious beliefs, and measures of religious culture provide the single best predictor of the type of morality policies a state will pursue.”

24. Indeed, in states in which the Catholic population is large and the church is especially powerful (e.g., New York, Massachusetts, New Jersey), living-will laws have been slow in coming, if they have come at all. These states may traditionally be very innovative with regard to economic policy trends, “but in this particular policy, it strongly appears that the Catholic church has successfully blocked legislation” (Glick, 1992, p. 159).

25. For example, the following cases all gave Catholic elites cause for concern: Saikewicz in 1980, Eichner in 1981, Bouvia in 1982, Colyer in 1983, Hier in 1984, and in one of the most serious blows to the Catholic position, Conroy in 1985 (New Jersey’s liberal decision allowing the withdrawal of ANH).

26. In this context, routine means that the principal is competent but not pregnant, that ANH is not involved, and that a valid, unambiguous living will has been executed.

27. On the one hand, the new law allows for the withdrawal of artificial nutrition and hydration, the designation of proxy decisionmakers, and the right to die for individuals in a persistent vegetative state; Pennsylvania’s law also bends ever so slightly in the liberal direction regarding the rights of pregnant women. On the other hand, Pennsylvania adopted the old, conservative definition of the concept “terminal condition” that was more popular with legislatures in the later 1970s and early 1980s.

28. The current governor, Robert Casey, can be included here. Although a committed Democrat, Casey is extremely sensitive to conservative Catholic positions.

29. The Catholic Conference and the Pro-Life Federation worked to keep the issue off of the legislative agenda first by linking the right to die to abortion and then by spreading fear that legislation would open the door to euthanasia and the legalization of death by lethal injection. The divisiveness of the issues surrounding the right to die and the link to abortion ensured it would never receive serious consideration.

30. It is often said of legislatures that “the power to delay is the power to kill” (Oleszek, 1989). Clearly, the power of the house to delay consideration of right-to-die legislation, combined with the power to take the time to load a bill down with conservative amendments, turned out to be sufficient to kill living-will legislation in Pennsylvania for five years running.

31. The Florida law has since been amended to allow for the withdrawal of artificial nutrition and hydration, under certain conditions.

32. For example, in at least five cases, state courts have specifically rejected state statutory provisions that precluded the withdrawal of artificial nutrition and hydration: Barber v. Superior Court (California), Corbett v. D’Alessandro and Satz v. Perlmutter (Florida), In re Gardner (Maine), and McConnell v. Beverly Enterprises, Inc. (Connecticut). In each case, the courts made it clear that statutes could not limit an individual’s constitutional right to refuse medical treatment (Glick, 1992, p. 161).

In California, the court has also explicitly criticized the legislature’s Natural Death Act for requiring a fourteen-day waiting period after a patient has been declared terminally ill before a living will can be executed. By that time, the court argued, many individuals—as many as half—would be unable to complete such a document (Glick, 1992, pp. 179–180).
The right to die for pregnant women may prove more problematic, however, even though the beginnings of a progressive trend are detectable. This will be the case, it seems fair to say, as long as abortion rights themselves remain in question.

Chapter 9

Catholics argue that the right to die is inimical to the sanctity-of-life principle. Pro-life groups see the fight against the right to die as a natural extension of their interests in prohibiting abortions. Disabled rights groups are worried that the right to die will someday degenerate into the right to take the lives of disabled individuals whose lives do not seem, in the eyes of some third parties, to be worth living (or supporting with public funds). The loud and persistent protests carried out by these kinds of groups—both outside hospitals and long-term care facilities where right-to-die scenarios are being played out, and inside courtrooms and legislative hearing rooms where rights to die are being considered—generally have retarded the mediation process.

Even Mad magazine has circulated its version of a model living will, including the stipulation: "While I am not morally or ethically opposed to so-called 'life-sustaining treatment,' I am vehemently opposed to the concept of hooking up such machinery to 'The Clapper.'"

Warm-water drownings are more problematic than cold-water drownings. In warm water, the lack of oxygen seriously and irreparably damages the brain and other organs after just a short time (a couple of minutes). In the case of a cold-water drowning, however, the body core temperature drops substantially, and metabolic rates slow to the point where the brain (and other organs) can be sustained without a supply of oxygen for extended periods of time (twenty minutes or longer, in some cases). If warming and resuscitation of a young cold-water drowning victim is completed under controlled conditions with medical supervision, the child—if he or she was healthy prior to the incident—can recuperate with little or no long-term damage.

Increasingly, patients, families, and physicians are conspiring to make bold decisions about forgoing life-sustaining treatments. According to American Hospital Association, many of the “6,000 deaths that occur in this country every day are somehow timed or negotiated by patients, families, and doctors who … armed with an amazing array of death-delaying technology … reach a very painful and a very private consensus not to do all that they can do and let a dying patient die” (Malcolm, 1990a).