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The Health Care Proxy and the Narrative of Death

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THE HEALTH CARE PROXY AND THE NARRATIVE OF DEATH

STEVEN I. FRIEDLAND¹

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On no subject are our ideas more warped and pitiable than on death. Let children walk with nature, let them see the beautiful blendings and communions of death and life, their joyous inseparable unity, as taught in woods and meadows, plains and mountains and streams of our blessed star, and they will learn that death is stingless indeed, and as beautiful as life, and that the grave has no victory, for it never fights.

- John Muir

I. INTRODUCTION

The subject of death holds a firm grip on the Western consciousness, as well as on the physical body. Commentary about death has been handed down through the ages from sources such as the scriptures, playwrights, and poets.² Woven around the subject of death is an entire narrative or conversation, what the French social historian, Philippe Aries, describes as "the hour of our death."³ The impact of this narrative is considerable, affecting death rituals and decisions about life-sustaining treatment alike. One significant impact is on the law concerning death-related decisions. As this paper argues, the prevailing narrative of "the hour of our death" has significantly affected the efficacy of requests to withdraw or withhold treatment for persons in persistent vegetative states. In particular, legal tools such as the health care proxy and living wills are underutilized precisely because of the dominant narrative of avoiding death.

The narrative of death has changed greatly over time. In an earlier era, a societal narrative of the tamed or good death existed⁴ - one considered death "both familiar and near, evoking no great fear or awe."⁵ This view of death as a transition contemplates the possibility of a gentle passing.

The dominant modern perspective minimizes the notion of the "good death." Today, Americans do not talk about death in the personal realm. It is not a part of one's life, but rather an event removed from home and culture, occurring primarily in the hospital, hospice or nursing home. The modern death is

²"In a Dark Time, the Eye Begins to See." JOSEPH CAMPBELL, *THE POWER OF THE MYTH* 39 (1988).

"Oh lord, give each of us his own death, The dying, that issues forth out of life In which he had love, meaning and despair."

Id.

"To everything there is a season, and a time to every purpose under heaven: A time to be born, and a time to die." *Ecclesiastes* 3:1.

³See PHILIPPE ARIES, *WESTERN ATTITUDES TOWARDS DEATH: FROM THE MIDDLE AGES TO THE PRESENT* (1974).

⁴This view is typified by the Indian tribal elder's statement in the film, *Little Big Man*, "Today is a good day to die." *LITTLE BIG MAN*.

⁵ARIES, *supra* note 3, at 13.

packaged and clean, with hospitals and burial homes overseeing the operation.⁶

Today, death is something that "one must avoid - no longer for the sake of the dying person, but for society's sake, for the sake of those close to the dying person - the disturbance and the overly strong and unbearable emotion caused by the ugliness of dying."⁷ The fear of death⁸ manifests itself in many ways, from a morbid curiosity about others' mortal injuries to a hesitancy in adopting advance directives such as the health care proxy. Any contemplation of a chosen death or of voluntarily deciding its circumstances is anathema to both cultural and legal norms. Indeed, the extension of life in any form is paramount.⁹

The current dominant narrative is largely attributable to advances in medical technology and the isolation of death-related medicine in hospitals. Medicine has contributed to longer and healthier lives, with great leaps forward in transplantation, surgery, genetic therapy, and many other areas involving human longevity. The average life expectancy in 1900 was forty-nine years; in 1950, 68.2 years; and today, seventy-six years.¹⁰ The exponential growth in longevity, when coupled with discoveries such as antibiotics, has created expectations that modern medicine will one day be able to eventually cure disease - whether it be AIDS, cancer or Alzheimer's - and find the key to aging.¹¹

Yet, these scientific advances paradoxically have fueled unrealistic expectations about medicine's ability to fight and eventually conquer disease.¹²

⁶One physician who has regularly dealt with death describes this phenomenon as follows:

We have created the method of modern dying. Modern dying takes place in the modern hospital, where it can be hidden, cleansed of its organic blight, and finally packaged for modern burial. We can now deny the power not only of death but of nature itself. We hide our faces from its face

SHERWIN B. NULAND, *HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER*, at xv (1994).

⁷ARIES, *supra* note 3, at 87.

⁸Within the American culture, death is life's leading antagonist.

⁹See *infra* note 83 and accompanying text. Nancy Beth Cruzan lay in a coma with no sense of her surrounding, yet she was deemed to be "living."

¹⁰In the year 2010, the average person is expected to live until the age of 77.9 years. See generally Lawrence A. Frolik & Alison P. Barnes, *An Aging Population: A Challenge to the Law*, 42 HASTINGS L.J. 683 (1991).

¹¹Cryogenics, involving the science of freezing life to be thawed at a later time, has gained increasing legitimacy. Especially after the freezing of embryos which were subsequently implanted successfully. JOHN BOWKER, *THE MEANINGS OF DEATH* 3 (1991).

¹²A corollary to America's obsession with avoiding death is its preoccupation with preserving youthfulness. Americans undergo cosmetic surgery, purchase youth enhancing products, and participate in exercise and diet programs, all to maintain youthful vitality.

The advances have helped foster a perplexing question¹³ - is death with dignity more important than lingering life?¹⁴ Medicine's ability to maintain human life in a persistent vegetative state¹⁵ with no hope of probable recovery, for example, (or its ability to extend life generally in its final stages of terminal illness), presents one of the more vexing aspects of the gains in modern medicine. Given the financial and emotional expense of maintaining life in a near-death¹⁶ state,¹⁷ can and should life be maintained at all cost?¹⁸

America's obsession with immortality is evident from its passion of death and death-related rituals. Even burial rituals are laced with defiance - proclamations of enduring spirit, if not flesh. For example, Americans have been buried in their sports cars or cremated and loaded into a bullet with instructions to be shot at an animal during hunting season. 15 HARPER'S INDEX (1993).

¹³Another way of asking this question: Is there a point in time when life should succumb to death? Norman L. Cantor, *Quinlan, Privacy and the Handling of Incompetent Dying Patients*, 30 RUTGERS L. REV. 243, 268 (1977).

¹⁴What of the cost of dying in hospitals, far away from loved ones and a familiar nurturing environment? What of the price of continuing treatment when there is no reasonable hope of a return to a gainful sapient life?

¹⁵The phrase "persistent vegetative state" is attributed to Dr. Fred Plum, Professor and Chairman of the Department of Neurology at Cornell University. Dr. Plum explained:

Vegetative state describes a body which is functioning entirely in terms of its internal controls. It maintains temperature. It maintains heart beat and pulmonary ventilation. It maintains digestive activity. It maintains reflex activity of muscles and nerves for low level condition responses. But there is no behavioral evidence of either self-awareness or awareness of the surroundings in a learned manner.

In re Jobs, 529 A.2d 434, 438 (1987).

A second commentator describes the persistent vegetative state as involving: [A] total loss of cerebral cortical functioning; they are permanently and irreversibly devoid of any awareness, thought, or feelings. Thus, the permanently vegetative patient's 'personality, memory, purposive action, social interaction . . . , joy, satisfaction and pleasure [are forever gone]'. Moreover, such patients do not and will never experience pain or suffering . . . A diagnosis of the permanent vegetative state usually can be made with a reasonably high degree of reliability within weeks or months after the original injury by a physician skilled in neurological diagnosis.

Robyn S. Shapiro, *The Case of L. W.: An Argument for a Permanent Vegetative State Treatment Statute*, 51 OHIO ST. L.J. 439, 441-42 (1990).

¹⁶The costs of extending life can be considerable. "[P]rolonged dying can involve considerable pain and suffering, not just a philosophical preference for controlling the time of death; this physical and psychological impact on the moribund patient must be considered." Cantor, *supra* note 13, at 248.

¹⁷In a persistent vegetative state there exists a "contrast between severe mental loss and the subject's preserved autonomic or vegetative functioning." FRED PLUM & JEROME POSNER, *THE DIAGNOSIS OF STUPOR AND COMA* 6 (3d ed. 1980) (explaining that the patient's brain stem maintains its functioning but the patient is not cognizant of any such functioning and has no higher thought processes). See also Elizabeth D. McLean,

The legal response to this conflict in values has not kept pace with medical advances. The legislatures in all fifty states¹⁹ have acted, as well as the Supreme Court.²⁰ Legislatures have adopted some form of "advance directives," which permit a patient in advance of becoming incompetent to maintain autonomous control over his or her health care decisions.²¹ One such directive is the durable power of attorney on health care decisions, also known as the health care proxy. With the proxy, a surrogate decision-maker is appointed to make health care decisions in the event the subject becomes incapacitated.²²

Yet, the health care proxy and other advance directives are themselves dying from disuse. Few people know about the health care proxy mechanism, and of those, few sign it.²³ The legal apparatus appears to be failing.

Comment, *Living Will Statutes in Light of Cruzan v. Director, Missouri Department of Health: Ensuring That a Patient's Wishes Will Prevail*, 40 EMORY L.J. 1305, 1306 n.6.

¹⁸This issue has provoked a plethora of opinions. For example, S. Norman-Culp, *Trying to Die with Dignity Has its Price*, THE OR. REG., May 6, 1993, at G1; C. Crosby, *Internists Grapple with How They Should Respond to Requests for Aid in Dying*, THE INTERNIST Mar. 1992, at 10.

¹⁹See, e.g., CONN. GEN. STAT. § 19A-575 (1993) (stating that any person eighteen years or older may execute a document which shall contain directions as to specific life support systems which such person chooses to have administered); see also DEL. CODE ANN. tit. 16, § 2502 (1993) (providing that an individual, legally adult, who is competent and of sound mind, has the right to refuse medical treatment or surgical treatment if such refusal is not contrary to existing public health laws); ARK. CODE ANN. § 20-17-202 (Michie 1993) (providing that an individual of sound mind and eighteen or more years of ages may execute at any time a declaration governing the withholding or withdrawal of life-sustaining treatment).

²⁰The Court gave its official imprimatur to the right to refuse life-sustaining medical treatment, including nutrition and hydration in *Cruzan v. Missouri Dept. of Health*, 110 S. Ct. 2841 (1990).

²¹A patient who utilizes an advance directive retains the choice whether to continue life-sustaining treatment.

²²While Aries' narrative of death impacts on our collective experience, it also rumbles loosely in the interstices of western legal thought. To examine advance directives without also examining the social impact of the hour of our death narrative would be naive at best. This narrative cuts across disciplinary lines and impacts legal principles.

Yet, the efficacy of the health care proxy is subject to great doubt. Studies, both formal and informal, show that the support for such measures is far greater than their actual use. This may be due to the legal devices and tools created by the western legal tradition, including the health care proxy, being premised on a rationality of behavior described as legal competency. Specifically, the competent decision-maker is believed to be autonomous. Autonomy means that people will make conscious, knowing, and voluntary choices in their lives. Since volitional conduct is autonomous, actors will be held responsible for their choices. This vision of social responsibility and autonomy, however, seems to disintegrate when the subject matter is death. More specifically, the law has trouble overcoming mythology, culture, and religion in creating workable rules regarding life-prolonging decision-making for patients who lack the capacity to make their own decisions.

²³See, e.g., Nova Southeastern University Law Center Survey, 1994, where 92% of

This paper examines whether and how the legal apparatus, specifically the health care proxy, can be made more effective. The paper argues that while the objectives of law and medicine may conflict,²⁴ the differences between the two mischaracterize the terrain of the debate. It is not so much that law and medicine approach death differently, but rather that neither discipline features a supportive societal death conversation or narrative.

Only when there exists a narrative of the good death will the legal apparatus be more successful with death-related issues. The adoption of a new narrative will permit the modification of the current historical bright-line test used to describe life and death, will foster the reimagining of death in the personal realm, and will promote the efficacy of the legal framework.²⁵

This article is divided into three sections. After this introduction, section II features a brief history of the narrative of death, explores the role of heroism in the death narrative, describes the "miracles" of modern medicine, and analyzes some of the resulting adverse transformations wrought by the advances. The transformations include the unrealistic expectations of longevity and obsession with youthfulness, the removal of death from the personal realm, and the change in the nature of death. Section III examines the legal apparatus erected to meet the issues created by the medical advances, including the redefinition of death, and Constitutional, common law, and legislative enactments. The legislative response includes advance directives such as living wills and health care proxies. Section IV examines the reasons for the disuse of the health care proxy. Section V offers a proposal to increase the effectiveness of the health care proxy and the legal apparatus in general. Specifically, this section proposes a modification of the prevailing narrative of death to promote greater acceptance of death as a part of the life cycle.

those surveyed would designate someone to make such decisions for them, yet only 26% had actually designated a surrogate.

²⁴The legal community theories about whether such actions are within the confines of the law; the medical community ponders the ethics of terminating a life; and the religious community debates the implications to a person's afterlife." Michele Yuen, *Letting Daddy Die: Adopting New Standards for Surrogate Decision-Making*, 39 UCLA L. REV. 581, 582 (1992).

²⁵The article highlights the inapplicability of the assumption in modern western legal thought that a competent person's decision-making process is autonomous. Particularly in the area of death, such an assumption is far removed from reality. It is not merely the lack of the linguistic turn that incapacitates legal analysis in this area; the rarified language is simply indicative of minimized social, economic, and political relations, which have removed central structures and formations to the historical sidelines. BRYAN D. PALMER, *DESCENT INTO DISCOURSE* 5 (1990) ("for all the exhortations and prefatory gestures toward language and its complexities, those social historians who champion a history informed by discourse (or critical/literary linguistic) theory seldom betray much of an interest in the very key that they contend can open the hermeneutic door to the past"). *Id.*

II. BACKGROUND

A. *The Narrative of Death*

"The prospect of death . . . wonderfully concentrates the mind."²⁶

A narrative is a representative context, a prism through which the world is described. On one level, it is a story or dialogue about a specific event, person, situation or time. On another level, it reveals a vision of world, replete with values, assumptions, and beliefs about how the world works.

The usefulness of narrative is predicated on the belief that "[t]he way people talk about their lives is of significance, that the language they use and the connections they make reveal the world that they see and in which they act."²⁷ Thus, an understanding of the rhetoric contained in a narrative sheds light not just on the meaning of words, but on relationships and power configurations as well. The narrative is a connector,²⁸ a potent means of bridging different concepts, understandings and values, or even the antinomies of life. It is a method of piecing together experience into a grander schematic.²⁹ One apt illustration of narrative is myth, a form that synthesizes truth and belief. In myths handed down from generation to generation, from ancient Greece or Egypt to the frontier Old West, to any hero's grand adventure, there is a "point of wisdom beyond the conflicts of illusion and truth by which lives can be put back together again."³⁰

The context of the narrative, such as the setting, also impacts greatly on the message communicated. The context affects the relationship between the rhetoric and its interpretation, creating an aesthetic.³¹ The aesthetic is defined

²⁶ERNEST BECKER, *THE DENIAL OF DEATH* ix (1973).

²⁷CAROLE GILLIGAN, *IN A DIFFERENT VOICE* 2 (1982).

²⁸The narrative takes other forms as well, including oral history or even song. Its flexibility extends so that the narrative may be ceremonial or simply habitual. It need not be passed down from one generation to the next, and can be written as well as verbal. It also can be embodied in nonverbal conduct.

²⁹It is, in a sense, "an interior roadmap of experience . . ." CAMPBELL, *supra* note 2, at xvi (Bill Moyers, *Introduction*).

³⁰*Id.* at xviii. "We're so engaged in doing things to achieve purposes of outer value that we forget that the inner value, the rapture that is associated with being alive, is what it's all about." *Id.* at 6.

³¹If the meaning of a narrative depends more on its tenor, feeling or visualization than its text, it may be viewed as a kind of aesthetic. This can be viewed as an application of "the medium is the message" theory. Yet, it is much more. An aesthetic is created by more than the medium, but by all factors influencing interpretation. It is more a reflection that "plain meaning" is not to be found in the rhetoric of a text but in a combination of rhetoric, context, and intersubjective factors that influence the premises of interpretation. See generally Stanley E. Fish, *Normal Circumstances, Literal Language, Direct Speech Acts, the Ordinary, the Everyday, the Obvious, What Goes Without Saying and*

by the narrative's intersubjective parts. For example, rhetoric is not communicated neutrally, but by a person with experience, interests, and biases, who possesses a particular style of delivery. The same can be said of the receiver, who may have a totally different set of experiences, interests, and biases, along with a different style of receiving.³² Timing, location, and other variables affect the narrative's interpretation. Thus, the meaning of a narrative depends on its intersubjective parts.

2. The Narrative of Death

The narrative of death is that conversation which structures the individual and societal vision of death. This narrative is based on interpretive constructs that essentially act as a foundation for the perspectives held about life - what it is, how it endures, and how it ends.

The narrative of death, far from severing the thread of life, often serves to sharpen life's narrative. The prospect of death can inform, motivate, and define the way in which life is lived.³³ The use of the death narrative to "concentrate the mind" about life, however, is often stifled by fear.

3. A Dominant Characteristic of the Narrative - Fear of Death

The current dominant narrative of death is characterized by fear.³⁴ This fear concerns the prospect of our own death and manifests itself as a psychological inability to visualize the state of death.³⁵

Other Special Cases, 4 CRITICAL INQUIRY 625 (Summer 1978), reprinted in STANLEY E. FISH, IS THERE A TEXT IN THIS CLASS? 269 (1980).

³²Even how this paper is "received" depends on the interaction with the reader and the experiences the reader brings to it. The text is therefore not autonomous, but exists only in the eyes of the reader. It is not a question of whether it will be interpreted, but how. See Paul Campos, *That Obscure Object of Desire: Hermeneutics and the Autonomous Legal Text*, 77 MINN. L. REV. 1065 (1993).

³³"Death is not the ultimate tragedy of life. The ultimate tragedy is to die without discovering the possibilities of full growth. The approach of death need not be the denial of that growth." - *Norman Cousins*

³⁴"We all labor against our own cure, for death is the cure of all diseases." SIR THOMAS BROWNE, RELIGIO MEDICI PART II, Section ix, G. (1968) (1st ed. London 1642). "Next not his ghost, oh, let him pass! He hates him. For that would upon the rack of this tough world. Stretch him out longer." WILLIAM SHAKESPEARE, THE FIFTH PART OF KING LEAR, act 3.

³⁵As on physician describes it:

None of us seems psychologically able to cope with the thought of our own state of death, with the idea of a permanent unconsciousness in which there is neither void nor vacuum - in which there is simply nothing. It seems so different from the nothing that preceded life. As with every other looming terror and looming temptation, we seek ways to deny the power of death and the icy hold in which it grips human thought.

NULAND, *supra* note 6, at xv.

The pervasiveness of this fear and the avoidance it causes can not be understated. The fear of death embraces human existence³⁶ and "haunts the human animal like nothing else; it is a mainspring of human activity - activity designed largely to avoid the fatality of death, to overcome it by denying in some way that it is the final destiny for man."³⁷ Death, while recognized as inevitable, is only intellectually, rather than emotionally cognizable.³⁸ The full impact of it is suppressed.³⁹ It is translated, transformed, and hidden from view.

While death is secreted away from the American conscious, the fear of death runs unchecked. The calming view of death as a final promotion - embraced by primitive societies⁴⁰ - has become vestigial. With death no longer seen as an advancement or a continuation of a journey, most people in the Western world are unwilling to contemplate their own mortality.⁴¹

³⁶Thus, it is not a great leap to observe that death is central to human life; "that of all things that move man, one of the principle ones is his terror of death." BECKER, *supra* note 26, at 11. Even though death might be hidden and intentionally obscured, it is everpresent. As William James wrote:

Let sanguine healthy-mindedness do its best with its strange power of living in the moment and ignoring and forgetting, still the evil background is really there to be thought of, and the skull will grin at the banquet.

Id. at 16 (quoting William James).

³⁷*Id.* at ix.

³⁸As one commentator noted:

Therefore in normal times we move about actually without ever believing in our own death, as if we fully believed in our own corporeal immortality. We are intent on mastering death . . . a man will say, of course, that he knows he will die someday, but he does not really care. He's having a good time with living, and he does not think about death and does not care to bother about it - but this is a purely intellectual, verbal admission. The affect of death is repressed.

Id. at 17 (quoting Zilborg); see also KURT R. EISSLER, *THE PSYCHIATRIST AND THE DYING PATIENT* 277 (1955).

³⁹Death often serves as the harbinger of life. As author William James observed, "death is 'the worm at the core' of man's pretentions for happiness." BECKER, *supra* note 26, at 15.

⁴⁰Primitives often celebrate death - as Hocart and others have shown - because they believe that death is the ultimate promotion, the final ritual elevation to a higher form of life, to the enjoyment of eternity in some form. Most modern Westerners have trouble believing this any more, which is what makes the fear of death so prominent a part of our psychological make-up.

Id. at ix.

⁴¹The fear of death is a commonality of human existence, not simply an isolated or anecdotal occurrence. See generally GEORGE BURNELL, M.D., *FINAL CHOICES: TO LIVE OR TO DIE IN AN AGE OF MEDICAL TECHNOLOGY* 1 (1993). The fear transcends and unites the many disciplines that deal with death issues. See BECKER, *supra* note 26, at ix. "The col-

4. A Brief Historical Review of the Death Narrative

Attitudes towards death have changed dramatically during the past several centuries in Western civilization. In earlier times, the narrative included the possibility of the "good death." Rather than something to be feared, death was considered salvation.⁴² Indeed, death was even believed to be spiritually healthy.⁴³ The good death had its genesis in religion, but could be observed in medicine and law as well.

One belief common to many of the world's major religions is that death is not permanent, but rather a temporary state. Human existence is a pathway involving many more stages than solitary life and death. Buddhists, for example, consider death to be a transitory stage, one that continues until an awareness of the inevitability of transience occurs.⁴⁴ Hindus believe that death is not a single, final event, but one that will reoccur numerous times. Consequently, it should not be treated with significance.⁴⁵ Islamics also view death as transitory, a process leading to a final judgment.⁴⁶

The Judeo-Christian perspective of death is somewhat different than that of the far eastern religions. This perspective does not involve the dead being reborn on earth in different forms as a matter of course. While there is an afterworld, death has more finality. In Christianity, death "does not evacuate . . . the pain . . . by some compensatory promise of resurrection."⁴⁷ Additionally, the Jewish understanding of death differs somewhat from that of Christians. Judaism views death as an affirmation of faith.

A medical history also reveals transformation of attitudes towards death. In prior eras, medicine served to comfort the dying as much as to delay death. For example, in outbreaks of plague or significant disease such as tuberculosis,

lective attitude toward death has led to a universal fear of the dying experience in our society . . ." BURNELL, *supra* note 41, at 5.

⁴²Faith in the possibility of such a scenario [of the good death] has ever been a tradition of Western societies, which in centuries past valued a good death as the salvation of the soul and an uplifting experience for friends and family and celebrated it in the literature and pictorial representations of *ars moriendi*, the art of dying.

NULAND, *supra* note 6, at xvi.

⁴³"Originally, *ars moriendi* was a religious and spiritual endeavor, described by the fifteenth-century painter William Caxton as 'the craft for to deye for the helthe of mannes sowle.'" *Id.*

⁴⁴There must be "recognition, that nothing is immune from that transience" BOWKER, *supra* note 11, at 204.

⁴⁵"[Death] will happen many times; and one should not be involved in it in any anxious way." *Id.* at 142.

⁴⁶"So Death is not itself a punishment: it simply brings to an end a particular stage in a much longer process culminating in the day of resurrection and the final judgment." *Id.* at 105. Moreover, it can occur only as a result of God's will. *Id.* at 104.

⁴⁷*Id.* at 86.

doctors often were ineffective in providing anything other than moral support to their patients. Until the 20th Century, doctors had very few administrable remedies for illness.⁴⁸ In devising all kinds of diagnoses and remedies, from "overexcited," requiring bloodletting, to "exhaustion," requiring a prescription of whiskey,⁴⁹ the patient that survived did so as much despite the doctor as because of him or her.

The age of antibiotics brought significant changes in how medicine was practiced.⁵⁰ By achieving the apparent defeat of various diseases with antibiotics, death became an enemy that could be delayed or potentially defeated. Yet, belief in death with dignity did not leave the medical profession completely. "Although physicians have learned to hate death as an enemy to be defeated, many physicians, especially those who see death daily or weekly, recognize death as ending pain or bringing peace at the end of a long and productive life."⁵¹

A legal history of the narrative of death also exists. The common law had adopted a bright-line test for defining death, generally described as the cessation of cardiovascular functioning.⁵² The law endorsed more than a predictable and uniform measure, it emphasized the sanctity of life in any form. This was seen in the criminalization of any deprivation of life. Intentionally shortening a mortally wounded victim's life by any length of time, for example, would constitute murder under the common law.⁵³

⁴⁸"19th-Century medicine knew only a handful of useful treatments for specific diseases - cinchona bark for malaria, mercury (generally but not invariably in nonlethal dosages) for syphilis, digitalis for heart failure." Jerry Adler, *The Age Before Miracles*, NEWSWEEK, Mar. 28, 1994, at 52.

⁴⁹"With no understanding of infection, physicians often regarded disease as the sign of an organism whose inner workings had mysteriously gone out of balance An 1866 medical text recommends treating pneumonia with, among other things, castor oil, chloroform, ammonia, cold water brandy and the popular, although useless, opium." *Id.*

⁵⁰With disease-specific antibiotics, doctors began to treat the disease, rather than the patient. *Id.* The doctor no longer needed to have a continuing relationship with the patient or the patient's family. Since the focal point was the disease, not the person, a continuing relationship was not essential. DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE* 129 (1991).

⁵¹BURNELL, *supra* note 41, at 65.

⁵²*In re T.A.C.P.*, 609 So. 2d 588, 591 (Fla. 1992).

⁵³Murder at common law was the unlawful killing of another human being with malice aforethought. Intentionally shortening another person's life could constitute murder.

5. The Narrative of Death and Heroism

"One such vital truth that has long been known is the idea of *heroism* . . . [W]e like to be reminded that our central calling, our main task on this planet, is the heroic."⁵⁴

One concept that underlies the past and present death narrative is heroism.⁵⁵ Heroism provides meaning in life⁵⁶ and is central to the way society is constructed.⁵⁷ It appears to offer an explanation of the "good death."

Ernest Becker suggests that heroism is based in part on Freud's concept of narcissism, in which each human is hopelessly absorbed in his or her self. As Becker puts it, "[i]f we care about anyone it is usually ourselves first of all. As Aristotle somewhere put it: luck is when the guy next to you gets hit with the arrow."⁵⁸ Narcissism embodies the belief that the only necessary person to survive is oneself. "This narcissism is what keeps men marching into point-blank fire in wars: at heart one doesn't feel that *he* will die, he only feels sorry for the man next to him."⁵⁹ The selfishness of narcissism is neither Machiavellian nor deceptive. Instead, it is enmeshed with a person's feelings of self-worth.⁶⁰ This self-worth, in turn, is dependent on the desire for meaning in life.⁶¹

⁵⁴BECKER, *supra* note 26, at 1.

⁵⁵*Id.* at 1 - 8.

⁵⁶Becker reconciles the claim of heroism as the desire to create meaning or specialness on the earth. *Id.*

⁵⁷The urge to be a hero is crucial to social organization within society. Collective heroism is thus a societal organizing principle:

[T]he problem of heroics is the central one of human life, that goes deeper in human nature than anything else because it is based on organismic narcissism and on the child's need for self esteem as *the* condition for his life. Society itself is a codified hero system, which means that society everywhere is a living myth of the significance of human life, a defiant creation of meaning.

Id. at 7.

⁵⁸BECKER, *supra* note 26, at 2.

⁵⁹*Id.*

⁶⁰*Id.* at 3.

⁶¹The narcissistic desire to be a hero, to stand out, can be understood as the desire for meaning. Becker says:

Whatever is achieved must be achieved from within the subjective energies of creatures, without deadening, with the full exercise of passion, of vision, of pain, of fear, and of sorrow. How so we know - with Rilke - that our part of the meaning of the universe might not be a rhythm in sorrow? Manipulative, utopian science, by deadening human sensitivity, would also deprive men of the heroic in their urge to victory.

Heroism in modern Western society is intricately linked to advances in science and medicine. Society is hopeful that science, money, and goods make humans count for more than any other animal.⁶² Medical advances in particular indicate human-kind's heroic advances against the inexorable march of nature.

Yet medicine has contributed to a waning belief in the desire for traditional heroism.⁶³ The moral and pragmatic decay of society, particularly the erosion of civility, may in part be attributable to a diffusion of the heroic urge. Heroism had provided the glue that cemented the social fabric; it had offered unity of direction and purpose. Now, a new heroism has developed. Rather than welcoming death in heroic fashion, the new heroism is almost an anti-heroism, embodying a belief that death can be beaten or delayed.

6. The New Heroism - Defeating Death

The demise of the belief in the good death has prompted the adoption of a new form of heroism, one that involves beating death, not accepting it with dignity. As a result, medicine has become side-tracked.⁶⁴ As society strives for a health care system that works, it is distracted by the need to prolong and delay dying, which is in part fueled by our obsession with health and our fear of death. This obsession has two parts:

[o]ne moral, the other medical. The moral part is the belief that we have an unlimited obligation to combat death and lethal disease. That is essentially the mission of biomedical research, which, with enormous public support, conducts unrelenting wars against death. The medical part is the potent assumption that death is essentially an accident, correctable with enough money, will and scientific ingenuity: if smallpox could be conquered, then so can heart disease. If typhoid fever was eliminated, someday Alzheimer's disease will be beaten as well.⁶⁵

Id. at 284.

⁶²BECKER, *supra* note 26, at 1-8.

⁶³Becker suggests that the socially constituted society has lost the feeling that heroism really counts. This is particularly true for today's youth. Rather than heroes, the youth of society instead worship anti-heroes, people who shun the heroic urge. *Id.* at 5-8.

⁶⁴As one commentator has noted:

Today, that confusion between the realms of nature and choice continues to plague efforts to develop a sensible health-care system. Nowhere is it more evident than in our attitudes toward medicine and mortality. As a health-obsessed society, we do not know what to do with death, other than to try to control it. In all of the debate about health care, virtually no one has confronted this central problem: our determination to prolong life has distorted the mission of American medicine.

Daniel Callahan, *Our Fear Of Dying*, NEWSWEEK, Oct. 4, 1993, at 67.

Rather than constructing a dialogue of death, society hopes that death will be conquered through a massive research effort.⁶⁶ Instead of recognizing the futility of this mission, Americans choose to wage war against death.

The fight against aging shows up in many different ways in our society. From infomercials hawking return-to-youth products to antibiotics, transplants, chemotherapy, and the rise of cryogenics, considerable energy and passion is dedicated to avoiding death and its creeping, inexorable grip. Fighting it at all costs - never giving up - has become a rallying cry of the new heroism,⁶⁷ which, if nothing else, has served to obfuscate and distort the narrative of death.⁶⁸

B. The Miracles of Modern Medicine

Over the past several decades, advancements in modern medicine have modified the prevailing view of heroism, creating the hope that death can be denied and beaten in the foreseeable future. The progress in medical technology, from research discoveries to transplantation to the development of new techniques, has been nothing short of revolutionary. The discovery and dissemination of antibiotics, for example, has changed the way medicine is practiced,⁶⁹ as well as Americans' views of doctors.⁷⁰ Several of the more significant scientific advancements are discussed below.

Numerous discoveries have exponentially increased scientific knowledge about disease. As a result of these discoveries, drug and transplantation

⁶⁵*Id.*

⁶⁶One pulmonary physician has noted:

AIDS is going to bankrupt the world. The reason why is the concept of medical futility has been addressed. In the absence of a *terminal* condition, the presence of a *futile* condition still permits extreme and extensive medical measures. If you have AIDS and only have days to live, you can still insist on everything possible being done and it will be done.

Telephone Interview with Dr. Richard Reid, Baptist Memorial Hospital, in Jacksonville, Fla. (Feb. 11, 1994).

⁶⁷See, e.g., basketball coach Jim Valvano's last public speech before he succumbed to cancer, in which he stated, "Never give up."

⁶⁸IN HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER, surgeon Sherwin B. Nuland, attempts to "demythologize the process of dying." This demythologizing, however, misses the point. It is not that society needs to know the details of dying to better deal with it, but rather society must incorporate the dying process into the dialogue of the living. It is important for society to recast its image of death. Dr. Nuland's premise that people's curiosity about death will be satiated if they knew the reality of it just does not seem to be relevant to transforming the death narrative. See generally NULAND, *supra* note 6.

⁶⁹Dr. David Rothman, Professor of Social Medicine at the Center for the Study of Society and Medicine at Columbia University Medical School, has suggested that the increased use of penicillin led to a diminishment of personal service such as house calls. See ROTHMAN, *supra* note 50, at 131.

⁷⁰See, e.g., Adler, *supra* note 48, at 52.

techniques have been developed permitting medicine to extend human life.⁷¹ A medical advancement with a tremendous impact on longevity is antibiotics. There are now more than 100 varieties of antibiotics used to treat lethal diseases, such as bacterial meningitis and endocarditis, as well as other debilitating diseases, such as pneumococcal pneumonia, gonorrhea, malaria, and even strep throat.⁷²

Gene therapy, which involves identifying parts of the human genome⁷³ and using the information to correct, prevent, or manipulate genetic defects, is an area of scientific advancement with considerable potential for influencing longevity. "[O]nce perfected, [gene therapy] will enable doctors to 'fix' the genetics diseases . . .⁷⁴ Along similar lines, gene therapy is being used in combination with drug therapy to fight brain cancer.⁷⁵ This therapy may have an impact in treating other diseases as well, including muscular dystrophy, heart disease, hemophilia, and AIDS.

Organ transplantation is another area in which medical science has advanced dramatically. Once unknown, now more than 16,000 solid-organ transplants occur annually in the United States.⁷⁶ Ninety percent of those patients who receive an organ transplant survive for at least one year and fifty percent survive for more than five years.⁷⁷

Discoveries several decades old have become refined and an accepted part of the medical culture. Dialysis, for example, has become a widely used medical treatment.⁷⁸ Dialysis machines can be used in treating hereditary disorders,

⁷¹ See *infra* note 91 and text accompanying.

⁷² Recently, antibiotics have been used in the fight against cancer. Scientists have discovered "magic bullets," also known as monoclonal antibodies, which are like "biological guided missiles specially designed to zero in on cancer cells." Injected through chemotherapy, these "bullets" can fight cancer cells or even a tumor by enlisting the assistance of white blood cells. Bill Lawren, *Miracle Cures That May Save Your Life*, FAMILY CIRCLE, Feb. 1994, at 48. Additionally, certain kinds of bacteria-fighting antibiotics can slow the development of new cancer cells by preventing the growth of new blood vessels.

⁷³ The human genome comprises the approximately 100,000 genes located within human DNA. This gene system is accountable for much of the way humans are, including the susceptibility to and the occurrence of numerous diseases.

⁷⁴ Jeff Miller, *Gene Therapy: What It Is and How It Saves Lives*, GOODHOUSEKEEPING, June 1993, at 201. There is hope that gene therapy may be used to cure such diseases as cystic fibrosis and melanoma. *Id.*

⁷⁵ Lawren, *supra* note 72, at 48.

⁷⁶ John A. Robertson, *Spare Parts: Organ Replacements in American Society*, SCIENCE, Jan. 1, 1993, at 109 (book review).

⁷⁷ This technique is not without its costs. Transplants are expensive and go to a relatively small number of candidates while many others die waiting for a transplant. *Id.* at 110.

⁷⁸ Dialysis is most commonly known as a substitute for the human kidney because it fulfills the function of filtering toxins out of the blood.

high blood pressure, and diabetes. Today, about 170,000 Americans receive some form of dialysis treatment.⁷⁹

Scientific advances also have permitted the maintenance of life. Machines, such as ventilators, have the ability to sustain sapient life, even though a person has no noticeable cognitive functioning. Perhaps most telling about science's ability to delay death is that as of 1990, approximately 10,000 people in a persistent vegetative state were being kept alive in the United States by artificial means.⁸⁰

In the past several decades, advances in medicine not only extended life, but also permitted people to apparently retard the aging process as well. Surgeons cosmetically change people's appearances to maintain their youthfulness, drugs such as minoxidol permit the regeneration of hair to overcome baldness, the drug Retin A has been found to reduce wrinkle,⁸¹ and techniques such as liposuction provided instant weight loss.⁸²

C. The Adverse Consequences of Advancing Medical Technology

In reality, Nancy [Cruzan] lay in a bed, contorted with irreversible muscular and tendon damage, her hands bent so far over that her fingernails pressed into her wrists. She stared with unseeing eyes, oblivious to her environment, unable to drink or eat. She was fed through a tube in her side; another tube carried away waste. Her brain was atrophying, replaced by a pool of cerebrospinal fluid. Yet, experts indicated that she could have "lived" in this condition - if this could have been called "living" - for as long as 30 years.⁸³

The advances in modern medicine have had significant and far-reaching adverse consequences. While these consequences breach disciplinary lines, the epicenter of the tremors has been the narrative of death. Scientific advances, by affecting the nature and location of death and even its definition, have unrealistically expanded society's expectations relating to longevity. When

⁷⁹Susan Brink, *Dialysis By Numbers*, U.S. NEWS AND WORLD REP., Feb. 14, 1994, at 58.

⁸⁰*Id.*

⁸¹Perhaps one of the most startling attempts at retarding the aging process has occurred in Beverly Hills, California. There, plastic surgeon William Binder fights wrinkles by injecting botulinum toxin into facial muscles. Botulinum toxin is better known as the toxin that causes botulism. This technique is also catching on in other cities. Mary Roach, *Beauty Poison*, HEALTH, Jan. 1994, at 68-69.

⁸²The effort to avoid hair loss, for example, is an approximately two billion dollars a year industry. Theodore Berland, *Baldness "Cures:" Does Anything Really Work?*, CONSUMERS' DIGEST, July 1993, at 68. The motivation to spend this money lies in "feelings that baldness makes them look older and in physical and sexual decline. *Id.*

⁸³FRED H. CATE & BARBARA GILL, THE PATIENT SELF-DETERMINATION ACT: IMPLEMENTATION ISSUES AND OPPORTUNITIES 5 (1991).

combined with the removal of death from the personal realm, these expectations have served to solidify the narrative of avoidance.

1. The Promotion of Unrealistic Expectations⁸⁴

"Our society thinks that with enough time, researchers and computers, we can know everything."⁸⁵

a. Society's Expectations

"Every person has a secret desire to achieve immortality."⁸⁶

Within the past several decades, the concern with youthfulness and longevity has reached a "fever pitch unknown to previous generations."⁸⁷ Society's expectations are fueled by scientific discoveries such as antibiotics, growth hormones, and human gene therapy.

The preoccupation of society with immortality manifests itself in a myriad of ways. It includes surgery, special diets, and the resurgence of cryogenics, which involves freezing a body until such a time that a discovery for endless life would be possible. In the introduction to *The Prospect of Immortality*, the author stated: "Most of us now breathing have a good chance of physical life after death - a sober, scientific probability of revival and rejuvenation of our frozen bodies"⁸⁸ The book concluded with the following alluring assertion: "With your active co-operation, the next death in your family need not be permanent."⁸⁹

⁸⁴Cf. "[T]he principal task of civilization, its actual *raison d'être*, is to defend us against nature . . . [But] no one is under the illusion that nature has already been vanquished; and few dare hope that she will ever be entirely subjected to man." SIGMUND FREUD, *FUTURE OF AN ILLUSION* 11-12.

⁸⁵James D. Davis, *Life's Journey: An Un-Power Trip?*, FT. LAUDERDALE SUN-SENTINEL, Apr. 13, 1994, at E1.

⁸⁶Stephen Powelson, seventy-six years old, in response to inquiries as to why he memorized the 600 pages of Homer's *Illiad*. *Id.* at A-1.

⁸⁷NULAND, *supra* note 6, at 86.

[W]hy do we persist in heretofore-vain attempts to live beyond the possible? Why cannot we reconcile ourselves to the immutable pattern of nature? Although recent decades have seen our concern with our bodies and their longevity reach a fever pitch unknown to previous generations, these kinds of hopeful seekings have always motivated at least some members of those societies that have left records of their existence.

Id.

⁸⁸BOWKER, *supra* note 11, at 4.

⁸⁹*Id.*

The unrealistic expectations about the potential for extended life are promoted by many segments of society.⁹⁰ From advertisers to medical consumers, the desire for extended life is used as an alluring - and realistic - possibility. It is almost as if America is addicted to medicine - the more it gets, the more it craves.⁹¹ As one writer suggested, the desire for immortality may be the last bastion of omnipotence.⁹² These expectations are not necessarily medicine-specific and may be endemic of a more general malaise - a societal narcissism.⁹³

While hope of overcoming certain death from the hepatitis B virus has been created by several baboon-to-human liver transplants, the disappointing length and quality of life resulting from the transplant has arguably undermined its propriety.⁹⁴ Further, the belief that antibiotics would eradicate infectious disease has been illusory.⁹⁵ In 1992 alone, drug resistant strains of bacteria accounted for 13,300 hospital deaths.⁹⁶

In fact, the oversubscription of antibiotics by doctors has apparently propelled the growing number of drug-resistant strains of bacteria.⁹⁷ The more

⁹⁰According to Roy Porter, a medical historian, the problem with medical extensions of human longevity result from "the price of progress and its attendant unrealistic expectations." George F. Will, *Facing the Scope Beneath the Skin of Life*, NEWSWEEK, Mar. 7, 1994, at 74.

⁹¹"Medicine has become a prisoner of its success. As the Western World becomes healthier, it craves more medicine until . . . medicine's mandate becomes muddled. Medical maximization becomes a patient's right and a doctor's duty." *Id.*

⁹²"Wanting to live forever is the castle keep of the mind, its last domain of omnipotence. Strange, how all that is left of castles is their decayed battlements." K. BRADFORD BROWN, *SIGNS OF LIFE* 124 (1990).

⁹³Yet, alternatives exist. Dr. Leon Kass says that children are "life's answer to mortality, and their presence in one's home is a constant reminder that one no longer belongs to the frontier generation." Will, *supra* note 90, at 74.

⁹⁴The Chief of the Transplant Division at the University of Pittsburgh, where several such transplants have occurred, commented on the first one, saying, "We were on the border of success." R. Davis, *Ethics, Surgery Collide*, U.S.A. TODAY, Jan. 12, 1993, at 3A (quoting Dr. John Fung). The University is committed to such transplants because "[m]ore and more people are dying needlessly," according to hospital president Jeffrey Romoff. *Id.* Approximately 2,500 people die each year while waiting for an organ transplant. Of those, 500 or so are waiting for liver transplants. *Id.*

⁹⁵"Indeed, it looks like medicine declared victory and went home too soon. Every disease-causing bacterium now has versions that resist at least one of medicine's 100-plus antibiotics. Some resist all but one Drug-resistant tuberculosis now accounts for one in seven new cases" Sharon Begley, *The End of Antibiotics*, NEWSWEEK, Mar. 28, 1994, at 47.

⁹⁶*Id.* (based on information from the Centers for Disease Control and Prevention in Atlanta, Georgia).

⁹⁷"Antibiotic usage has stimulated evolutionary changes unparalleled in recorded biologic history." *Id.*

antibiotics are prescribed,⁹⁸ the opportunity for resistant strains to develop and spread increases.⁹⁹ Drug-resistant strains of bacterium breed and multiply in ingenious manners, sharing their resistance with unrelated microbes as well as passing it on to up to 16,777,220 "offspring" within one twenty-four hour period.¹⁰⁰ Far from being a panacea that removes disease from the human realm, scientific discoveries such as antibiotics often lull humans into false perceptions about the ability of science to deny or delay mortality.

The utilization of many of these scientific discoveries in one location, the hospital, has fueled unrealistic expectations. If a person returns from the hospital, survival is often attributed to the special treatment received there. If a person dies in the hospital, it is all too easy to believe that science was simply not strong enough this time in the war against disease - certainly not that the science did not delay (or even cause) the death that resulted.

Thus, expectations about longevity and aging have been consistently unmet. While science supported predictions of the elimination of infectious diseases in our lifetime,¹⁰¹ the emergence of AIDS and the proliferation of cancer, coupled with the growing number of drug-resistant strains of bacteria, have sadly proven those predictions wrong. As fast as scientists are discovering cures to existing diseases, new illnesses, strains of existing diseases, or resistances are occurring. The unrealized expectations, however, rather than disappearing, have simply become hardened and rigidified, as if the new heroism denying death will someday be proven correct. Thus, the vigil in believing that science can and will unlock the door to longevity in the near future remains.

⁹⁸Significantly, antibiotics are ingested as a result of more than just medical prescription. Animals are given numerous antibiotics, which are passed on in their meat and milk. While milk is permitted to carry traces of up to eighty antibiotics, compliance is questionable due to inadequate enforcement. The U.S. Food and Drug Administration sets limits on how much of the eighty antibiotics milk can contain, and insists that the less than 1% of milk that violates these limits is dumped. But a 1992 study by Congress' General Accounting Office found that states test for only four of the federally regulated antibiotics. The GAO's own tests discovered traces of sixty-four antibiotics at levels "that raise health concerns:" they could produce resistant germs in milk drinkers. In a recent study at Rutgers University, antibiotics at levels deemed safe by the FDA increased the rate at which resistant bacteria emerged by 600 to 2,700. *Id.* at 48-49.

⁹⁹The bacteria practice resisting the antibiotic until a mutation occurs and the antibiotic is neutralized. "The more widely you use these newer antibiotics, the greater the chances that [bacteria] will develop resistance," states Dr. David Kessler, Commissioner of the Food and Drug Administration. Dr. Frank Rhame, director of infection control at the University of Minnesota Hospital and Clinic, adds, "If I use an antibiotic too much, I'm making it less useful for everyone." Geoffrey Cowley, *Too Much of a Good Thing*, NEWSWEEK, Mar. 28, 1994, at 50.

¹⁰⁰Begley, *supra* note 95, at 48.

¹⁰¹Dr. Thomas Beam of the Buffalo, N.Y. VA Medical Center asserted, "The perception [in the 1980s] was that we had conquered almost every infectious disease." *Id.* at 47.

b. Medicine's Expectations

While unrealistic expectations about prolonged life have been created by society's refusal to direct its attention to its own mortality, the medical culture must also receive its share of the blame. As Senator John C. Danforth stated:

More and more it is arguable that [doctors] play God by subjecting people to unwanted and sometimes unnecessary treatment, treatment that unnaturally prolongs the dying process. Our health care system has become obsessed with extending life, at times neglecting the caring component of medicine and trampling on the rights of patients.¹⁰²

The doctor has become less a care-taker than a healer, a conqueror of disease. The ready access to antibiotics, for example, almost invited doctors to overprescribe such drugs¹⁰³ if those drugs prolonged life. According to Dr. Sheldon Nuland, a surgeon, medicine has been overwhelmed by its own hubris.

It has lost humility in the face of the inexorable and still superior power of nature. Instead, medicine still believes in the "fantasy of controlling nature."¹⁰⁴ This lack of humility is arguably one result of the arduous nature of medical training. The socialization of medical students, who work extremely long hours and face death on a regular basis, likely contributes to the loss of humility in the medical culture.¹⁰⁵ This loss, characterized by a corresponding overestimation of a doctor's power over life, fuels the increased expectations.

2. The Removal of Death From the Personal Realm

Rick was only 40, a nice, funny guy, a good husband, a dedicated lawyer, a father of a little boy who needs him. He didn't "choose death"; he wanted desperately to live, but a brain tumor was killing him and the doctors couldn't do a thing. He had only one choice: die in the hospital or die at home.¹⁰⁶

¹⁰²CATE & GILL, *supra* note 83, at 5 (quoting Senator John C. Danforth (R-Mo)).

¹⁰³Cowley, *supra* note 99, at 50. ("The misuse of antibiotics isn't a new problem. Since the 1970s, various studies have concluded that fifty to sixty percent of all outpatient prescriptions are inappropriate . . . Americans like quick fixes and when a doctor doesn't offer one, they look for a doctor who will.")

¹⁰⁴Will, *supra* note 90, at 74 (quoting Dr. Sherwin Nuland).

¹⁰⁵See, e.g., E. Rosenthal, *How Doctors Learn to Think They're Doctors*, N.Y. TIMES, Jan. 14, 1994, (Living Section), at 1. ("Doctors feel special because their experiences set them apart . . . Some doctors say the rigors of training actually squelched their humanity, by forcing them to operate in a high-stress atmosphere where compassion, patience and giving are not high priorities." *Id.* at 1, 5).

¹⁰⁶Anne Ricks Sumers, M.D., *I Want to Die at Home*, NEWSWEEK Apr. 4, 1994, at 14.

The modern death, as compared to the deaths of the 1800s which generally took place at home, in private, before one's loved ones, most often occurs in a hospital, hospice or nursing home. Out of the approximately two million people who die in the United States each year, 80% die in hospitals.¹⁰⁷ Of those who die in hospitals, 70% die after a decision has been made not to pursue life-sustaining treatment.¹⁰⁸

The role of the hospital in near-death treatment has been significant. It has contributed to a change in the location and style of death, from a personal and symbolic transition from life, to an impersonal, foreign, and often protracted failed rescue of an organism. No longer is death part of a cultural or familial ritual led by the dying person. No longer is there a regular ceremonial observance, celebrating the life of the honoree by family members and friends.¹⁰⁹ Instead, death has become a "technical" occurrence, something to be marked and observed after it has been duly recorded by the appropriate medical professional. In the hospital culture,¹¹⁰ death is public, more impersonal, and subject to numerous intrusions of privacy at any point in time.¹¹¹

The removal of death to the hospital has served to sustain the belief that death need not be a part of life in modern times. If it is neither seen nor heard from, and youthful appearances can be maintained by people in their fifties and sixties, then the denial of death may be readily inferred by those wishing to believe so.

Why the substitution of the hospital as a place to die? One dies in the hospital because the hospital has become the place to receive care which can no longer be given at home. Previously the hospital had been a shelter for the poor, for pilgrims; then it became a medical center where people were healed, where one struggled against death.¹¹²

¹⁰⁷Helene L. Lipton, 256 JAMA 1164, 1168 (1986). In 1949, only 50% of the deaths occurred in hospitals; in 1958 it was 61%, and in 1977 the figure was 70%. NULAND, *supra* note 6, at 255.

¹⁰⁸Lipton, *supra* note 107, at 1168.

¹⁰⁹Says Phillippe Aries:

Death in the hospital is no longer the occasion of a ritual ceremony, over which the dying person presides amidst his assembled relatives and friends. Death is a technical phenomenon obtained by a cessation of care, a cessation determined in a more or less avowed way by a decision of the doctor and the hospital team. Indeed, in the majority of cases, the dying person has already lost consciousness.

ARIES, *supra* note 3, at 89.

¹¹⁰The hospital culture has its own mission and objectives, sometimes superseding or clashing with the interests of the state and the patient's autonomy. The strength of the hospital culture even refracts existing legal rules and principles to adapt them to the hospital setting.

¹¹¹ARIES, *supra* note 3, at 89.

¹¹²*Id.*

The hospital, by default or design, has thus become the designated supervisor of death.¹¹³ Death in the hospital has created more than a simple change in location - it has fostered a shift in the locus of control over death decision-making as well. The institutional basis of the hospital decision-making process has served to streamline the patient's autonomy. In so doing, the hospital employees became "the masters of death - of the moment as well as of the circumstances of death."¹¹⁴

It is more than just irony, then, that the hospital environment, designed to heal diseased persons for their return to society, instead has come to provide an artificial and unfamiliar place where people go to die. The gleaming metal, futuristic equipment, and well-intentioned health care providers act as a double-edged sword - the patients are "separated from reality by the very biotechnology and professional standards that are meant to return people to a meaningful life."¹¹⁵

The hospital has served to recreate the death process in other respects as well. The transcendence of life to death as a logical progression of the state of nature has become a discordant interregnum of hospital machinery and technology. Hospital deaths are "too often tangled in webs of wires and tubes in intensive care units which are . . . the purest form of our society's denial of the naturalness, and even the necessity, of death!"¹¹⁶ The wires and tubes symbolize the artificiality of the hospital environment, but perhaps even more significantly, the fact that the patient no longer needs or is dependent on family and friends.¹¹⁷ In this last stage of life, humans are sustained completely by machinery.¹¹⁸

¹¹³*Id.*

¹¹⁴*Id.*

¹¹⁵NULAND, *supra* note 6, at 254.

¹¹⁶Will, *supra* note 90, at 74 (quoting Dr. Sherwin Nuland).

¹¹⁷As Franklin Delano Roosevelt once said:

Our civilization cannot endure unless we, as individuals, realize our personal responsibility to and dependence on the rest of the world. For it is literally true that the self-supporting man or woman has become as extinct as Stone Age man. Without the help of others, everyone of us would die, naked and starved.

J. Zentner, *Healing Springs*, SUN SENTINEL, Mar. 27, 1994, at J4.

¹¹⁸See, e.g., NULAND, *supra* note 6.

By and large, dying is a messy business . . . [a]nd even for those who do achieve a measure of serenity during separation, the period of days and weeks preceding the decline of full awareness is frequently glutted with mental suffering and physical distress. Too often, patients and their families cherish expectations that cannot be met, with the result that death is made all the more difficult by frustration and disappointment with the performance of the medical community that may be able to do no better - or, worse yet, does no better because it continues to fight long after death has become inevitable. In the anticipation that the great majority of people die

By gaining such control over the modern death process, and removing it from the realm of the personal, the hospital has profoundly affected society's death narrative. When death moved to the hospital, so did the "sights and smells that in the early nineteenth century were part of daily life, along with suffering and illness. The physiological effects have passed from daily life to the aseptic world of hygiene, medicine and morality."¹¹⁹ Passing away along with the physiological experience of death was its narrative, particularly that of the good death.

3. The Nature of Death

"Death keeps taking little bits of me."¹²⁰

In many ways, the nature of death for human beings has not changed over the millennium. The maximum life expectancy has not increased¹²¹ and there has been no solid evidence that a drug or elixir exists which will reverse the inevitable process of aging.¹²² Death still occurs in a common manner for all. Atherosclerosis, infections such as pneumonia, strokes and other diseases, in conjunction with the aging process, sap the body of life. As Dr. Milton Helpern, Chief Medical Examiner of New York City, stated, "Death may be due to a wide variety of diseases and disorders, but in every case the underlying physiological cause is a breakdown in the body's oxygen cycle."¹²³

Yet, for all that death remains the same, subtle but powerful changes in the nature of death have been evoked by scientific advances in recent decades. Because medicine has been able to prolong the last stages of life, sometimes for years, the motion picture version of death as one great cataclysmic event is less valid than at any point in history. Instead:

Death has been dissected, cut to bits by a series of little steps which finally makes it impossible to know which step was the real death, the one in which consciousness was lost, or the one in which breathing stopped. All these little silent deaths have replaced and erased the great dramatic act of death, and no one any longer has the strength or

peacefully in any event, treatment decisions are sometimes made near the end of life that propel a dying person willy-nilly into a series of worsening miseries from which there is no extrication . . .

Id. 142-143.

¹¹⁹*Id.* at 255 (quoting Aries).

¹²⁰*Id.* at 67 (quoting an elderly patient of Chicago physician Walter Alvarez, after suffering a series of small strokes).

¹²¹NULAND, *supra* note 6, at 85.

¹²²*Id.* at 86.

¹²³*Id.* at 67 (quoting Dr. Milton Helpern).

patience to wait over a period of weeks or a moment which has lost a part of its meaning.¹²⁴

A striking example of the confrontation between mortality and a protracted dying process supported by modern medicine involves the disease AIDS. The lives of those suffering from AIDS can be extended temporarily, and the quality of life apparently improved incrementally through the administration of a variety of drugs and treatment modalities.¹²⁵ Yet, this disease confronts persons with a choice in the nature and circumstances of death, and of the narrative to be used about that death. The current treatment of AIDS is ill-equipped to dispose of questions about the value of life in a diminished form.

The nature of death is also greatly affected by the cost of health care. New medical technology is often expensive, and the demand for it outstrips the supply.¹²⁶ For many people, the medical technology that could save or improve their lives exists, but is simply not affordable. This is most obvious in areas such as organ transplants, dialysis, and expensive tests, such as magnetic resonance imaging, or other treatments.¹²⁷ The concept of health care rationing, far from being a hypothetical subject of academic discourse, has become a guiding factor in the decision-making of health care institutions as well as practicing physicians.

The removal of death to the hospital, with ready access to technology, has impacted on the nature of death as well. The hospital death has allowed the concentration of resources to prolong the dying process, has permitted the hospital to control the appearance of the patient in his or her last hours, and has provided the hospital with greater authority over the timing of death. The hospital death has, in short, complicated the dying process:

Once short, incurable diseases are now protracted terminal illnesses fraught with ethical, legal, spiritual, medical, and economic decisions. The dying patient often ends up bound in soft restraints and gagged by the endotracheal tube, lying mute in limbo, while medical and legal options clash by twilight over his bed.¹²⁸

¹²⁴ARIES, *supra* note 3, at 88-89.

¹²⁵Currently, the treatment of this disease includes the use of drugs such as AZT and ddI. Although these drugs do not cure the disease, they do retard the rate at which the virus spreads. Various drugs such as rifabutin and pyrimethamine are used to treat the side effects of AIDS that can include lung ailments which mimic tuberculosis and meningitis.

¹²⁶Many people die waiting for an organ transplant, for example, and many others do not have access to health care that can detect or treat disease in an early stage.

¹²⁷The average cost of a liver transplant, for example, is between \$175,000 and \$225,000. Davis, *supra* note 94, at 3A.

¹²⁸Richard P. Dooling, *Damage Actions for Non-Consensual Life Sustaining Medical Treatment*, 30 ST. LOUIS L.J. 895, 896 (1986).

These changes have contributed to the paradox of the nature of the modern death - while death is to be avoided in modern society, it has become a more protracted and larger part of the life cycle. The paradox is reinforced by the extension of the death process as there is more time to contemplate the prospect of death. The process has become more surreal, particularly for the majority of Americans who die in hospitals. These persons are "likely to meet their end . . . in a sedated or comatose state; betubed nasally, abdominally and intravenously; and far more like manipulated objects than like moral subjects."¹²⁹

III. THE LEGAL APPARATUS

The law's response to advances in life-sustaining technology has developed along two fronts: reexamining the legal conception of death and setting up a framework where patients and the medical culture can negotiate a satisfactory course of treatment regarding the provision of life-sustaining measures.

A. *Defining and Redefining Death: The Blurring of the Bright Line*

"If technology has blurred the traditional distinction between a man alive and a man dead, then there is an urgent and pressing reason to restore clarity." David Lamb, *Death, Brain Death, and Ethics*.

The fallout from medical progress in extending life has reached legal death-related epistemology.¹³⁰ The numerous instances of persons residing in or near a persistent vegetative state has created "a vast gray area between traditional notions of life and death."¹³¹

Historically, there was no significant debate about the definition of death, since the two major systems responsible for life, the cardiac and respiratory systems, would cause the body to fail if they themselves failed. That is, when the heart and lungs failed, the whole organism seemed to die at once. The difficulty began to arise with the creation of artificial support systems for the heart and lungs. When that occurred, the death of the human being became more fragmented, and much more difficult to define.

1. Traditional Definitions of Death

Black's Law Dictionary defines death as "the cessation of life; permanent cessation of all vital functions and signs the ceasing to exist; defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital function consequent thereupon, such as respiration,

¹²⁹CATE & GILL, *supra* note 83, at 6.

¹³⁰"Contrary to the President's Commission, human death is hardly the 'one great certainty.'" KAREN G. GERVAIS, *REDEFINING DEATH* 216 (1986).

¹³¹Dooling, *supra* note 128, at 896.

pulsation,"¹³² The dictionary definition focuses on the cardiac function, while other definitions differ.¹³³ One of the most widely used definitions of death is from the 1968 Report of the Ad Hoc Committee of the Harvard Medical School designated to examine the definition of brain death.¹³⁴ The *Harvard Criteria* defined death based on various characteristics of a person in an irreversible coma, meaning a person who has a permanently non-functioning brain.¹³⁵ Several or all of the *Criteria's* characteristics may exist, however, with reversible brain losses caused by such things as drug intoxication and hypothermia.¹³⁶ Doctors must rule out these distinguishable causes before pronouncing death.

2. Redefining Death

In the face of a protracted dying process caused by advancements in medical technology and greater ambiguity as to when life precisely ends, many commentators have argued for a change in the legal definition of death. The costs of perpetuating ambiguity on a societal and personal level are simply too great:

[d]eath has become a great uncertainty for us, at both the conceptual and public policy levels. Some uncertainties are tolerable; others are not. Since dying and death are sources of the deepest, most intractable anguish humans can suffer, uncertainty here is morally intolerable, for it promises only to compound that anguish, not diminish it.¹³⁷

The uncertainty associated with the modern death is compounded by the lack of sufficient rhetoric to describe the death process. "The technology of

¹³²BLACK'S LAW DICTIONARY 400 (6th ed. 1990).

¹³³For one commentator, death requires three separate conditions: "Death is irreversible cessation of *all* of the following: (1) total cerebral function, (2) spontaneous function of the respiratory system, and (3) spontaneous function of the circulatory system." GERVAIS, *supra* note 130, at 26 (quoting Halley & Harvey).

¹³⁴*Id.* at 6.

¹³⁵These characteristics include:

1. Total unresponsiveness and unreactivity. This means that the person is totally unaware of her or his surroundings and does not respond to painful stimuli.
 2. No movements of spontaneous breathing for three minutes while off the respirator, which means that all spontaneous movements, spontaneous respiration, and responses to pain, touch, sound and light have ceased.
 3. No reflexes. Pupils will not dilate; eyes will not turn when the head is turned; and tendon flexes no longer exist.
 4. Flat e.e.g. (electro encephalogram) for at least ten minutes and no evidence of any electrical activity in the brain.
 5. No change in the results of the test repeated at least 24-hours later.
- BURNELL, *supra* note 41, at 69.

¹³⁶*Id.*

¹³⁷GERVAIS, *supra* note 130, at 216.

life-support systems is so new, that little clear and subtle language exists concerning life-prolonging procedures and their application."¹³⁸

Alternative standards attempt to create more predictability and stability in the occurrence of death. Standards such as the permanent loss of consciousness have been proposed.¹³⁹ This standard, for example, intends to treat the human as "person" and not simply as an "organism".¹⁴⁰ Yet, why is consciousness the standard? Is not an unconscious person clearly alive? Is there really finality associated with an "irreversible" loss of consciousness? The difficulties illustrated by this proposed alternative standard of death involve which set of criteria are to shape and define the definition - those that are biological, those that are moral, those that are ontological or those that are metaphysical?¹⁴¹

Many other inquiries and proposals have been advanced. According to Robert S. Morison, for example, the conceptualization of death is widely mis-

¹³⁸Note, *The Living Will: Preservation of the Right-to-Die Demands Clarity and Consistency*, 95 DICK. L. REV. 209, 215 (Fall 1990).

¹³⁹States one commentator:

The brain-death criterion commits us to a redefinition of our concept of human death, a redefinition that involves a shift of perspective from the human as organism to the human as person. We ought to be concerned about the death of the person in declaring death. I have developed an ontological argument in the form of a conservative mentalist personal identity theory showing that personal existence ceases with the permanent cessation of consciousness. Since the persistence of consciousness must be considered the *sine qua non* of human personal life, the brain-death criterion, as well as the neo-cortical-death criterion or any criterion whose fulfillment is conclusively associated with persistent vegetative existence, is justified.

GERVAIS, *supra* note 130, at 215-216.

¹⁴⁰*Id.*

¹⁴¹Various commentators have used this question to pose additional inquiries:

[T]he death of a person does not coincide with the cessation of all biological activity in the organism, or "biological death," even in the case of the traditional criteria; and . . . the use of any criterion for declaring death rests on a decision of significance, that is, a decision concerning the features that humans must possess to be regarded as living persons rather than dead persons. Since the death of a person does not coincide with biological death, how is the death of a person to be conceptualized - as a biological event, or as a metaphysical and moral one? Should the death of a human being be construed as a biological event, subject to biological inquiry into the permanent change in the status of the organism? Or should it be considered an essentially non-organismic event in the life of a person, so that personal death will be irreversible loss of those features we take to be necessary for personal existence?

Id. at 5-6.

used.¹⁴² Morison suggests that death is not so much as a single, solitary event, but a continuous process of "growth and decay."¹⁴³ In essence, once a life is created, it is in the process of dying.

The protraction of the dying process has prompted suggestions for a more radical reformation of the definition of death.¹⁴⁴ These revisions are predicated on the belief that a human life is characterized by a continuing personality and intellectual function:

At the heart of that debate is the philosophical and psychological issue of whether we remain the same person, legally and morally, throughout our earthly existence, or whether there are psychological and intellectual transformations of such magnitude and import that when they take place, it legitimately can be concluded that the former person has ceased to exist and a new person has come into being.¹⁴⁵

The leading proponent of this modified definition of death is philosopher Derek Parfit.¹⁴⁶ According to Parfit, there is effectively no unitary, continuous, and identifiable self-persisting during the entirety of a person's life. The discontinuity occurs when a threshold level of psychological continuity ceases to exist.¹⁴⁷ A person in a persistent vegetative state is not experiencing joy, satisfaction, love, or pleasure - these are permanently absent. Therefore, the organism's "life" is without benefit.¹⁴⁸

¹⁴²Morison calls it a "fallacy of misplaced concreteness . . ." (i.e., regarding or using an abstraction as if it were a thing). Robert S. Morison, *Death: Process or Event?* 173 SCIENCE 694 (1971).

¹⁴³Morison adds that a particularly frequent hazard is the:
[U]se of abstractions to introduce artificial discontinuities into what are essentially continuous processes Clearly we are dealing here with a continuous process of growth and decay. There is no magic moment at which "everything" disappears. Death is no more a single, clearly delimited, momentary phenomenon than is infancy, adolescence, or middle age.
Id. at 694-695.

¹⁴⁴[S]ince each of us has a particular personal identity consisting in a particular set of psychological traits, the assertion, "Patient Jones is still alive" implies both that "the patient is alive" and that "the patient is [remains] Jones." In other words, the patient retains that set of psychological traits we have always associated with Jones The circumstances in which the patient is alive, yet Jones is dead, is an uncomfortable one.
GERVAIS, *supra* note 130, at 113.

¹⁴⁵Ben A. Rich, *The Values History: A New Standard of Care*, 40 EMORY L. J. 1109, 1122-23 (1991).

¹⁴⁶*See, e.g.,* DEREK PARFIT, REASONS AND PERSONS (1984).

¹⁴⁷*Id.* at 205-06, 223-26.

¹⁴⁸Rebecca Dressler, *Relitigating Life and Death*, 51 OHIO ST. L.J. 425, 428-30 (1990).

If Parfit's analysis is followed, when a person's psychological continuity courses below a certain threshold level, a new personal identity exists, permitting differential treatment of that individual. This analysis has great implications for the legal and ethical approach to death. It permits a person in a persistent vegetative state, whose personality is permanently destroyed, to be declared legally dead.¹⁴⁹ This approach provides a philosophical basis for declaring death for a person in a persistent vegetative state. It supplements a growing unease about where to draw the line in declaring death.¹⁵⁰ Depending on the laws of the jurisdiction, it also permits an inference that the person does not wish to continue in such a state.¹⁵¹ In essence, those advocating such a neocortical standard of death are effectively arguing that a more "direct and intellectually honest approach to terminating treatment of such patients may be to define them as dead."¹⁵²

Parfit's modified definition of death has its own attendant problems, including questions relating to the measurement of neocortical death - how certain is such a standard and is it really an improvement,¹⁵³ the fluctuation in

¹⁴⁹This uncertainty is anathema to the orderly progression from life into death, even raising the specter of undignified death.

¹⁵⁰As one commentator noted:

Once neocortical death has been unequivocally established and the possibility of any recovery of consciousness and intellectual activity thereby excluded, the question must be asked, although the patient breathes spontaneously, is he or she alive? . . . In essence, it seems that a person who resumes spontaneous respiration after cardiac arrest, yet exhibits an isoelectric EEG, is to be regarded as "alive" while another surviving the same accident, also with an isoelectric EEG but whose cardiac function depends upon mechanical ventilation, may be regarded as "dead." Clearly this distinction between "alive" and "dead" attaches cardinal importance to the function of respiration and none to those higher functions of the nervous system that demarcate man from the lower primates and all other vertebrates and invertebrates.

GERVAIS, *supra* note 130, at 13 (quoting Brierley, et al).

¹⁵¹If the exact point of death can not be clearly fixed, should the patient's intent play a greater role in the determination? A significant question in the corollary epistemology of patient autonomy arises. In accord with the patient's right to self determination, is a subjective test appropriate? Many courts have considered a wide variety of evidence in determining the subjective intent of the patient. Jill Hollander, Note, *Health Care Proxies: New York's Attempt to Resolve the Right to Die Dilemma*, 57 BROOK. L. REV. 145, 151 at n.29 (Spring 1991).

One commentator suggests that the use of a wide variety of evidence undercuts the subjective nature of the test and becomes more closely aligned to an objective analysis. "[T]he point is that even someone critical of an objective standard is in the end unavoidably drawn to it." Dressler, *supra* note 148, at 429.

¹⁵²Shapiro, *supra* note 15, at 448.

¹⁵³One commentator framed the debate as follows:

In order to support [the contention that the persistent vegetative state is sufficient grounds for the pronouncement of death], there must be unequivocal certainty, substantiated by medical data and

the standard that may arise as medical discoveries occur, and the ethical issues that relate to labeling a breathing human being as functionally dead.¹⁵⁴

It is clear, however, that a predictable and uniform definition of death is a necessary condition precedent for the legal apparatus to adequately deal with the death-related decision-making process.¹⁵⁵ Otherwise, the legal process will remain handicapped and ineffective.

B. The Constitution and Common Law Response

Advance directives permitting patients to direct health care decision-making are often predicated on various constitutional and common law rights. These include a constitutional right to refuse treatment, common law rights in tort, such as battery and negligence actions, and an emerging theory called "wrongful life."

1. The Constitutional Right to Refuse Medical Treatment

The seminal case, *Cruzan v. Director, Missouri Department of Health*¹⁵⁶ established a due process right to refuse medical treatment by a person in a persistent vegetative state. While this 1990 Supreme Court decision was essentially a case of first impression for the Court, it was preceded by several important lower court decisions.¹⁵⁷

experience, empirically verifiable, and supported by autopsy studies confirming the clinical analysis (as currently exists, we believe, for the total brain death concept), that is no functioning of the cerebral cortex. Merely a severe degree of disfunctioning is insufficient evidence for pronouncing death. From a medical standpoint, such a case may be established for a variant of the persistent vegetative state, viz. "neocortical death."

GERVAIS, *supra* note 130, at 12-13.

¹⁵⁴There appear to be three chief schools in the debate:

those who think that the decision about what constitutes the death of the person is biological in nature, and therefore requires a biological argument in its support; those who consider that we are in realm of the moral, so that our concern is not so much with what features constitute the death of the person as with the determination of the circumstances under which a person ought to be declared dead; and those who take the problem to be ontological or metaphysical in nature, and hence to require the articulation of an adequate theory of personal identity in its defense.

Id. at 15-16.

¹⁵⁵The "medical and legal professions must strive to provide precise and consistent terminology so that society can enjoy the benefits of living wills and guard against the possibility of an undignified death." Note, *The Living Will: Preservation of the Right-to-Die Demands Clarity and Consistency*, *supra*, note 138, at 215.

¹⁵⁶110 S. Ct. 2841 (1990).

¹⁵⁷*See, e.g., Cruzan*, 110 S. Ct. at 2887-88 n.21 (Stevens, J., dissenting) (collecting a list of cases in which the removal of sustaining treatment was allowed); *see also* *Clay v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988); *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987)

a. Quinlan

Perhaps the most significant antecedent was *In re Quinlan*,¹⁵⁸ decided by the New Jersey Supreme Court. The case involved Karen Ann Quinlan, a comatose young woman in a persistent vegetative state. Ms. Quinlan was being kept alive on a respirator. Her parents petitioned the courts of New Jersey to have the respirator removed. The New Jersey Supreme Court held that a right to privacy existed that included the right to refuse life-sustaining medical treatment. This right was not absolute, however. It had to be balanced against the state's interest in preserving life. Upon balancing the interests, the court granted the parents' request to turn Karen's respirator off.¹⁵⁹

b. Cruzan

On January 11, 1983, a young woman named Nancy Beth Cruzan, then twenty five years old, lost control of her car in Jasper County, Missouri. The car overturned and Ms. Cruzan was seriously injured. She soon lapsed into a coma and persistent vegetative state. Consequently, she was implanted with feeding and hydration tubes. With virtually no chance of recovering her cognitive abilities, her parents, acting as her co-guardians, sought to remove the artificial feeding and hydration tubes, leading inevitably to her death. The hospital refused to disconnect the tubes without a court order. Thus began an odyssey in the legal system ending with the United States Supreme Court.¹⁶⁰

The Court considered whether Ms. Cruzan had a constitutional right to require the hospital to withdraw life-sustaining treatment. The Supreme Court carved out broad rules and principles regarding the constitutional protections involving a person's right to refuse or withdraw from life-sustaining measures.

The Court held that there was a constitutional right, protected by the term "liberty" within the due process clause, for a competent person to refuse life-saving measures, including hydration and nutrition.¹⁶¹ The Supreme Court went further than some other courts' decisions, whose outcomes were based solely on common law informed consent principles. Yet, the Court never explained why it chose the particular locus of the constitutional due process right in the word "liberty," or why it found that the right extended to those

(en banc); *In re Gardner*, 534 A.2d 947 (Me. 1987); *In re Jobes*, 529 A.2d 434 (N.J. 1987); *Brophy v. New England Sinai Hosp., Inc.*, 497 N.E.2d 626 (Mass. 1986); *In re Quinlan*, 355 A.2d 647 (N.J.), *cert. denied, sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976), *overruled in part, In re Conroy*, 486 A.2d 1209 (N.J. 1985).

¹⁵⁸355 A.2d 647 (N.J. 1976).

¹⁵⁹*Quinlan*, 355 A.2d at 663-64, 671-72.

¹⁶⁰*Cruzan*, 110 S. Ct. at 2845-46.

¹⁶¹Ms. Cruzan's father stated after the decision that "Because of Nancy, I suspect hundreds of thousands of people can rest free, knowing that when death beckons they can meet it face to face with dignity, free from the fear of unwanted and useless medical treatment." CATE & GILL, *supra* note 83, at 6.

persons who were incompetent to make such a decision. The Court insisted on restricting the legal analysis to the meaning of liberty in the 14th Amendment, refusing to extend it to the right to privacy.¹⁶²

Instead, the Supreme Court recognized that significant competing interests existed. Because the Court concluded that the choice between life and death was "a deeply personal decision of obvious and overwhelming finality,"¹⁶³ the Court also held that a state can constitutionally require a showing of clear and convincing evidence "to safeguard the personal element of this choice."¹⁶⁴ The Court did not clarify, however, the precise nature of evidence that would satisfy such a standard. Specifically, the Court did not opine whether oral testimony would be sufficient or whether a written statement of intent could be challenged as deficient. Chief Justice Rehnquist, writing for the Court, noted that "the Due Process Clause protects an interest in life as well as refusing life sustaining treatment."¹⁶⁵

2. The Scope of the Right to Refuse Treatment

While it is well established that a right to refuse medical treatment exists, it is far less certain whether the right includes a refusal of nutrition and hydration. In *Corbett v. D'Alessandro*,¹⁶⁶ for example, the court concluded that the right to

¹⁶²The Court stated: "Although many state courts have held that a right to refuse treatment is encompassed by a generalized constitutional right of privacy, we have never so held. We believe this issue is more properly analyzed in terms of a 14th amendment liberty interest." *Cruzan*, 110 S. Ct. at 2851 n.7. Justice Sandra Day O'Connor, concurring, stated that: "Because our notions of liberty are inextricably entwined with our idea of physical freedom and self-determination, the Court has often deemed state incursions into the body repugnant to the interests protected by the Due Process Clause." *Id.* at 2856 (O'Connor, J., concurring).

Significantly, had the Court held that the locus of the right to refuse medical treatment was privacy, then it likely would not have permitted the state to impose a restriction on such a right by requiring clear and convincing evidence of the patient's wishes.

¹⁶³*Cruzan*, 110 S. Ct at 2852.

¹⁶⁴*Id.* at 2853.

¹⁶⁵This does not mean, however, that a state must impose a clear and convincing evidence standard; a lesser standard would be permissible. One major problem with the *Cruzan* decision was not that it recognized the right to die, but that it placed the right squarely within the liberty interest of the Due Process Clause of the 14th Amendment. According to one commentator:

The problem with identifying his right as a liberty rather than a privacy interest is that incompetent patients who now have clear and convincing directives called competent are more likely to have their treatment determined by physicians and judges because their autonomy - an essential aspect of their exercise of liberty - cannot survive incompetence.

Rich, *supra* note 145, at 1110.

¹⁶⁶487 So. 2d 368 (Fla. Dist. Ct. App. 1986).

refuse treatment included the withdrawal of nutrition and hydration.¹⁶⁷ The case involved a seventy-five year old comatose woman being kept alive on a nasogastric feeding tube. Her husband petitioned the court to remove the tube. The court concluded that the right to have the tube removed was "a constitutionally protected right that existed under the circumstances."¹⁶⁸ Significantly, the court did not differentiate between a nasogastric feeding tube and other artificial life sustaining measures.¹⁶⁹

In *Brophey v. New England Sinai Hosp., Inc.*,¹⁷⁰ the court concluded that nutrition was part of the medical treatment that could be permissibly withdrawn from a patient. Mr. Brophy lay in a persistent vegetative state following a massive aneurysm. His wife petitioned the court to have the gastrostomy tube providing his nutrition and hydration removed. The trial court had concluded that the patient had a right to refuse treatment. It added, however, that the hospital and physician also had a right to refuse to comply with a request to remove the tube and consequently decided for the hospital. On appeal, the Supreme Judicial Court of Massachusetts recognized the hospital and physician's right to refuse to comply with the request, but held that Mr. Brophy should be transferred to a hospital where physicians would honor the patient's request.¹⁷¹

a. Tort

In addition to the Constitution, tort law has protected a patient's autonomy in making health care decisions.¹⁷² The common law right of self-determination, or more specifically, autonomous control over one's body, was not initially Constitutionally grounded, but rather was based on the laws of trespass and battery. As Judge Cardozo stated:

¹⁶⁷*Id.* at 370-72. The Florida statute at that time permitted the withdrawal of life prolonging procedures even though Mrs. Corbett did not have a living will or health care advance directive so long as a consultation with a physician occurred and there was a written agreement with various individuals, including the patient's spouse. FLA. STAT. ANN. § 765.07.

The court held that Florida's living will statute, section 765.03(3)(b), permitted the withdrawal of both feeding and hydration, reversing the trial court's decision. *Corbett*, 487 So. 2d at 370-72.

¹⁶⁸*Corbett*, 487 So. 2d at 372.

¹⁶⁹*Id.* The court could have viewed the provision of sustenance as different than other artificial life-sustaining medical treatment.

¹⁷⁰497 N.E.2d 626 (Mass. 1986).

¹⁷¹*Id.* at 639.

¹⁷²In *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977), the court observed that the state's interest in saving human life where the infliction is curable is greater than the state's interest when the issue is not whether life can be extended, but how long and at what cost to the individual. *Id.* at 425-26.

Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.¹⁷³

Based on this analysis, the provision of medical treatment generally required the informed consent of the patient. To ensure informed consent, a patient must have adequate information to make a decision. To facilitate the free flow of information, several courts placed a fiduciary duty on medical staff to disclose information to the patient. This informational interest is considered essential to a patient's decision-making process. If it is violated, an action in fraud may arise.

In *Estate of Leach v. Schapiro*,¹⁷⁴ for example, the claimant alleged that the patient had been placed on life support without consent. The Ohio Court of Appeals found that a physician had an obligation "to fully inform the patient of his condition and to obtain the patient's informed consent to the medical treatment."¹⁷⁵ Observed the court:

Because the importance of adequate disclosure increases as the patient is placed at a greater informational disadvantage, we join those courts holding that a physician's non-disclosure may give rise to an action in fraud independent of malpractice . . . [W]e also conclude that when a patient becomes incompetent the physician's fiduciary obligations of full disclosure flow to the person acting in the patient's behalf.¹⁷⁶

The court's mandate of disclosure goes beyond what was required in *Miranda v. Arizona*.¹⁷⁷ The court's requirement demands affirmative information, as opposed to warnings, in order for a patient to intelligently determine his or her care.

b. Interference with the Right to Die

Some courts have found that non-consensual medical treatment may satisfy the requirements of a tort labeled "wrongful life."¹⁷⁸ This tort essentially involves interference with the right to die. Commentators and courts alike have

¹⁷³*Schloendorff v. Society of New York Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

¹⁷⁴469 N.E.2d 1047 (Ohio Ct. App. 1984).

¹⁷⁵*Id.* at 1052.

¹⁷⁶*Id.* at 1054.

¹⁷⁷What the court has prescribed is functionally equivalent to the warnings demanded by the Court in *Miranda v. Arizona*, 384 U.S. 436 (1966).

¹⁷⁸*See, e.g., Rich, supra* note 145, at 1161; *Dooling, supra* note 128, at 896; A. Samuel Oddi, *The Tort of Interference with the Right to Die: The Wrongful Living Cause of Action*, 75 GEO. L.J. 625 (1986); *see also, e.g., Anderson v. Saint Francis/St. George Hosp.*, 614 N.E.2d 841 (Ohio Ct. App. 1992).

reasoned that autonomy over one's body extends to unwanted life-sustaining treatment.¹⁷⁹

For example, in *Anderson v. Saint Francis/St. George Hosp.*,¹⁸⁰ a nurse resuscitated the patient even though directions had been left to the contrary. The court concluded that while there must be some legally recognized harm to recover actual damages, nominal damages may result if a person's life had been extended by this violation.¹⁸¹ In a different case, *Estate of Leach v. Shapiro*,¹⁸² the court found that a cause of action existed for wrongfully placing and maintaining a patient on a life support system contrary to her and her family's expressed wishes and desires.¹⁸³

c. Payment Issues

Litigation has arisen over who will pay for continuing treatment when it is not desired. In *Grace Plaza of Great Neck v. Elbaum*,¹⁸⁴ a husband sued a nursing home for continuing to keep his wife on a life support system. The husband refused to pay the medical bills attendant to his wife's treatment. He claimed that in his surrogate capacity, treatment should have been stopped when he requested it. The court held for the nursing home. It was not liable for continuing life-saving medical treatment to a comatose patient over the objection of the patient's conservator when there was no evidence of an intent to discontinue treatment.¹⁸⁵

3. Building on the Constitutional and Common Law Framework: Advance Directives

Although courts have laid the foundation for autonomous patient decision-making by recognizing a right to refuse medical treatment and

¹⁷⁹For example, "[o]nce it has been established that a person has the right to die, medical personnel who might otherwise be under a duty to act on behalf of that person are not only relieved of that duty but also restrained by a diametrically opposite duty not to interfere with that person's right to die." Oddi, *supra* note 178, at 637.

¹⁸⁰614 N.E.2d 841 (Ohio Ct. App. 1992).

¹⁸¹*Id.* at 846. The court recognized that non-consensual medical treatment may constitute a battery.

¹⁸²469 N.E.2d 1047 (Ohio Ct. App. 1984).

¹⁸³The court stated:

While the patient's right to refuse treatment is qualified because it may be overcome by competing state interests, we believe that, absent legislature to the contrary, the patient's right to refuse treatment is absolute We perceive this right as a logical extension of the consent requirement and conclude that a patient may recover for a battery if his refusal is ignored.

Id. at 1051-52.

¹⁸⁴588 N.Y.2d 852 (N.Y. App. Div. 1992).

¹⁸⁵*Id.*

corollary interests, cases such as *Cruzan* did not resolve the dilemmas created by a protracted hospital dying process. In light of the growing uncertainty of rights and obligations involving death-related treatment decisions, and the increasing problem of incompetent patients being artificially kept alive with virtually no realistic prognosis for recovery, many states and the federal government have passed responsive legislation called advance directives. These measures permit patients to direct health care decisions in advance of becoming incompetent.¹⁸⁶

The primary forms of advance directives are living wills and health care surrogates. A living will is a writing that directs health care decisions, including palliative care, under specific circumstances.¹⁸⁷ A durable health care power of attorney, (i.e. a health care proxy or surrogate), is a more expansive measure, one that authorizes another person to make health care decisions for the principal.¹⁸⁸ The durable health care power of attorney operates when patients become incompetent.¹⁸⁹ These devices allow individuals to maintain control over the treatment provided at the end of their life.

Today, all fifty states¹⁹⁰ permit some form of advance directives by case law or statute. Congress also has enacted a general law in the area, the 1991 Patient

¹⁸⁶The controlling statutes do not permit, however, active euthanasia, meaning an act that terminates or shortens life. Such euthanasia questions have also reached the courts, most notably in the case of Dr. Jack Kervorkian, who has engaged in a variety of highly publicized physician-assisted suicides. Euthanasia, however, is not the subject of this paper.

¹⁸⁷A living will, for example, is described as "a written declaration . . . stating a declarant's desire for medical care or non-care, including palliative care, and other related matters such as organ donation and body disposal." TENN. CODE ANN. § 32-11-103(4) (1995).

¹⁸⁸For example, this instrument "authorizes an attorney in fact to make health care decisions for the principal." IDAHO CODE § 39-4503(4) (1993).

¹⁸⁹For example, one state defines the proxy as "a person eighteen (18) years old or older appointed by the patient as attorney-in-fact to make health care decisions including the withholding or withdrawing of life-sustaining treatment if a qualified patient, in the opinion of the attending physician, is permanently unconscious, incompetent, or otherwise mentally or physically incapable of communication." ARK. CODE ANN. § 20-17-201(10) (Michie 1993).

¹⁹⁰For example, North Dakota has adopted the Uniform Rights of the Terminally Ill Act, based on the legislative intent that every competent adult has a right to control decisions relating to the adult's own medical care. N.D. CENT. CODE § 23-06.4-01 (1993).

California has adopted The Natural Death Act, which provides that "an adult person has the fundamental right to control the decisions relating to the rendering of his or her own medical care, including the decision to have life-sustaining treatment withheld or withdrawn". CAL. HEALTH AND SAFETY CODE § 7185.5(A) (1993).

Self Determination Act.¹⁹¹ According to one of the bill's sponsors,¹⁹² the Act supplies "people with information so that they can decide their own fate"¹⁹³ The purpose of the federal law is similar to the purpose of the various state laws. This law co-exists with, but does not supersede, those state laws.

Questions have been raised about the value of advance directives. These inquiries were posed almost as soon as the measures were adopted.¹⁹⁴ For example, it has been contended that people do not understand how advance directives work, including those persons who use them.¹⁹⁵ Further, it has been claimed that even when people are aware of advance directives, they are hesitant to deal with issues of death in the personal realm.¹⁹⁶ It also has been asserted that an advance directive adopted at a fixed time and place does not adequately take into account changes over time in either the patient's medical condition or attitude about treatment decisions. Additionally, there is no evidence of hospitals and treating health care providers actually complying with the wishes expressed in a signed advanced directive. Finally, including information about advance directives as part of a packet of forms upon admission to a hospital or health care facility is problematic for several reasons. It is the wrong time to present such information given the stresses and pressures of being admitted to a hospital. Also, furnishing information on advance directives along with numerous other forms obscures the special importance of the advance directive mechanism.¹⁹⁷

¹⁹¹The law went into effect on December 1, 1991. 42 USCS § 1395cc(f) (Law. Co-op. 1991).

¹⁹²Senator Danforth, (R-Mo.), co-sponsored the bill with Senator Daniel Patrick Moynihan (D-N.Y.).

¹⁹³CATE & GILL, *supra* note 83, at 3 (quoting Senator John C. Danforth). Proclaimed Senator Danforth, "Let's let people have the dignity of deciding what they want and what they don't want." *Id.*

¹⁹⁴Although patients may make their preferences known through any of the [advance directives] described above, these methods are rarely used due to lack of public awareness and sophistication and the reluctance of patients to deal with issues concerning their own deaths. *Id.*

¹⁹⁵Yuen, *supra* note 24, at 595.

¹⁹⁶See PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, 2 MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP, 241-42 (1982) (36% of individuals surveyed gave instructions about how they wanted to be treated regarding their eventual incapacity to make health care decisions; 23% of the people surveyed put such requests in writing); see also Yuen, *supra* note 24, at 595 ("although patients may make their preferences known through any of the three methods described above, these methods are rarely used due to lack of public awareness and sophistication and the reluctance of patients to deal with issues concerning their own deaths").

¹⁹⁷CATE & GILL, *supra* note 83, at 22-23.

Yet, advance directives are still considered by many to be the most appropriate response to continually advancing medical technology. The two major types of directives, living wills and health care proxies, are given more careful scrutiny below.

C. The Legislative Response

1. Living Wills

Living will statutes vary from state to state.¹⁹⁸ Many living wills statutes apply only in cases involving terminal illness or a persistent vegetative state.¹⁹⁹

There are numerous problems associated with living wills which arguably undermine their efficacy. Living wills are too often dependent on specific circumstances that cannot cover the many permutations that may arise.²⁰⁰ For example, living wills generally do not cover all forms of treatment, but rather pertain only to "life-sustaining procedures."²⁰¹ This coverage appears to be unduly narrow in scope. Also, living wills attempt to install firm rules of treatment when broader principles would be preferable.²⁰²

Another significant difficulty is that many living wills statutes generally become operative only if there is a terminal condition. An initial question is whether such a condition is definable. The medical profession disagrees on its

¹⁹⁸See Christopher J. Condie, *Comparison of the Living Wills Statutes of the Fifty States*, 14 J. CONTEMP. L. 105 (1988); Gregory Gelfand, *Living Will Statutes: The First Decade*, 1987 WIS. L. REV. 737; SOCIETY FOR THE RIGHT TO DIE, *HANDBOOK OF LIVING WILL LAWS* (1987). For example, in 1976, California adopted the "Natural Death Act." This Act provided both civil and criminal immunity to health care providers who abided by living wills.

¹⁹⁹The cases that have resulted in litigation have mostly concerned patients who are in a persistent vegetative state. Elizabeth D. McLean, Comment, *Living Will Statutes in Light of Cruzan v. Director, Missouri Dept. of Health: Ensuring That a Patient's Wishes Will Prevail*, 40 EMORY L.J. 1305, 1317 at n.56 (1991).

²⁰⁰As one commentator has noted:

Living wills drafted pursuant to existing statutes are problematic; even if directives are executed properly, they cannot cover all of the circumstances in which a patient may want to refuse treatment because the statutes are not complete. Ambiguities in the statutes cause clarity gaps in the living wills that later may be subject to court interpretation. In order for an average adult to provide clear and convincing evidence of his intentions, he must have a living will that thoroughly covers foreseeable contingencies.

Id. at 1318.

²⁰¹See e.g., CALIFORNIA HEALTH AND SAFETY CODES, § 71.87(c) (West 1990).

²⁰²Former Surgeon General C. Everett Koop commented about the Karen Ann Quinlan situation: "There is no way that there can be a set of rules to govern this circumstance. Guidelines perhaps are possible, but not rules." Paul W. Armstrong & B. D. Colen, *From Quinlan to Jobs: The Courts and the PVS Patient*, THE HASTINGS CTR. REPORT at 37, 40 (Feb./Mar. 1988).

meaning.²⁰³ Some observers suggest that terminal illness can be confused with a chronic, progressive disease. Along a somewhat similar vein, it also is arguable that there is no scientifically valid standard for measuring terminal illness.²⁰⁴

An illustration of this problem involved a woman named Estelle Browning, a Florida resident who executed a living will in November of 1985. In her living will, Mrs. Browning stated, "I do not desire that, nutrition and hydration (food and water) be provided by gastric tube or intravenously if necessary."²⁰⁵ Mrs. Browning's living will further directed that physicians should refrain from life-prolonging measures when "death is imminent" and where those procedures would "serve only to artificially prolong the dying process."²⁰⁶ Subsequent litigation arose as a result of the phrase "death is imminent." The lower court measured imminence of death based on circumstances other than a lack of food or water.²⁰⁷

The court concluded that Mrs. Browning was not terminal, and denied a petition by Mrs. Browning's legal guardian to terminate artificial life support systems.²⁰⁸ On appeal, the Florida District Court of Appeals found that Mrs. Browning had a right to die. Consequently, the life-prolonging procedure should be withdrawn due to the common law right to self-determination.²⁰⁹ The Florida Supreme Court agreed with the district court of appeals and affirmed.²¹⁰

Mrs. Browning's subsequent death did not end the controversy over how to interpret living wills and give them predictability. In fact, it illustrated the difficulty of interpretation in such an area,²¹¹ particularly regarding the limited scope and inflexibility of living wills.

²⁰³See, e.g., George J. Annas & Leonard H. Glantz, *A Right About Patients to Refuse Life-Sustaining Treatment*, 64 MILBANK Q. 95, 97 (Supp. 2 1986); Rich, *supra* note 145, at 1114.

²⁰⁴[T]he Concept of Terminal Illness cannot be readily or definitively distinguished from the chronic, progressive disease. Furthermore, a reliable clinical measures of such concepts do not now exist." Rich, *supra* note 145, at 1114-15.

²⁰⁵*In re Browning*, 543 So. 2d 258, 275 (Fla. Dist. Ct. App. 1989).

²⁰⁶*Id.* at 275.

²⁰⁷*Id.* at 264.

²⁰⁸*Id.* at 261.

²⁰⁹*Browning*, 543 So. 2d at 266. See also *In re Conroy*, 486 A.2d 1209 (1985); *In re Storar*, 420 N.E.2d 64 (1981), *cert. denied*, 454 U.S. 858 (1981).

²¹⁰*In re Browning*, 568 So. 2d 4 (Fla. 1990).

²¹¹One corollary problem associated with the development of living wills involved the legal standard of substituted judgment. This doctrine concerns whether a surrogate would be permitted to make medical treatment decisions for an incompetent decision-maker. See *Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (1986). The substituted judgment doctrine applies when a surrogate is permitted to decide what medical treatment the patient would have desired. A surrogate takes into account "the patient's

2. The Health Care Proxy

The limitations of the living will led many states to pursue alternative advance directives such as the health care proxy. Instead of a piece of paper governing end of life decisions, a majority of states began to permit an alternative human decision-maker, a surrogate for adults who become incapacitated. Different types of surrogates have been created. Some states permit surrogates with limited powers to carry out the wishes expounded by patients in living wills. Other states permit agents with almost plenary power, also referred to as health care proxies.

Health care proxy laws have numerous implications. Perhaps foremost among these is the removal of death-related decision-making issues from the judicial arena.²¹² The proxy mechanism provides some predictability to an otherwise ambiguous subject matter.²¹³

a. An Illustration: The New York Law

One illustration of the codification of the health care proxy is the law in the State of New York.²¹⁴ The laws of many other states are similar to this code, and face similar pitfalls and obstacles.

i. The History of the New York Law

The 1990 New York Health Care Proxy Law, which became effective in 1991, had to overcome numerous political and substantive objections by various groups, religious and otherwise. The New York State Task Force on Life and the Law, a gubernatorial commission, helped shape and promote the law. Even with the stewardship of the Task Force and the support of former New York Governor Mario Cuomo, the health care proxy law constituted a bold legisla-

condition, the patient's personal traits, and any relevant statements concerning treatment that the patient may have made before becoming incompetent." Yuen, *supra* note 24, at 597.

The difficulty with this standard, however, is that it is a legal fiction, not based on the actual statements necessarily of the patient, but on what the patient would be projected to have wanted. It is well established, moreover, that many patients who are or become incapacitated do not provide sufficient instructions on the precise nature and type of medical treatment they desire.

²¹²Stephen Haimowitz & Robin A. Goldman, *A Patient Returns From "Death With Dignity: Uncertainty and the Right to Die*, Oct. 1990 N.Y. BAR ASS'N, 58, at 60.

²¹³The advanced directive laws do not remove all decisions from judicial oversight, however. Erroneous medical decisions are still subject to the "professional judgment" standard in medical malpractice cases and expert medical testimony on the matter is still permitted subject to "a reasonable degree of medical certainty." *Id.*

²¹⁴That law is codified in N.Y. HEALTH CARE AGENTS AND PROXIES LAW § 2980 (McKinney 1992).

tive initiative during an election year. The termination of life-sustaining treatment was a sensitive subject, and it took considerable effort to pass it.²¹⁵

ii. The Particulars of the Law

The New York Health Care Proxy Law was enacted to supplement, not replace other forms of advance directives in New York.²¹⁶ A separate statute governing "do not resuscitate" (DNR) orders, as well as established precedent governing living wills and the right to refuse medical treatment - even life-saving measures, have been left intact.

In addition to the statutory requirements of the proxy law, New York case law requires the existence of clear and convincing evidence of the patient's wishes concerning decisions to withdraw or withhold life-sustaining treatment.²¹⁷ Unlike other jurisdictions, the New York Court of Appeals expressly rejected permitting the termination of life support based on "substituted judgment," a standard independent of the patient's expressed wishes.²¹⁸

iii. What the New York Law Provides

The New York proxy law permits competent adults to delegate all forms of medical treatment decisions to a human decision-maker. The law is triggered when the adult becomes incompetent, losing the ability to understand and appreciate the nature and consequences of health care decisions, including the benefit of alternatives.²¹⁹ The initial determination of capacity is made by the attending physician. If that determination is contested by the principal, the principal prevails unless a court finds otherwise.²²⁰

²¹⁵It is not surprising, then, that political maneuvering was significant. Senate Majority Leader Marino's support was crucial for its passage, for example, and he had reservations about the law, fearing abuses if the law was enacted. Yet, here is where the auto accident involving Nancy Cruzan had its impact on New York. Within a week of the decision in Cruzan, the N.Y. proxy bill was adopted by the legislature.

²¹⁶The legislative intent of the N.Y. law states:

This legislation is intended to establish a decision-making process to allow competent adults to appoint an agent to decide about health care treatment in the event they lose decision-making capacity. The legislature does not intend to encourage or discourage any particular health care decision or treatment This legislation confers no new rights N.Y. Code § 2980.

²¹⁷The State of Missouri also required clear and convincing evidence, as did the Cruzan court. *See Cruzan v. Harmon*, 760 S.W. 408 (Mo. 1988).

²¹⁸In the Matter of Westchester County Hospital, 531 N.E.2d 607 (N.Y. 1988).

²¹⁹The law states: "The capacity to make health care decisions' means the ability to understand . . . consequences . . . and to reach an informed decision." New York Code § 2980.

²²⁰*Id.* § 2983(1) & (5).

A proxy must act based on the patient's wishes or, if those wishes are not known, in the patient's best interests.²²¹ A special exception has been carved out for decisions about artificial life-sustaining nutrition and hydration.²²² In those cases, the proxy must affirm that he or she has knowledge of the patient's wishes. This knowledge can arise from various sources, including written statements or oral conversations.²²³ Without actual knowledge of the patient's wishes, a proxy cannot act simply in the patient's best interests.

To effectuate a health care proxy, the directive must: (1) be in writing; (2) contain a statement of delegation of health care decision-making power; (3) indicate who is delegating the decision-making authority and who is to be the agent; (4) be signed by two adult witnesses, neither of whom will serve as the proxy; and (5) signed by the principal.²²⁴ The proxy need not sign the form or consent to serve as proxy. Furthermore, an alternative proxy can be designated.

Health care professionals can object to a proxy's decision in certain limited circumstances, namely those decisions based on moral grounds or religious beliefs to which the professional would object even if made by a competent patient. The law provides that the care of the patient then shall be transferred to another health care professional.²²⁵

The proxy law not only applies to patients and treating physicians, but also applies to hospitals, nursing homes, hospices, diagnostic and treatment centers, home health agencies, and Health Maintenance Organizations.²²⁶ The law requires that these organizations provide all adults upon admission—or enrollment in a Health Maintenance Organization—with written information about their rights under New York law.²²⁷ The law also requires these organizations to document in the patient's record whether a proxy or advance directive has been chosen.²²⁸ The law mandates, as does the federal law, that these institutions conduct community education on advance directives.²²⁹

IV. THE PROBLEM: THE DISUSE OF THE HEALTH CARE PROXY

It is not surprising that despite the creation of legal advance directives, including the flexible and readily implemented health care proxy, the edifice is practically vestigial. To illustrate, a 1987 Gallup Poll of almost one thousand

²²¹*Id.* § 2982(2).

²²²*Id.*

²²³Note: the "knowledge" limitation does not require proof by clear and convincing evidence.

²²⁴*Id.* § 2981.

²²⁵*Id.* § 2984(4).

²²⁶See N.Y. Code § 2980.

²²⁷*Id.* § 2991(1).

²²⁸*Id.* § 2984(1).

²²⁹*Id.* § 2991.

people showed that 70% of those polled preferred not to be on life support if they were in an irreversible coma. The same poll indicated, however, that less than 10% of those polled utilized advance directives to have such wishes followed.²³⁰ Several studies have reached similar conclusions,²³¹ including one study of law students conducted specifically for the purposes of this paper. That study is described in greater detail below.

A. The 1994 Nova Law Center Survey

In February of 1994 a survey was conducted of 300 Nova Law Center students²³² about their views and conduct regarding advance directives.²³³ The results essentially corroborated other studies and polls. Only 24% of those surveyed understood the meaning of advance directives. While 92% would consider appointing a surrogate, only 26% of the respondents had actually designated a surrogate decision-maker.²³⁴ Sixty percent of those respondents

²³⁰Steiber, *Right to Die: Public Balks at Deciding for Others*, HOSPITALS, Mar. 5, 1987 at 72.

²³¹In one study, 148 elderly outpatients were told about advance directives, given living will and health care proxy forms, and even provided with a reminder card to give to their physicians. Only 12 percent of patients actually completed the living will within one year. In a more recent study, involving 60 outpatients who were given written information about advance directives, not one completed a living will." CATE & GILL, *supra* note 83, at 22.

²³²The survey was submitted to approximately 850 students. Three hundred completed the survey.

²³³The Survey asked:

1. Do you understand the meaning of "advance directives?"
2. Do you have a living will?
3. Do you have someone designated as a surrogate who would make health care decisions for you if you were unable to do so?
4. Would you designate someone who would make health care decisions for you in the event you were physically or mentally unable to communicate your decisions?
5. Upon being admitted to the hospital, have you ever been given information concerning "advance directives", living wills, and/or surrogates?
6. While in any hospital have you ever been asked whether you had a living will or a designated surrogate?
7. Do you agree that every competent adult has the fundamental right of self-determination, including the right to refuse medical care?
8. If you had a terminal condition from which there was no reasonable probability of recovery, would you consider refusing any life-prolonging procedures?
9. Would you express this desire in a living will?
10. Would you appoint a surrogate (any person) to make that decision for you?
11. If you answered "no" to 8, 9, or 10, please indicate why.

²³⁴While 22% indicated they had signed a living will, there likely is substantial overlap as in other surveys with those persons who appointed a surrogate, particularly in light of the admitted lack of understanding about the nature of advance directives.

ever admitted to a hospital stated that they had received information on advance directives upon admission.²³⁵

The disparity between actions relating to advance directives and general beliefs about those same directives was again evident. Ninety-five percent of those surveyed believe that individuals possess a fundamental right to die. Ninety-one percent of those responding would consider the removal of life-prolonging procedures if they had a terminal condition.²³⁶ Ninety percent stated that they would express that desire in a living will, while 85% would appoint a surrogate.²³⁷ This data suggests that advance directives are conceptually appealing but practically abhorrent. It appears a free flow of information about the nature and value of advance directives does not exist, and the personalization of the subject matter is foreign if not uncomfortable for many students.²³⁸

B. Interviews and Other Information

Interviews with health care providers, people without proxies, and people with proxies all corroborate the observation that the health care proxy is widely deemed to be a welcome addition to a patient's choices. Almost everyone interviewed, however, recognized that the proxy may be grossly underused.

1. New York Interviews

Interviews were conducted with administrators at fourteen hospitals around New York state and in the State of Florida as part of a Columbia University Center for the Study of Medicine and Society project.²³⁹ Interviews also

²³⁵This response, however, may be skewed, since 90% of those surveyed had never been admitted to a hospital for major surgery.

²³⁶This percentage, of course, can be contrasted with the percentage of respondents who actually adopted advance directives.

²³⁷Survey, *supra* note 233.

²³⁸Some of the comments made by students who would not consider adopting an advance directive are illuminating:

"Who would I trust to make that decision? Things change."

"Since technology permits health institutions to prolong the life of a patient, I see no reason why one should not make use of it."

"No one should be faced with the responsibility of making such a choice for a loved one. From personal experience, I feel that the person who is left to make that choice will forever wonder if it was the correct one."

"Decision might be financially based."

"Others can be too emotionally attached to think clearly."

"There are certain decisions in life that should be made individually and not allocated. This is one of them."

"I don't trust people."

"I'm a sucker for long shot bets."

²³⁹These interviews mostly occurred in the fall of 1992 as part of the Columbia University project which culminated with a presentation in May of 1993 sponsored by

occurred with doctors at the various hospitals as well as patients and non-patients.

a. The Administrators

Various hospital administrators were interviewed. Interviews were mostly conducted with patient representatives, hospital ethicists, and chiefs of medicine. Several hospital vice presidents were interviewed as well.

As interviews and observations make clear, the administrators are fully informed about the details of the Health Care Proxy Law. Significantly, as a group they were highly sympathetic with its goals.

Administrators favored the Act for various reasons. Some believed that the Act had the potential to reduce hospital length of stay and avoid futile medical interventions. Others agreed with one administrator who noted, "it saves recourse to the courts." The majority of those interviewed favored the law because it promoted enhanced patient self-determination. The majority also believed that the law would not in fact save hospital resources, nor was it intended to do so.²⁴⁰

Based on the interviews, it appeared that all of the hospitals were in compliance with the mandate of the law. The hospitals have instructed their admissions offices to inquire of every entering patient whether he or she has appointed a proxy. If the answer is yes, that fact is duly noted in the patient information system. The Administration may then receive a daily print-out of all patients in the hospital who have a proxy. Also, the packet of hospital materials that the patient receives upon admission contains a copy of the proxy form and instructions on how to complete it. The Office of the Patient Representative in these hospitals is generally responsible for assisting patients in filling out the forms and answering any questions they may have. In addition, patients sometimes can view a video about the Health Care Agent Act (in both Spanish and English) by choosing the appropriate hospital channel on the television monitor in each room.

Empire Blue Cross. Additional interviews occurred in Spring 1993, Fall 1993, and Spring 1994.

The hospitals that participated in the interview process generally requested anonymity. The hospitals were of varying sizes and kinds, including large urban hospitals in New York City, medium rural hospitals in Cooperstown, New York, private religious hospitals such as Holy Cross in Ft. Lauderdale, Florida, and public non-religious hospitals in New York. Some of the physicians interviewed were not affiliated with any of the hospitals.

²⁴⁰It is questionable whether the proxy law really favors "death with dignity" as many people claim. The perception of some is that the real purpose of the law is substantive - to be able to withdraw treatment. This perception is perhaps fueled by calls to end futile medical care for dying patients or evidence such as that from medical experts who testified that Nancy Cruzan could have survived for 30 more years in her vegetative state. Perhaps, it is not just death with dignity the law favors, it may be unavoidable that this proxy law, as some have suggested, is really about the allocation of resources, about saving money.

On the basis of project observations and interviews, it is apparent that while specific inquiries are made about whether the patient has a proxy, the lack of time, skill, training, or information allow the matter only minimal attention. The proxy becomes a check-off box - yes, no, and then on to the next subject.²⁴¹

The problem of insufficient administrative attention is compounded by the timing of the delivery of proxy information at the admission. Given the tension that accompanies a hospital admission, administrators note that patients rarely pursue the topic at that point. Thus, only a small minority of patients take advantage of the proxy act on any given day. The proxy log of the Office of the Patient Representative at one institution highlights the difficulty inherent in discussing the proxy with patients at the admissions interview. As of May 1993, the log had 435 proxies on record.²⁴² Of the 435, 179 were designated as patients who had proxies on admission.²⁴³ Another fifty-five were designated as patients who named proxies because of interaction with the nursing staff about the proxy. A third group of fifteen was identified as patients who signed proxy forms at one of the various clinics affiliated with the medical center prior to admission. Of the remaining 186 patients with proxies, two were identified as having proxies due to their own initiative, and the remainder were designated as having proxies for "other" reasons or not having proxies at all. Taken together, patients with proxies on admission²⁴⁴ and patients appointing proxies as a result of interaction with the nursing staff represent two tenths of one percent of the institution's admissions during the two and a half year period that the list covers.

A different hospital,²⁴⁵ with 300 beds, performed an informal study of patients admitted to the hospital for a one week period in 1992.²⁴⁶ The study found that 28% of the admittees had never heard of the health care proxy or DNR law; 13% of the patients had signed a health care proxy; and 21% had signed a living will. Some of these patients had signed both. Seventy-two percent wanted more information about health care proxies and 67% wanted more information about living wills.

Another two hospitals estimated that only 8% to 10% of the patients admitted were signing advance directives. Several hospital administrators

²⁴¹If the patient does ask about it, he or she often will be told to consult the packet.

²⁴²The Office began collecting this information in January 1991, just as the New York Health Care Agent Act took effect.

²⁴³There is no way of knowing if the patient was admitted with a proxy or named one as a result of the admission interview.

²⁴⁴This analysis gives the benefit of the doubt to the hospital staff by presuming the proxy was elected on admission to the hospital.

²⁴⁵The hospital requested anonymity for the purposes of any report of its survey.

²⁴⁶Excepting serious cases in the emergency room and some patients from the maternity ward, 117 of the 167 patients admitted were interviewed. The ages of the patients ranged from twenty to eighty. Forty-one percent of those interviewed were male and 59% were female.

noted that patients were not the only group failing to sign proxies. One hospital assistant vice president observed that "few people in management had signed health care proxies." It was even noted that a former New York Commissioner of Health had not signed one and consequently had been kept alive for a sustained period of time on a life support system in a hospital. Even the majority of some hospital ethics committees were without proxies or other advance directives.

b. Some Observations about the Impact of the New York Health Care Act on Hospital Culture

i. The Act's Burden

The burden of implementing the Health Care Proxy Act has fallen almost entirely on hospitals' patient representative offices. It appears that the doctors, as well as other hospital staff, are either too busy or disinclined to promote the health care proxy. Doctors may be highly skilled and trained individuals, but this study revealed that their skills may not extend to conversations about things such as the health care proxy and the death of their patients. One psychologist who discussed end-of-life communication issues with physicians and patients, for example, concluded that the "two groups do not communicate well . . ." ²⁴⁷ Even if physicians and the hospital staff were superior communicators, the numerous other demands they face may lead to the same result. Said one patient relations coordinator, "the mandate of the Act was received with 'we'll do it because they tell us to do it.'"

The Administrators were ready to offer suggestions about improving implementation. One director of patient representatives remarked, "the Act should be implemented in doctors' offices as far ahead of time as possible." Another person said, "it should be implemented in an out-patient capacity."

ii. The Role of Physicians

Interviews with physicians practicing internal medicine at one hospital indicated that at least at that hospital, a split in approach to the proxy along generational lines occurred. The incident that provoked the most useful comments from doctors at that hospital was a proposal by the Hospital's Ethics Advisory Committee. The Committee suggested that the building adjoining the hospital, where affiliated physicians have offices, should include brochures and information about the proxy law in its waiting areas. Each waiting area is shared by a number of physicians. The Governing Committee refused permission, on the grounds that it would be too disturbing to patients to see the materials. Some observers suggested, however, that the decision was made because patients would ask too many questions and take too much time on the

²⁴⁷Faye J. Girsh, *Physician Aid-in-Dying: What Physicians Say, What Patients Say*, THE WESTERN J. OF MED. 188, at 188 (Aug. 1992) (the author is the founder of the San Diego Hemlock Society).

issue. It appeared that younger physicians were more disturbed by the Governing Committee's decision than older ones. Older physicians often still consider a discussion of these issues as too anxiety-producing for patients.²⁴⁸

There was disagreement on whether a medical "generation gap" existed, however. At another hospital, for example, one knowledgeable observer did not use age as a distinguishing factor, but specialty. The administrator suggested that the group of doctors most likely to ignore the Act were surgeons and neurosurgeons.²⁴⁹

Most of the doctors interviewed strongly supported the principles of the Act. The few doctors who engaged in a narrative with patients involving the health care proxy found it to be worthwhile.²⁵⁰ One doctor commented that even when discussions about the proxy did not result in an appointment, they were useful because they provided a forum for "getting things out on the table" and starting people thinking. Another doctor appreciated the advance planning a proxy discussion promotes. Without proxies, the doctor stated, "I've had families come to me and say: 'We believe in miracles, do everything you can,' and this despite the fact the patient is brain dead."

Yet, the doctors' affirmation of the principles underlying the proxy act does not mean that they actively promote it. Most of the doctors did not. The reasons for this omission ranged from a lack of time for discussion with patients, to the view that only the very sick needed to appoint proxies. Almost none of the doctors interviewed had attempted to educate their patients about the health care proxy other than, in a few rare instances, having the forms available in their own office. As one physician noted, "I don't talk with patients about it, but I probably should."

One reason for physicians' reluctance to educate their patients appears to lie in the fact that they think it will scare the patients. Stated one physician:

I think that it is a shared responsibility to a certain extent because if you as a physician approach a patient when he is coming into the hospital because of a supervening illness that [discussion of advance directives] carries a heavy connotation - 'Oh, by the way, we're bringing you into the hospital and what do you think about life

²⁴⁸However, one doctor who has been practicing for forty years and favors living wills stated: "Younger doctors tend in a way to be very well-trained technicians, but they are not really in command of a set of ethics with regards to death and the handling of this problem. Maybe they need to practice a little bit more." Interview with Dr. William Leen, surgeon, in Boca Raton, Fl. (Feb. 9, 1994) [hereinafter Leen Interview].

²⁴⁹One nurse stated: "A provider who is more receptive to patient's rights [is more likely to be receptive to proxy issues]; some of the younger guys can be just as controlling as older ones." Telephone Interview with Mary L. Reid, nurse practitioner, Jacksonville, Fl. (Feb. 19, 1994) [hereinafter Mary Reid Interview].

²⁵⁰The few doctors who had worked with proxies in making decisions about patient care found the proxies to be active decision-makers and well-informed about the patient's wishes.

support and all that?' The patient thinks, 'Well, there's something that he is not telling me.'

Other reasons for the lack of a dialogue on the health care proxy exist. One reason is the narrative of denial within the medical culture. Talking to a patient about death may be much more difficult than trying to extend the patient's life through life-sustaining measures. Another reason may be that many doctors remain unfamiliar with the law and do not really understand it themselves. Other doctors do not see why patients who are not seriously ill would need a proxy. Still other physicians have stated that they have always talked with the family about what to do for a patient in a persistent vegetative state and had no problem. Perhaps the failure of doctors to comply with the law may have as much to do with attitudes about the legislature as about the proxy law itself. As one physician noted, "what the legislature does is irrelevant to real life."

V. PROPOSAL: USING THE LAW TO PROMOTE A NEW NARRATIVE OF DEATH

This paper suggests that the prevailing narrative of death - in which avoidance and denial are paramount - contributes greatly to the resulting disuse of the health care proxy. To overcome the impediment of the current narrative of death, and to allow the socio-cultural and legal responses to catch up to advances in medical technology, the law can be used to facilitate the creation of a new narrative of death. This new narrative will focus society on the importance of facing death-related issues.

A significant premise of the proposal to use the law to create a new narrative is that "[n]owhere is communications more important, more lacking or less studied than in the interaction between physicians and their patients, patients' families, medical colleagues, and other professionals about life and death decisions."²⁵¹ The value of the legal apparatus, therefore, lies in the various conversations it creates. The law's promotion of enhanced communication may by itself serve to meet the end of a revised narrative. Such communication can increase awareness of the subject matter of death and propel the transfiguration of the moral geography lying underneath.²⁵² With the general lack of understanding about these matters, face-to-face communication may be essential.²⁵³

²⁵¹Newton N. Minow, former Chair, Federal Communications Commission, as quoted in the Ninth Annual James C. Hemphill Lecture at Northwestern University for the Rehabilitation Institute of Chicago, *Communications in Medicine: Do Doctors and Lawyers Know How to Listen?*. See CATE & GILL, *supra* note 83, at 3.

²⁵²As one New York hospital administrator observed, "The [health care proxy] Act assures patients a more meaningful conversation in entering a hospital."

²⁵³For example, how else will the public be informed that treatment may be terminated only if there is clear and convincing evidence pursuant to the particular state's law? How will individuals know what clear and convincing evidence is, even if they are aware of the standard? Even if the virtues of patient's rights are presented directly to the public, "If the law has baffled legal experts, legislators, and medical practi-

Thus, the purpose of a new narrative, as well as health care proxy laws and advance directives generally, is not to create unilateral medical warnings, i.e., the functional equivalent of *Miranda v. Arizona*,²⁵⁴ but to create a bilateral exchange between various groups:²⁵⁵ (1) between doctor (or health care provider) and patient; (2) between hospital and patient; and (3) between patients and their proxies (or simply between persons and their loved ones).²⁵⁶ These exchanges have their own subtexts that can be arranged or shielded from view by the law. It may be important in some of these subtexts, such as health care professional-patient, to delineate the content of the conversation; in other subtexts, such as patient-loved ones, it may simply be sufficient to carve out an opportunity to have it, rather than describe its content and structure.

The occurrence of such a conversation, however, does not ensure a successful dialogue; a reimagining of the hour of death is also imperative. This reconceptualization is fostered by the adoption of a new narrative of death, one which includes a restructuring of society's collective beliefs about death. Altering such collective beliefs takes time. It is a gradual process with various components. The components of this process include creating communication skills, delegitimizing the current narrative, changing that narrative's aesthetic, and, finally, substituting an alternate narrative.

A. Creating Communication Skills

In order for a new death narrative to occur, a predicate competency in communication must exist. While communication is often necessary for human survival and development, the skills necessary for competent communication are often omitted from formal education settings. Thus, highly skilled individuals in law, medicine or other professions may lack the communicative competency to implement the new narrative successfully.

These groups must learn that their substantive professional expertise likely does not provide competency in fostering a dialogue about death. The ability of scientists, doctors, and lawyers to resolve intractable medical and legal issues in the past does not mean that self-determination issues are on a similar plane or within their domain for resolution in the first place.²⁵⁷

tioners, how is a patient suppose to understand what her rights are?" Yuen, *supra* note 24, at 619.

254384 U.S. 436 (1966).

255As one commentator has observed, the purpose of the Patient Self-Determination Act is "education and communication, not the creation or modification of substantive legal rights." CATE & GILL, *supra* note 83, at 9.

256In addition to specialized dialogues with particular parties, the narrative of death is dependent on a more generalized conversation promulgated by the media and public speech, from the schools to the politicians to the special interest groups. To affect this generalized dialogue requires better communication of the substance of advance directives and the health care proxy and the message - or narrative - of its true value.

257As the former Chairperson of the Federal Communications Commission stated: "the extraordinary achievements of technology pose fundamental questions which

Formally educating these groups in the particulars and rationale of the new narrative may be required. They may have to be directly taught that communication skills are part of a separate competency. This competency involves skills that foster the creation of a safe environment for such a potentially sensitive area and permits discussion of the subject matter in an effective manner.

The skills training can occur during professional school education, including law, medical, and dental schools, among others. It could also occur in post-degree continuing education courses, as a special component of an existing course or as an entirely separate program. It is not just the professionals who must be taught, but the hospitals, health maintenance organizations and consumers as well. These groups can be required to devote a modicum of resources in educating their employees and consumers. There also can be education in colleges and other venues where a dialogue can be created.

The law can be used to encourage and coerce compliance with such a mandate. It can set up incentives to educate or penalties for failing to do so, and create a scheme by which the burden of implementation is dispersed. This will not ensure that a dialogue occurs, but it will at least increase the likelihood of the transformation of the narrative of death.

1. Delegitimizing the Dominant Narrative of Death

The current narrative of the denial of death must be shown to be illegitimate before it will be readily dropped. The illegitimacy of the narrative emerges in numerous ways. These include the costs of a technology-delayed lingering death or a hospital death; the recognition of the proxy as a multidisciplinary social issue, not simply a medical one; the costs of an illusory belief in immortality; and many other costs as well. Some of these costs are explored below.

Families and friends who witness a lingering and perhaps painful hospital death often regret the failure to have promoted a more peaceful and familiar death for their loved ones.²⁵⁸ Minimizing a family's pain and suffering over observing a loved one's lingering and painful death, as well as the avoidance of that suffering for the patient, is a valuable commodity, and should be treated as such. This pragmatic assessment of the value of the death narrative is in some ways no different than the valuation of either life or disability insurance.

The denial of the inexorable process of aging also has exacted a heavy price. It resulted in the hubris of science generally and a belief that science had

physicians, lawyers and judges cannot and should not answer alone." Newton N. Minow, in the Ninth Annual James C. Hemphill Lecture at Northwestern University for the Rehabilitation Institute of Chicago, *Communications in Medicine: Do Doctors and Lawyers Know How to Listen?*

²⁵⁸"A few friends shared with me their regret about their parents dying prolonged and painful deaths alone in the hospital, sedated or agitated, not recognizing their children If a family member is dying in a hospital and wants to return home, try to find the means to do it." Sumers, *supra* note 106, at 14.

succeeded in denying various diseases in particular. Instead of living fully in the present, individuals were conditioned to engage in the futile attempt to deny the inevitable.

2. The Importance of a Multi-Disciplinary Response

The dominant narrative of death is also constructed around an insular medical culture that appears to almost unilaterally govern itself without much overlap or interference from other cultures and communities, such as the law. The insularity of the medical hierarchy, built in part on a desire for self-governance and a hubris born out of isolation, however, is eroding. Many medical issues - such as life-sustaining treatment decisions - are now being viewed as more complex social issues that cut across legal, medical, psychological, and cultural boundaries. For the proxy law to succeed the medical culture can not engage in unilateral governance. Rather, cooperation in the medical, business, law, and social sciences communities is imperative.

The lack of insularity of the medical culture also assists in delegitimizing the medical view of the patient. Today, the principle of patient autonomy prevails. This principle also cuts across disciplinary boundaries.

The principle of autonomy motivates both the medical and legal disciplines in their resolution of issues pertaining to the right to die.²⁵⁹ This principle of choice is generally considered integral to patient self-determination,²⁶⁰ particularly with regard to the procedures used on the patient to promote the patient's physical and mental health.²⁶¹

²⁵⁹Yet, the conceptualization of autonomy is as fuzzy as the epistemology relating to the other definitions in this area. In the context of death, there is increasing recognition that, in the words of Thomas Mann, "A man's dying is more the survivors' affair than his own." This analysis requires a renewed inquiry into the meaning of autonomous decision-making by patients.

²⁶⁰See also Kathleen M. Boozang, *Death Wish: Recessitating Self-Determination for the Critically Ill*, 35 ARIZ. L. REV. 23, 40 n.78 (1993). Thus, the principle of autonomy does not extend to the right to obtain medically unnecessary or even harmful treatment.

²⁶¹Some commentators suggest that the legal system elevates autonomy as the principle value in the area of medical decision making. Allan S. Brett & Lawrence B. McCullough, *When Patients Request Specific Interventions*, 315 NEW ENG. J. MED. 1347, 1349. Other commentators suggest that patient autonomy involves both positive and negative rights - the positive right that the patient's desired treatment be implemented, and the negative right that the patient can refuse the suggested treatment. *Id.* Yet, the same commentators suggest that limits on patient autonomy exist. These include the physician's own moral principles and how well established the medical basis is for the patient's request. *Id.* The authors state that:

Moral and medical values obviously are not extraneous factors in clinical decision-making . . . if the physician facilitates the patient's request for an unnecessary or harmful intervention to satisfy a principle of respect for patient autonomy, the action reciprocally undermines the physician's autonomy.

Id.

3. Changing the Aesthetic of the Narrative

Revising the aesthetic of the narrative of death promotes its change. This supposition is premised on the belief that the meaning of a text or narrative is greater than its actual words, and extends to both nonverbal cues and an overall aesthetic. This aesthetic, governed by emotive, smell, and visual connotations, is often more important than the individual words.²⁶²

One way to affect the aesthetic of the narrative of death is to replace or diminish the role of fear, perhaps with respect or even reverence for death as a part of the evolutionary process. The aesthetic of death need not be viewed in the context of the individual losing connection to life, for example, but rather in passing the torch to the next generation of children who will carry it with them.

The new aesthetic contemplates the potential for the good death, one that is gentle and peaceful. It values both planning and "letting go" as preludes to freedom.²⁶³ This valuation applies to the doctors who can not provide any more treatment, who can let the patients walk away,²⁶⁴ the families of loved ones, and the dying persons themselves.

B. The Content of an Alternative Narrative

Significant elements of a modified narrative of death include the prospect of death in the personal realm - at home and not in the hospital - and the prospect of the good death, a gentle passing onward. This new dialogue will communicate that hospitals are not places to die,²⁶⁵ but are for other purposes

²⁶²The words of a text do not completely provide its meaning; the context and intent of the author also inform the meaning. The language of the health care proxy laws, for example, can and have been construed differently - and even misconstrued - by many sectors of the population, from the hospital administrators to the doctors to the patients. This indicates that the language is but one part of the meaning associated with the words; the context and subtext - or tenor of the words - are other parts. As one administrator essentially concurred: "Much depends on the humane concern of the health giver."

²⁶³"Doctors must learn to let go - if there's nothing more to offer the patient then nothing more should be done - let patients go home. We all should plan for this among ourselves - preparing our next of kin. Families, husbands, wives need not be fearful. If a family member is dying in a hospital and wants to return home, try to find the means to do it." Sumers, *supra* note 106, at 14.

²⁶⁴Some physicians consider it their role to aid the dying process when there is nothing else that can be done:

It means that you should help a person, realizing that that person is going to die, you should make it as easy as possible, as comfortable as possible, comfort the relatives, let them know what is going on, and then the patient dies- which, after all, is the destiny of everybody.

Leen Interview, *supra* note 248.

²⁶⁵One nurse practitioner who believes that death in the hospital can be avoided described how she speaks to her patient's family about taking care of their loved ones at home. The individual says to the family:

such as to have surgery, be treated for illness, and to have babies.²⁶⁶ While hospital deaths may allow people to avoid a fear of death at home, the narrative can inform people that a dead body is far from a macabre occurrence.²⁶⁷ The following illustration of an alternative narrative suggests that death in the home can be a welcome and gentle experience.

1. Rick's Death

As related by his sister, Dr. Anne Ricks Summers, Rick was a forty year old attorney with a wife and child who was told by doctors that he had an inoperable brain tumor.²⁶⁸ While in the hospital, he became disoriented and confused. The cancer was affecting his brain.²⁶⁹ His sister stated: "My brother was a strong guy. He kept getting up out of bed. The hospital staff tied him down. He was furious, humiliated, embarrassed, enraged, confused and frightened."²⁷⁰ The hospital was not able to provide further treatment for Rick. His wish, when he was lucid, was to go home.²⁷¹

The decision was made and the hospital released him. Dr. Summers describes Rick's last night at home:

Rick's last evening was wild, fun, tragic and exhilarating. Rick walked from room to room in his house, savoring a glass of red wine, eating a cookie, talking with his best friend, our mother and dad, our sisters and brothers. Neighbors stopped in with food and stayed for the conversation. Friends from the Quaker Meeting House stopped by. Cousins arrived. It was like a Thanksgiving - good food, lots of conversation, but the guest of honor would be dead in a few days, or hours.²⁷²

You know this is a terminal condition, can you all take care of her at home, do you want to take care of her at home, do you have the resources, are you comfortable with the fact that she is first going to slip into a coma and then she is going to stop breathing? And when she stops breathing you are not going to call 911 and bring her to the hospital. Call me at home before you call anybody if you need that support.

Reid Interview, *supra* note 249.

²⁶⁶As one ophthalmologist stated in arguing that death should occur at home: "Please don't misunderstand me; I like hospitals. Hospitals are great places to live, to struggle for life, to undergo treatments, to have surgery, to have babies. But not to die. If it's at all possible, people should die in familiar surroundings in their own beds." Summers, *supra* note 258, at 14.

²⁶⁷Some people are afraid or resistant to the prospect of having a dead body in the home. *Id.*

²⁶⁸*Id.*

²⁶⁹*Id.*

²⁷⁰Sumers, *supra* note 106, at 14.

²⁷¹*Id.*

The occasion was dignified, not macabre. There was a semblance of normalcy, fostered by the comfort of family and friends. Many of the activities that occurred were those of daily life. Stated Dr. Summers:

Although Rick was confused he wasn't frightened. Rick knew he was in his home, surrounded by friends and family. He was thrilled to be there. He ate. He cleaned. He was busy all evening, reminiscing, telling fragments of stories, neatening up, washing dishes, giving advice and eating well.²⁷³

When death came, it occurred in a warm, familiar and loving environment. While it was not ceremonial as in many cultures, it was personal:

He took his last breath with his wife and his best friend beside him, his family singing old folk songs in the living room. He was peaceful, quiet, never frightened or restrained. Rick died far too young. But everyone should hope to die like this; not just with dignity, but with fun and love, with old friends and family.²⁷⁴

In reflecting on Rick's final night, his sister observed that the cooperation of many groups was required to recreate death in the personal realm: "Rick's death was as gentle as a death can be. It worked because all parties - doctors, family, Rick and Rick's wife - were able to face facts and act on them."²⁷⁵

Dr. Summers shared with friends about Rick's death. They in turn disclosed their regrets about having parents die "prolonged and painful deaths alone in the hospital, sedated or agitated, not recognizing their children."²⁷⁶ The friends also expressed their fear about witnessing a dead body; "Wasn't it ugly?" they ask. No, it looked like he was sleeping.²⁷⁷

VI. CONCLUSION

A narrative of avoidance characterizes modern American society's view of death. This narrative has become dominant for several reasons. The promise of extended longevity through the miracles of medicine, Americans' desire for immortality that is propelled by continuous scientific discoveries, and the removal of death from the personal realm have enhanced a fear of death that underlies much, if not all, of life's experiences. This fear of death, in turn, has spurred its avoidance.

One of the many consequences of this narrative is the failure to utilize advance directives such as the health care proxy in dealing with individuals

²⁷²*Id.*

²⁷³*Id.*

²⁷⁴Sumers, *supra* note 106, at 14.

²⁷⁵*Id.*

²⁷⁶*Id.*

²⁷⁷*Id.*

kept alive in a persistent vegetative state or those persons in the advanced stages of terminal illness. To overcome this failure of the legal apparatus, the narrative of death must be transformed to permit and encourage a dialogue about the transition from life to death. Without a reemergence of the belief in the "good death" and a return of death to the personal realm, this transformation likely will not occur.

The transformation can be promoted by the legal apparatus. That apparatus can establish a framework for various dialogues, between health care professional and patient, patient and loved ones, and others, that revolve around advance directives specifically and the narrative of death generally. A predicate to success of such a framework involves educating those who deal with death-related issues professionally, including doctors and other health care providers, estate planning attorneys, life insurance agents, and religious leaders, in a new dialogical imperative, a narrative of the good and personal death. An awareness can be created that social constructs often take longer to build than associated technological advances, and that those social creations often require direct attention and work. Only then might the health care proxy be better utilized; only then might the death it concerns be recast as a "season" of life, just one inevitable part of life's natural progression.

