Gently into the Good Night: Toward a Compassionate Response to End-Stage Illness

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GENTLY INTO THE GOOD NIGHT: TOWARD A COMPASSIONATE RESPONSE TO END-STAGE ILLNESS

by GEORGE P. SMITH, II*

“Finished, it’s finished, nearly finished, it must be nearly finished.”1
—Samuel Beckett

End-of-life decision making by health care providers must respect individual patient values. Indeed, these values must always be viewed as the baseline for developing and pursuing patient-centered palliative care for those with terminal illness. Co-ordinate with this fundamental bioethics principle is that of beneficence or, in other words, respect for conduct which benefits the dying patient by alleviating end-stage suffering—be it physical or existential. Compassion, charity, agape and/or just common sense, should be a part of setting normative standards and of legislative and judicial responses to the task of managing death. Aided by the principles of medical futility, palliative care protocols, greater acceptance of a patient’s right to refuse treatment, and a spirit of basic humaneness, an ethic of adjusted care that seeks to secure dignity during the dying process without unreasonable interference by the state should be validated.

I. TOWARD A STANDARD OF HUMANE CARE

Caring, as a role and obligation for health care providers, may be seen as a moral obligation rooted in the time-honored principle of beneficence whose goal is to promote patient well-being.2 Considered as such, “caring indubitably incorporates empathy.”3 Incorporating caring into the

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* Professor of Law, The Catholic University of America. Parts of this essay are drawn from my article entitled, Refractory Pain, Existential Suffering, and Palliative Care: Releasing an Unbearable Lightness of Being, 20 CORNELL J. L. & PUB. POL’Y 469 (2011). This article is dedicated, with respect and admiration, to Joel G. Joffe, Baron Joffe, CBE, member of the House of Lords in the British Parliament—a strong and eloquent advocate for civil liberties, human rights, and the enactment of legislation validating compassionate assistance for those dying of terminal illness.

1. SAMUEL BECKETT, ENDGAME, act 1, sc. 1 (1957).
3. Id. The doctor-patient relationship has been termed a “moral relationship”—with care and empathy being at its core. Consequently, this gives rise to what is seen as a “morality of care” which imposes upon the physician a responsibility to accept patients as “concrete individuals” who, in turn, make concrete and immediate claims upon them in their role as physicians. Anjte du Bois-Pedain, The Duty to Preserve Life and its Limit in English Law, in
management of the terminally ill is, however, difficult. For the physician to convey to a patient that, “I could be you,” involves a sympathetic response which—ideally—may be initiated during the taking of the patient history. During this process, a one-on-one relationship may be commenced which provides a mechanism for physician assessment and identification of the emotion the terminally ill patient is experiencing. The physician’s determination of the reason for the display of emotion and then a response to the patient’s emotion allows the patient to see that the physician made a “connection” between the emotion and its root cause. A line of communication is then opened.

The physician’s establishment of an empathetic response has the direct effect of assuring patients that they will not be abandoned in their final days. For many physicians, however, non-abandonment is instinctively difficult to honor because of “the fear generated by confrontation of their own mortality when caring for a dying patient.” Because of this situation, patient avoidance—unintentional though it may be—only serves to heighten patient fears of impending death.

As a consequence of these concerns and inadequacies among physicians, more often than not, issues of “existential care” are left to the nursing staff. However, even in the daily hospital bed environment, it takes a special level of sensitivity for the nurses and health care assistants to understand questions raised by the patients, often indirectly, regarding the depth and severity of their distress over their terminal illness. Once understood, it remains for the nursing staff to devise a procedure for providing empathetic support—

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4. Rousseau, supra note 2, at 224-25.
5. Id. at 225.
6. Id.
7. Id.
8. Id.
10. See Rob Houtepen & David Hendriks, Nurses and the Virtues of Dealing with Existential Questions in Terminal Palliative Care, 10 Nursing Ethics 377, 377 (2003) (defining existential care situations as “cases where the patient’s question has such an existential, dramatic and personal purport, that the nurse experiences a special appeal to specific personal qualities in offering existential support”); see also Dean Whitehead, Beyond the Metaphysical: Health-Promoting Existential Mechanisms and Their Impact on the Health Status of Clients, 12 J. Clinical Nursing 678, 678 (2003) (noting that existentialism, in a health context, means “maintaining or heightening the overall positive well-being of an individual”). In the context of existential questions, “patients tend to talk to nurses while they are still uncertain themselves about the nature of their wants and needs. Houtepen & Hendriks, supra note 10, at 382. Thus, nurses’ communication with patients is of a more open and undetermined character than physicians’ communication.” Id.
11. Houtepen & Hendriks, supra note 10, at 381.
especially when a sense of an ending, *fin de siècle*, pervades.\(^\text{12}\)

**Alleviating Suffering**

While autonomy emerged in the 20\(^{th}\) century as the dominant or capstone principle in biomedical ethics—supporting and complementing beneficence, non-malefeance, and distributive justice—\(^\text{13}\) it is well to reconsider its pre-eminence in complex cases of refractory pain. Indeed, once cases are presented where one’s quality of life is so severely diminished because of suffering, it is proper to advance an argument that necessitates reconfiguring or enhancing autonomy so that compassion becomes the operative bioethical principle in decision making at this level.\(^\text{14}\) Accordingly, in cases where end-of-life pain is intractable, efforts to address this condition and thereby assure a dignified death become a paramount state interest.\(^\text{15}\)

The goal of alleviating suffering, if acknowledged as a *right* to relief, requires action by the state and the health care providers and imposes upon them a co-ordinate responsibility to make prudential judgments that validate this right.\(^\text{16}\) Acknowledging and honoring such a right then becomes an act of “responsible benevolence,”\(^\text{17}\) or compassion, which is properly seen as complementing the duty to undertake actions that benefit the dying patient.\(^\text{18}\) The duty to relieve pain is acknowledged as the “least disputed and the most universal of the moral obligations of the physician.”\(^\text{19}\) In reality, end-of-life

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12. *Id.* at 381-85.
13. See Albert R. Jonsen, *A History of Bioethics as Discipline and Discourse, in BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS, AND PRACTICE* 3, 11 (Nancy S. Jecker et al. eds., 2007) (explaining that bioethicists “worked out a general approach to ethical reasoning by affirming the relevance of a set of principles, namely, respect for autonomy, beneficence, non-malefices, and justice”); see also George P. Smith II, *Bioethics and the Law: Medical, Socio-Legal and Philosophical Directions for a Brave New World* 6-9 (1993) (explaining that the three duties within the field of bioethics are autonomy, beneficence, and justice).
14. See Lois L. Shepherd, *Sophie’s Choices: Medical and Legal Responses to Suffering*, 72 Notre Dame L. Rev. 103, 106 (1996) [hereinafter Shepherd, *Sophie’s Choices*] (“Once we decide that the suffering is sufficiently severe and the quality of life substantially diminished, then we are justified in treating the individual sufferer differently; we are justified in making decisions that erode autonomy and equality in the name of providing relief from suffering.”).
15. See *id.* at 118 (“Autonomy is firmly grounded in our Constitution’s protection of individual liberty; accordingly, liberty interests have been relied upon to support a Constitutional right to physician-assisted suicide and withdrawal of life support.”).
16. *Id.* at 146-47.
17. See Lielz Van Zyl, *Death and Compassion: A Virtue-Based Approach to Euthanasia* 197-98 (2000) (“For euthanasia to be an act of responsible benevolence, it has to be considered as a last resort, when nothing else can be done to provide sufficient relief from suffering.”).
autonomy is actually fortified by and through this new right of compassion. Of necessity, then, compassion becomes the denominator in health care decisions for end-of-life care\(^{20}\) and directs that efforts should be undertaken which not only refrain from causing pain or suffering but relieve it as well.\(^{21}\)

II. LEGAL CARING RESPONSES IN A JUST SOCIETY

American history shows rather remarkably that instead of being perceived as vital to maintenance of a just society, the capacity to care has been often seen as antithetical to it.\(^{22}\) There “has been a deformation of both the private ethic of care \textit{and} the very public ethic of legal justice”\(^{23}\)—all as a direct result of this attitude. This, in turn, has meant that not only have the ideals and practices of justice been uncaring, but the ideals and practices of care “have been unjust” with a “deflation of both virtues” resulting.\(^{24}\) Rather than viewing caregiving as an emotional, morally arbitrary response, it should be more properly accepted as an ethical activity—with the beliefs and the values of care accepted as “integral to the development of just people and a just society.”\(^{25}\) Indeed, care or compassion must be recognized as a universal

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\textit{Clinical Ethics of Pain Management in the Terminally Ill, 17 Hosp. Formulary 1493, 1493 (1982)).
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\(^{20}\) Id. at 126.

\(^{21}\) MARGARET P. BATTIN, ENDING LIFE: ETHICS AND THE WAY WE DIE 90-91 (2005) \textit{(hereinafter BATTIN, ENDING LIFE). See Robin M. Henig, A Life-or-Death Situation, N.Y. TIMES MAG., July 21, 2013, at 27 (describing Margaret Battin’s personal family tragedy of being forced to deal with her husband’s medical condition—since 2008—as a quadriplegic and her distress in attempting to honor and to be responsive to her husband’s ambiguous and fluctuating communications regarding the continuation or cessation of his medical treatment. Discerning what is an informed and abiding decision by her husband to die from a response to transient despair is problematic).

\(^{22}\) See ROBIN WEST, CARING FOR JUSTICE 9 (1997) (“For most of our history \ldots our capacity to care has not been regarded as necessary to the capacity to do justice (indeed, it is more typically regarded as antithetical to it) \ldots \ldots ”). For a discussion of society’s views on the compatibility of justice and care, see MICHAEL D. FINE, A CARING SOCIETY?: CARE AND THE DILEMMAS OF HUMAN SERVICE IN THE 21ST CENTURY 52-74 (2007) (“Justice is portrayed in many of these discussions as an essentially masculine value involving the application of abstract and impersonal principles to the public world, while the ideals of care are seen as values deriving from the personal and private world of the home and family \ldots In this dichotomous way, care came to be seen as an essentially feminine perspective, emphasizing the ties between people rather than their autonomy.”); and see also JONATHAN HERRING, OLDER PEOPLE IN LAW AND SOCIETY 127 (2009) (discussing generally the disparate focuses of the ethics of justice and the ethics of care, but concluding that the two separate ethics are interdependent in the care context: “it is so important that those sympathetic to an ethic of care emphasize the importance of upholding justice within relationships”).

\(^{23}\) WEST, supra note 22, at 9.

\(^{24}\) Id.

\(^{25}\) FINE, supra note 22, at 63 (quoting Margaret Moore, The Ethics of Care and Justice, 20 WOMEN & POL. 1, 14 (1999)); see also HERRING, supra note 22, at 124-27 (discussing five aspects relating to an ethic of care). Specifically, Herring states that “the values that are promoted within an ethic of care are not isolated autonomy or the pursuance of individualized rights, but rather the promotion of caring, mutuality, and interdependence.” HERRING, supra
moral principle, which is vital to the very fabric of social justice.

Within every adjudication, it has been suggested that neutral principles of law, or those standards that transcend the instant case, should operate. Perhaps these principles or standards are to be found within the very principle of equity and from equity flows — arguably — mercy, sympathy, compassion, humaneness or love. David Hume, an eighteenth century British philosopher, opined that the basis for a system of justice and social solidarity was, in fact, tied to expressions of natural sympathy for others. Arthur Schopenhauer, the German philosopher, maintained that compassion “is the real basis of all voluntary justice.” Accordingly, for an action to have moral value, it must derive from compassion.

Defined as an acknowledgment of another’s suffering, which prompts a response to assist in alleviating the suffering, compassion is often regarded as the motivation for subsequent merciful acts. Mercy is oftentimes used synonymously with compassion or benevolence. Indeed, acts of this nature

note 22, at 126. See also HERRING, CARING AND THE LAW, supra note 3, at 320-22 (discussing the idea of social justice).

26. See FINE, supra note 22, at 60-61 (“The principles of care should be able to provide universal moral guidelines if it can be shown that they meet two essential tests. First, the principles of care must be able to provide moral guidance on important decisions. Second, they must be capable of being developed as a set of abstract principles that could be employed for regulating public life.”); ALBERT R. JONES, THE NEW MEDICINE AND THE OLD ETHICS 126 (1990) (discussing in care how to balance competence and compassion, stating “[c]ompassion must be circumscribed, just as competence is restrained. The circumscription does not mean any diminution of human feeling, but instead its universalization”).

27. See MARIAN BARNES, CARING AND SOCIAL JUSTICE 158 (2006) (“Care-giving makes a significant contribution to social well-being and the achievement of social justice — not only directly through support received by particular individuals which can contribute to their capacity to resist oppression and participate in social life, but also by offering practical examples of an ethical basis for social relations which recognize equality as an objective to be achieved.”).


29. See generally WILLIAM Q. DEFUNJAK, HANDBOOK ON MODERN EQUITY, ch. 1 (2d ed. 1956) (discussing equity and jurisprudence); Garrard Glenn & Kenneth Redden, Equity: A Visit to the Founding Fathers, 31 VA. L. REV. 753, 756 (1945) (“Equity exists . . . for corrections of situations wherein the law, by reason of its universality, is deficient.”). Equity may be defined as not only “the quality of being equal or fair . . . but, “given in accordance with natural justice . . . something fair and right.” V OXFORD ENGLISH DICTIONARY 358 (2nd ed. 1989).


33. SCHOPENHAUER, supra note 32, at 144.


35. Tudor, supra note 30, at 81.
have been termed “responsible benevolence”36 or “compassionate mercy.”37
For others, charity is seen as the ultimate value in caring for the dying,38
and they suggest beneficence and benevolence may combine, properly, to
become “loving charity.”39 When there is suffering, its elimination or
management is central to a caring response and can well be seen as trumping
the biomedical principle of autonomy.40

Modernly, it has been urged that sympathy and compassion must be
integrated into contemporary law.41 A contemporary and principled rule of
law, then, needs notions of decency and compassion within its sinews42 and
does not have to conflict with a rule of love.43 Others have called for the law
to be empathetic or to incorporate concepts of love, altruism, and
sympathy.44

36. VAN ZYL, supra note 17, at 197.
37. BATTIN, ENDING LIFE, supra note 21, at 66; see also TIMOTHY E. QUILL, DEATH AND
DIGNITY: MAKING CHOICES AND TAKING CHARGE 129-32 (1994) (illustrating how the difficult
decision of how to approach end-of-life care with a loved one can be perceived as both agonizing
and admirable).
38. See Edmund D. Pellegrino, Decision at the End of Life: The Use and Abuse of The
Concept of Futility, in THE DIGNITY OF THE DYING PERSON 219, 222-23 (Juan De Dios Vial
Correa & Elio Sgreccia eds., 2000) [hereinafter Pellegrino, Decision] (explaining that Christians
have an obligation to care for the sick and the vulnerable).
39. Id. at 225, 241.
40. Shepherd, Sophie’s Choices, supra note 14, at 119-24 (analyzing the constitutional,
medical, and ethical conflicts that exist between the right to be free from suffering and the right
to autonomy). See generally du Bois-Pedain, supra note 3, at 319-24 (discussing the tenuous
relationship between a doctor’s moral and legal duties in caregiving and alleviating end-of-life
suffering).
(criticizing the Supreme Court of the United States for taking an unbending position on the Rule
of Law—one that fails to account for “sympathy and compassion”).
42. Id. at 731.
43. Id. at 729; see also SAMUEL FLEISCHACKER, INTEGRITY AND MORAL RELATIVISM 7-8
(Michael Krausz ed. 1992) (discussing how both cultural relativism and individual desires impact
ethical orientations); JOHN FLETCHER, SITUATION ETHICS: THE NEW MORALITY 69-71 (1966)
(arguing that, so long as one’s intention to act is anchored in love, the end result justifies the
means); Hugh LaFollette, The Truth in Ethical Relativism, 22 J. SOC. PHIL. 146, 146 (1991)
(arguing that a “cultivated moral judgment” should be the normative standard of conduct, rather
than a routine application of existing moral rules).
44. See Lynne N. Henderson, Legality and Empathy, 85 MICH. L. REV. 1574, 1576 (1987)
(arguing that empathy, or lack thereof, is helpful in understanding many important Supreme
Court decisions in the last century). For Adam Smith, the process of judging involves a lesson in
learning the importance of impartiality by imagining how an impartial spectator would act in a
particular situation: “Moral judgment is either approval or disapproval of an action. Judging is a
complex matter and forms the last step in a process which relies upon human beings’ capacity for
sympathizing. Sympathy does not mean compassion; Smith defines it in a neutral way to mean
what we call empathy.” James E. Alvey, The ’New View’ of Adam Smith and the Development
of his Views Over Time, in NEW PERSPECTIVES ON ADAM SMITH’S THE THEORY OF MORAL
SENTIMENTS 66, 71 (Geoff Cockfield et al. eds., 2007) (internal citation omitted). See RICHARD
A. POSNER, HOW JUDGES THINK 117 (2008) [hereinafter POSNER, JUDGES] (observing that an
element of judicial decision making is “good judgment,” which is a compound of several
qualities, including empathy and common sense).
One of the inherent weaknesses of the rule of law has been said to be its all too often efforts to distance itself from human experience. Certainly, by introducing human values or attitudes into the judicial process, a strong claim could be made that these elements might well conflict with the ideal of judging, which is sustained by rational and objective argumentation, not by feelings and emotions. Indeed, empathetic discourse in the courtroom may well be seen as either irrelevant or merely as “policy” and, thus, treated dismissively.

**Principles, Emotions, and The Holmesian Caveat**

While principles provide the foundational framework for standards of normative conduct, feelings are important when individuals or micro issues arise which, in turn, test the extent to which principles are valid in their application within the context of a given situation or norm of conduct. It is asserted that “the morally good person is not just principled, but also compassionate.” In addition, that person not only exhibits “practical wisdom” but “common sense” in assuring patient dignity or quality of life.

45. See John T. Noonan, Jr., Persons and Masks of the Law: Cardozo, Holmes, Jefferson, and Wythe as Makers of the Masks 111-51 (1976) (describing how the law dehumanizes the very people to whom it applies, such as, for example, Helen Palsgraf, the blinded plaintiff in Palsgraf v. Long Island R.R., 162 N.E. 99 (1928), who is referred to simply as “A” in the Restatement of Torts as presented to the American Law Institute in 1929).

46. See Benjamin Zipursky, DeShaney and The Jurisprudence of Compassion, 65 N.Y.U. L. Rev. 1101, 1122 (1990) (“An apparent problem with advocating the judicial embrace of compassion is that it seems to conflict with the ideal of judging as a rational and objective activity.”). But see Martin L. Hoffman, Empathy and Moral Development: Implications for Caring and Justice 270 (2000) (“Empathy can contribute to both sides of caring-justice dilemmas because of empathy’s congruence with both, though it is less likely to contribute to the justice side when productivity is the issue, as is usually the case in our society.”).

47. Henderson, supra note 44, at 1588 (“Law as a closed system that is self-referential can draw the line in such a way as to dismiss empathic discourse or understanding as ‘irrelevant’ or as ‘policy’ argument beyond the auspices of the law.”). See David Brooks, The Limits of Empathy, N.Y. Times, Sept. 30, 2011, http://www.nytimes.com/2011/09/30/opinion/brooks-the-limits-of-empathy.html (referencing a recent paper by Professor Jesse Prinz, of the Graduate Center Philosophy department at the City University of New York, who argued that empathy “subverts justice” where it allows the individual “to experience the illusion of moral progress without having to do the nasty work of making moral judgments” and “to experience delicious moral emotions without confronting the weaknesses in our nature that prevent us from actually acting upon them”).

48. Fiona Randall & R.S. Downie, Palliative Care Ethics: A Good Companion 12-13 (1996) (“Principles provide the framework, but we must remember our feelings; the morally good person is not just principled, but also compassionate.”).

49. Id. at 13.

50. Id. at 24 (“As a result of their professional experience those involved in palliation may be able to offer a range of advice and discussion based on practical wisdom generated by interaction between their own personality, and their experience of health care and life in general.”).

51. Id. at 73 (“Common sense has a part to play in health care ethics . . . . Ordinary reasoning and moral intuition lead to the conclusion that the effective relief of suffering in terminal illness may sometimes justify the use of measures which entail a risk of shortening life.”).
is preserved throughout all palliative care treatments.\textsuperscript{52}

The best way to assure this mandate or goal of compassion throughout cases of adjusted palliative care management is to embrace a test of medical utility in determining what end-stage options should be made available as treatment.\textsuperscript{53} Accordingly, a benefits-to-burdens/risk calculus should be utilized to assess the utility of one medical treatment over another.\textsuperscript{54} Anchoring such an evaluation should be the doctrine of medical futility, which acknowledges the practical limits of medical treatment in all cases.\textsuperscript{55}

While compassion is experienced and evaluated subjectively,\textsuperscript{56} it need not stigmatize a valid legal theory.\textsuperscript{57} Indeed, in the case of \textit{DeShaney v. Winnebago County Department of Social Services},\textsuperscript{58} Justice Harry Blackmun, in dissent, addressed the importance of compassion in judicial analysis and interpretation by observing that “compassion need not be exiled from the province of judging.”\textsuperscript{59} He went further and stated that when courts remove “natural sympathy” from a case, they are thereby prevented “from recognizing either the facts of the case before it or the legal norms that should apply to those facts.”\textsuperscript{60}

Eschewing emotion as a dominant vector of force in truth seeking in law,\textsuperscript{61} Oliver Wendell Holmes, Jr. urged that the reasoning behind a particular rule’s adoption “ought to be of paramount importance.”\textsuperscript{62} And,

\textsuperscript{52} Id. at 71; Annette F. Street & David W. Kissane, \textit{Constructions of Dignity in End-of-Life Care}, 17 J. PALLIATIVE CARE 93, 95, 99 (2001).

\textsuperscript{53} RANDALL & DOWNIE, supra note 48, at 192 (asserting that medical utility “include[s] patient need and the ability to benefit from both the process of care and the specific interventions of care”).

\textsuperscript{54} Id. at 116-18.

\textsuperscript{55} Id.

\textsuperscript{56} Zipursky, supra note 46, at 1142.

\textsuperscript{57} Id. at 1147; see also Lois Shepherd, \textit{Face to Face: A Call for Radical Responsibility in Place of Compassion}, 77 ST. JOHN’S L. REV. 445, 449, 457 (2003) [hereinafter Shepherd, \textit{Face to Face}] (calling for a greater prominence for caring responses in law and a sense of “shared humanity”).

\textsuperscript{58} 489 U.S. 189 (1989).

\textsuperscript{59} Id. at 213 (Blackmun, J., dissenting).

\textsuperscript{60} Id. at 212.

\textsuperscript{61} See OLIVER WENDELL HOLMES, JR., THE ESSENTIAL HOLMES: SELECTIONS FROM THE LETTERS, SPEECHES, JUDICIAL OPINIONS, AND OTHER WRITINGS OF OLIVER WENDELL HOLMES, JR. 119 (Richard A. Posner ed. 1992) [hereinafter HOLMES, SELECTIONS] (asserting that with regard to seeking the truth in law, “it is useful to omit the emotion and ask ourselves what those [imperfect social generalizations that make up our system of morality] are and how far they are confirmed by fact accurately ascertained”).

when the reasons for structuring the rule have disappeared, it is improper to maintain the rule “from blind imitation of the past.”

Surely, the reasons behind the prohibitions and restricted use of terminal sedation as a means of care in palliative treatment of patients in end-stage care need to be, at minimum, re-evaluated and even expanded to include such care of terminally-ill patients suffering severe psychological distress. An individual suffering at the end of his or her life may display forms of emotional, psychological, and existential suffering such as despair, helplessness, isolation, and loss of self-respect. The legal system should acknowledge a right not to suffer. Accordingly, physicians should have a professional responsibility to validate this right to the extent that they can under sound medical practice, and alleviate the suffering.

III. A CONTEMPORARY MODEL IN LEGAL DECISION MAKING

The law should accord a greater “caring response” or a “sense of shared humanity” in its interpretation and application. Indeed, a caring response is one of several humanistic values essential to sustaining the rule of law. Oftentimes, however, such values are challenged as being in conflict with abstruse “moralistic abstractions about liberty, equality and dignity.”

Unquestionably, decisions in health care concerning the maintenance of life and the hastening of death often pose complicated moral questions, which are anchored in normative reasoning, which—in turn—may, or may not, be relevant or cogent because of changing contemporary values. If moral reasoning is either ambiguous or ineffectual, courts will tend to rely on “moral intuitions,” or “assumptions about intrinsic normative order” found

proportions of people with the type of behaviors and problems that dominate the nation’s social policy agenda have limited cognitive ability).


VAN ZYL, supra note 17, at 196.

THOMASMA & GRABER, supra note 18, at 192.

See Shepherd, Face to Face, supra note 57, at 449 (arguing that caring responses should play a bigger role in law and policy decisions); see also du Bois-Pedain, supra note 3, at 324 (“[E]ven if care morality and its demands can only be imperfectly translated into legal norms, the law . . . must strive to do so even at the cost of some compromise to legal certainty and to the internal requirements of rule-based governance.”).

See Shepherd, Face to Face, supra note 57, at 456-57 (explaining the differences between compassion and pity).


Siegel, supra note 68, at 1030.

implicitly “in the natural course of life.”” Determining normative assumptions that animate moral judgments is a difficult task, and analytical frameworks of this nature that rely on non-verifiable subjective values often invite conflict.

In order to lend greater legal precision to their analyses, courts can choose to embrace the philosophy of Holmes, which prizes logic over experience. By adhering to legal formalism, moral judgments are avoided altogether—in large part because there is an awareness that it is very difficult to safeguard and sustain social solidarity if emotional values are given recognition in the processes of judicial decision making. If, however, formalism is rejected, judicial deference can then be given to “tradition and convention” as a construct for discerning moral convictions or discovering shared humanity instead of a rigid adherence to “academic reasoning.”

The best approach to, or model for, judicial decision making is one that achieves a balance between logical reasoning and, when appropriate, “critical morality” as opposed to traditional conventional morality. As such, courts must endeavor to apply a situation ethic rather than an unyielding and rigid normative standard, and then proceed to acknowledge love or agape as the controlling moral principle in all judicial decision making. Stated otherwise, guided by compassion or humaneness, the judiciary should interpret ever-evolving social values and the social conditions that shape those values.

71. Id. at 1589 (internal quotation marks omitted).
72. Id. at 1590.
73. See Holms, SELECTIONS supra note 61, at 237, 239 (explaining the evolution of law based on tradition to law based on logic).
74. Smith, De-Moralized, supra note 70, at 1589-90.
76. Smith, De-Moralized, supra note 70, at 1590.
77. Id.
78. See id. (explaining how courts side with “tradition and convention,” but academics side with “critical morality” and “reasoning”). Judge Richard Posner suggests that judges employ a type of reasoning termed “cultural cognition.” Posner, Judges, supra note 44, at 116. Cultural cognition is “a valid though flawed sense of knowledge” because when a judge uses cultural cognition, he is allowed to consider his personal vision of those policies important to him in order to advance his model of a good society. Id. at 117. “The personal, the emotional and the intuitive” are factors used in judicial making—with the intuitive being a salient factor in appellate review. Id. at 120.
79. See Fletcher, supra note 43, at 52 (defining “situation ethic” as a method of decision making that does not rely strictly on pre-conceived rules, but rather asks “how to do good for whom, not what is love but how to do the most loving thing possible in the situation”).
80. Siegel, supra note 68, at 981.
These values and conditions necessarily change with the facts of each case and, thus, so do the extent to which compassion and humaneness are pertinent. The ultimate goal of judicial decision making should, in the end, be a “practical realization of the rule of law.”

IV. DETERMINING PATIENT VALUES AND BEST MEDICAL INTERESTS

Patient values must always be viewed as the baseline for developing and pursuing patient-centered palliative care for terminal illness. Best patient care, ideally, is adjusted to a patient’s changing medical condition. Palliative care provides adjusted care by endeavoring to relieve end-stage suffering of all kinds—physical and psychological. If relief from suffering is viewed as a patient right, then, health care providers and the state have a basic responsibility to establish policies designed to validate this right and follow a course of action that seeks to honor a patient’s desire for an easeful death.

Ultimately, the determination of the parameters of a patient’s best

81. Id. at 979; see also George P. Smith, II, Judicial Decisionmaking in the Age of Biotechnology, 13 NOTRE DAME J.L. ETHICS & PUB. POL’Y 93, 101 (1999) (explaining that the law serves to define and protect individual rights, ensure public order, resolve disputes, optimize economic efficiency, dispense justice, and provide for a structure for preventing or compensating injury, among other things).


83. THE PRESIDENT’S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 216-17 (2005); see also THOMASMA & GRABER, supra note 18, at 192 (discussing the right to control decisions regarding one’s own medical conditions).


85. THOMASMA & GRABER, supra note 18, at 192.

86. Margaret P. Battin, Euthanasia: The Fundamental Issues, in READINGS IN HEALTH CARE ETHICS 363, 363 (Elisabeth Boetzkes & Wilfred J. Waluchow eds., 2000). See generally du Bois-Pedain, supra note 3, at 321 (“The explanation [of the recognition of care morality within the criminal law]... lies, quite simply, in the presence of the doctor’s duty of care which exhorts him to relieve the patient’s suffering. It is this duty which counterbalances and ultimately overrides certain prohibitions of actions.”).

medical interests is shaped by policies of reasonableness*88 and compassion.*89 Neither reasonableness nor compassion are capable of a precise formulation, but rather are tied inextricably to issues of proportionality or cost/benefit analysis,*90 which, in turn, must remain fact-sensitive and shaped by the “accepted standards of medical . . . practice” applicable within each medical case presented.*91

A. Medical Futility and Proportionality

The popular notion within American society—that there is a required prescription to treat under all circumstances—needs to be re-evaluated and brought into contemporary focus through acceptance of the doctrine of medical futility.*92 Under this recognized doctrine, when medical care is complemented by the test of proportionality imbedded presently in the principle of double effect,*93 the central treatment question becomes whether the burdens of treatment clearly outweigh its benefits to the patient and would be inhumane if continued.*94 In those cases where medical treatment is


*89. See EDMUND D. PELLEGRINO & DAVID C. THOMASMA, FOR THE PATIENT’S GOOD: THE RESTORATION OF BENEFICENCE IN HEALTH CARE 55 (1988) (describing compassion as one of the ideal characteristics that physicians should possess in addressing patients’ wishes). See also MARGARET SOMERVILLE, THE ETHICAL IMAGINATION: JOURNEYS OF THE HUMAN SPIRIT 222 (2009) (observing that “compassion and courage are companions”).

*90. See BARRY R. SCHALLER, UNDERSTANDING BIOETHICS AND THE LAW 4 (2008) (using the term “ethinomics” to “describe the convergence of ethics and economics” and recognizing the concern of some that acknowledging this convergence could dehumanize the process of medical decision making); Joseph Boyle, Enriching Proportionalism Through Christian Narrative in Bioethics: The Decisive Development in Richard McCormick’s Moral Theory?, 14 CHRISTIAN BIOETHICS 302, 304, 306-08 (2008) (discussing proportionalism as a consequentialist form of moral analysis where, in order to reach a moral judgment, all aspects of an action—including its side effects—are compared or balanced in terms of their ultimate effect on the human good).

*91. SMITH, FINAL CHOICES, supra note 88, at 173-74; see LAWRENCE J. SCHNEIDERMAN ET AL., MEDICAL FUTILITY: ITS MEANING AND ETHICAL IMPLICATIONS, IN BIOETHICS: AN INTRODUCTION TO THE HISTORY, METHODS, AND PRACTICE 408, 409 (Nancy S. Jecker et al. eds., 2d ed. 2007) (explaining that the doctrine of medical futility can be understood and applied in a practical and common sense way).

*92. See DANIEL CALLAHAN, THE TROUBLED DREAM OF LIFE 199 (1993) (“There is a deeply embedded presumption in medicine: when life is at stake, there should always be a bias in favor of treatment.”); id. at 203-06 (explaining the five stages of rejection of life-extending treatment, ranging from “a refusal to respond to all health threats” to “an eagerness to pursue any medical treatment”).

*93. The principle of double effect, stated succinctly, sets forth a ethical framework for determining when it is permissible to undertake action that achieves a good result (e.g., the alleviation of pain and suffering of end-stage illness) even though a negative or bad result (e.g., a hastening of death) will flow from the initiating conduct. SMITH, FINAL CHOICES, supra note 88, at 47-49, 55-59, 101-05. See also GEORGE P. SMITH, II, REFRACTORY PAIN, EXISTENTIAL SUF FERING, AND PALLIATIVE CARE: RELEASING AN UNBEARABLE LIGHTNESS OF BEING, 20 CORNELL J. L. & PUB. POL’Y 469, 500 (2011) [hereinafter SMITH, REFRACTORY PAIN] (explaining the doctrine of double effect).

*94. For Callahan, testing the burdens and benefits of treatment modalities is tied ultimately
seen as futile, terminal sedation should be recognized as but a part of end-stage total symptom management and validated as an integral part of palliative management.\textsuperscript{95} Once end-stage, terminal suffering is managed more effectively, the law must change the legal taxonomy and reliance on the principle of double effect in testing whether assistance in ending life is capital murder or euthanasia.\textsuperscript{96} Instead, the degree of necessity for providing compassionate assistance to dying patients—together with an assessment of the soundness of the medical judgment of the health care providers rendering the assistance—should be pivotal in legal analysis of end-stage care. Indeed, the central or “fundamental part” of the end-of-life “equation” for making rational medical decisions must always be seen as “the patient’s quest for a dignified death”\textsuperscript{97} or, alternatively, the “least worst death.”\textsuperscript{98} A good death is
said, commonly, to be one that occurs “after a long and successful life, at home, without violence or pain, with the dying person being at peace with his environment and having at least some control over events.”

B. The Right to Refuse Treatment

Rather than continue a quest to establish a constitutional right to assisted suicide, perhaps—in the final analysis—the time-honored common law right to refuse treatment should be seen as the corner stone for building a more compassionate and enlightened ethic of understanding in managing end-of-life issues. This right of refusal is not a right to hasten death, but rather merely a right to resist unwanted physical invasions.

With the passage of the Patient Self-Determination Act in 1990, Congress took a bold first step to validate the right to refuse treatment. This legislation strengthened patient autonomy by allowing newly-admitted hospital and nursing home patients to choose whether they wished to accept or refuse specified medical treatment during the course of their confinement.

Additional steps in building an arsenal to safeguard a framework for


100. See, e.g., George J. Annas, The Bell Tolls for a Constitutional Right to Physician-Assisted Suicide, 337 NEW ENG. J. MED. 1098, 1098 (1997) (“The debate about a constitutional right to physician-assisted suicide, on the other hand, was abruptly ended on June 26, 1997, the day the U.S. Supreme Court issued two unanimous rulings on the issue.”) (footnotes omitted).

101. See id. at 1102 (“The right to refuse treatment, on the other hand, is a long-recognized right that physicians are legally and ethically required to honor. Patients have a right to insist that their bodies not be invaded without their consent.”).

102. NEW YORK TASK FORCE ON LIFE & THE LAW, SUPPLEMENT TO WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT 7 (2006), available at http://www.health.ny.gov/regulations/task_force/reports_publications/select_reports/assisted_suicide_and_euthanasia/docs/supplement.pdf; see also LOIS SHEPHERD, IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO 59-60 (2009) (“A number of state courts recognizing the right to refuse treatment have chosen instead to rely on the right against unwanted intrusions of the body found in the common law . . . , explicit rights to privacy in state constitutions . . . , statutory rights, or some combination of these legal sources.”). See NEIL M. GORSUCH, THE FUTURE OF ASSISTED SUICIDE AND EUTHANASIA 181-215 (2006) (discussing case law addressing the intersection of the right to refuse treatment and the “inviolability of life” with regards to competent and incompetent patients and those with and without an intent to die).


105. Id.
principled decision making in end-of-life cases were taken by the development of the Uniform Health Care Decisions Act,\textsuperscript{106} the successful efforts of some states to enact pain relief statutes,\textsuperscript{107} the Death with Dignity statutes of Oregon\textsuperscript{108} and Washington,\textsuperscript{109} and the medical protocols for use of palliative (hospice) care and terminal sedation.\textsuperscript{110} These “weapons” in the arsenal serve to protect and encourage sound, reasonable medical judgments and, thus, in a very real way, balance physicians’ powers and protections with patient rights of autonomy.

C. Utility, Common Sense, and Compassion

Utility,\textsuperscript{111} most assuredly, comes into play after medical conditions are

\begin{itemize}
  \item \textsuperscript{107} Some twenty-one states have pain relief laws—with eighteen allowing marijuana to be used for medicinal purposes (e.g., the relief of pain). State Medical Marijuana Laws, Nat’l Conf. State Legislatures, http://www.ncsl.org/issues-research/health/state-medical-marijuana-laws.aspx (last visited May 31, 2013); see also Jessica Chiu et al., Access to Therapeutic Opioids: A Plan for Donors, NGOs and Governments, 24 Temp. Int’l & Comp. L. J. 417, 442 (2010) (indicating the need for clear goals and funding strategies at a national level in order to make opioid medication more accessible to individuals who need it).
  \item \textsuperscript{109} Wash. Rev. Code § 245.020 (2009). Although not declaring a constitutional right to die with dignity, the Montana Supreme Court held on December 31, 2009, that—under the state’s Rights of The Terminally Ill Act—competent terminally ill patients can request physician assistance in obtaining a prescription for a lethal dose of medicine to be self-administered; and, further, the Act shields physicians from civil or criminal liability for any such assistance. Baxter v. Montana, 224 P.3d 1211, 1215 (Mont. 2009). The Vermont Legislature passed legislation comparable to that in place in Oregon and Washington in May 2013. Vt. Stat. Ann. tit. 18, § 5281 (2013). See Paula Span, Vermont Passes ‘Aid in Dying’ Measure, N.Y. Times The New Old Age Blog (May 14, 2013, 10:18 AM), http://newoladge.blogs.nytimes.com/2013/05/14/vermont-passes-aid-in-dying-measure/?_r=0 (“Vermont will become the fourth state to make it legal for a physician to prescribe lethal medication to a terminally ill, mentally competent patient who wants to end his life.”). See also Jessica Chiu et al., Access to Therapeutic Opioids: A Plan for Donors, NGOs and Governments, 24 Temp. Int’l & Comp. L. J. 417, 442 (2010) (indicating the need for clear goals and funding strategies at a national level in order to make opioid medication more accessible to individuals who need it).
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  \item \textsuperscript{109} Wash. Rev. Code § 245.020 (2009). Although not declaring a constitutional right to die with dignity, the Montana Supreme Court held on December 31, 2009, that—under the state’s Rights of The Terminally Ill Act—competent terminally ill patients can request physician assistance in obtaining a prescription for a lethal dose of medicine to be self-administered; and, further, the Act shields physicians from civil or criminal liability for any such assistance. Baxter v. Montana, 224 P.3d 1211, 1215 (Mont. 2009). The Vermont Legislature passed legislation comparable to that in place in Oregon and Washington in May 2013. Vt. Stat. Ann. tit. 18, § 5281 (2013). See Paula Span, Vermont Passes ‘Aid in Dying’ Measure, N.Y. Times The New Old Age Blog (May 14, 2013, 10:18 AM), http://newoladge.blogs.nytimes.com/2013/05/14/vermont-passes-aid-in-dying-measure/?_r=0 (“Vermont will become the fourth state to make it legal for a physician to prescribe lethal medication to a terminally ill, mentally competent patient who wants to end his life.”).
assessed and evaluated and a treatment prognosis is charted.\textsuperscript{112} It is within the boundaries of utility that the principle of medical futility is tested and determined to be efficacious or, as to a particular case, invalid.\textsuperscript{113} Cost/benefit (or, simply proportional) analysis of treatment options is central to a determination of medical futility,\textsuperscript{114} since this determination is—first and foremost—but a clinical judgment and not an encompassing moral evaluation or principle on the “worthlessness” of a life.\textsuperscript{115} Whether the operative normative standard for policy making be termed agape,\textsuperscript{116} charity,\textsuperscript{117} compassion,\textsuperscript{118} love,\textsuperscript{119} or mercy,\textsuperscript{120} the common or unifying denominator to palliative care is a humane, morally responsible approach to dealing with intractable suffering at the end-stage of life.

Good judgment is to be expected of judicial decision makers just as it is for healthcare providers. As a quality in reasoning, good judgment is characterized as “an elusive faculty best understood as a compound of empathy, modesty, maturity, a sense of proportion, balance, a recognition of human limitations, sanity, prudence, a sense of reality and common sense.”\textsuperscript{121} individuals.” \textit{Id.}

\textsuperscript{112}. \textit{Id.} at 28 (explaining that utility should be determined by “weigh[ing] the gravity of the harm in allowing lifesaving actions versus the utility of the benefits stemming from the actions,” a balancing test which requires that the medical condition be thoroughly evaluated).

\textsuperscript{113}. See \textit{id.} (“The utility of the benefits would be measured in terms of an evaluation of the positive consequences that flow to the threatened individual and to society. In truth, then, this balancing test seeks to arrive at a cost-effective decision through a cost-benefit analysis.”) (footnotes omitted).

\textsuperscript{114}. See Vijay N. Joish & Gary M. Oderda, \textit{Cost Utility Analysis of Quality Adjusted Life Years}, 19 J. PAIN & PALLIATIVE CARE PHARMACOTHERAPY 57, 57 (2005) (explaining how cost-benefit analysis can help allocate limited medical treatment resources). It has been suggested that any determination of futility should be jointly made by the physician, patient, and surrogate decision maker, with an eye to “strike[] a balance between three criteria: effectiveness, benefit, and burden,” in achieving the patient’s good. Pellegrino, \textit{Decision, supra} note 38, at 227.


\textsuperscript{117}. See Pellegrino, \textit{Decision, supra} note 38, at 241 (advancing charity as an attribute of end-of-life care and treatment).

\textsuperscript{118}. Defined as “pity that inclines one to spare or to succor.” \textit{III Oxford English Dictionary} 597 (2d ed. 1989).

\textsuperscript{119}. Defined as “[t]hat disposition or state of feeling with regard to a person which . . . manifests itself in solicitude for the welfare of the object . . .” \textit{IX Oxford English Dictionary} 52 (2d ed. 1998); see Joseph Fletcher, \textit{Love Is the Only Measure,} 83 COMMONWEALTH 427, 429 (1966) (“Good is first and foremost the good of people. Christians call it ‘love,’ meaning neighbor-concern or agape. This love means, of course, a social attitude, not the romantic emotion that the word has come to connote in popular literature.”).

\textsuperscript{120}. Defined as a “[d]isposition to forgive or show compassion.” \textit{I Oxford English Dictionary} 625-26 (2d ed. 1989).

\textsuperscript{121}. Posner, Judges, \textit{supra} note 44, at 117.
Elusive though such judgment may be to capture or own, sound, reasoned judgments in medico-legal decision making must be the norm and not the exception.

To initiate or continue with medically futile treatment should be recognized as simply wrong; for, acting in such a manner not only denies the fact of human finitude but additionally imposes unnecessary effort, expense, and emotional trauma on both patients and other affected parties. When efforts to treat futile medical conditions are undertaken, such actions serve as a total abnegation of one of the cardinal principles of medical ethics—namely beneficence.

It has been argued persuasively that while the state may declare a legitimate interest in morality, for it to meet a heightened level of judicial scrutiny on review of such end-of-life declarations, it faces an increasingly difficult challenge to justify a decision to sacrifice “claims of associational autonomy”—grounded as such “in ‘expressive’ association or in ‘intimate’ association”—in order to protect public morality. Accordingly, the state must take care to eschew administrative, judicial, or legislative determinations that abridge “choices central to personal dignity and autonomy, [which] are central to the liberty protected by the Fourteenth Amendment.”

It is logical to assume that the right to compassionate care in end-stage illness is, indeed, grounded in a liberty interest and, thus, cannot be unduly challenged or restricted by a state interest in judging the “morality” of autonomous actions designed to give purpose and promote the basic interest in liberty to die with dignity.

Society’s central obligation is to refrain from mandating one moral code over another, and, instead, to define and safeguard “the liberty of all” and promote social policies which address

122. Pellegrino, Decision, supra note 38, at 234 (suggesting that refusing treatment due to economic concerns “could . . . be an act of charity in the interests of one’s family or to society at large”).
123. Id. at 223; see PELLEGRINO & THOMASMA, supra note 89, at 29 (discussing several examples of court cases that emphasized “patient’s wishes . . . as a means for protecting the patient’s best interests”).
125. Id. at 1936.
126. Id.
129. Casey, 505 U.S. at 850. The right of privacy from governmental intrusions, expressed in Griswold v. Connecticut and Eisenstadt v. Baird, add to the strength of the liberty of associational expression found in Lawrence; in arguing for a right to die with dignity without unduly burdensome state interference. See Griswold v. Connecticut, 381 U.S. 479, 484-86 (1965) (explaining that various guarantees in the Bill of Rights create “zones of privacy”); Eisenstadt v. Baird, 405 U.S. 438, 453 (1972) (“If the right of privacy means anything, it is the right of the
suffering with charity, compassion, and common sense.\textsuperscript{130} Integral to this societal obligation is recognition of a co-ordinate duty of health care providers “not to prolong dying.”\textsuperscript{131} This duty arguably coalesces with and, indeed, validates the very principle of beneficence,\textsuperscript{132} and—accordingly—shapes a new “right” of the terminally ill not to endure refractory pain and existential suffering at the end-stage of life,\textsuperscript{133} and, thus, ensure that death occurs with some semblance of dignity.\textsuperscript{134}

\textsuperscript{130} See \textsc{David C. Thomasma}, \textit{Human Life in the Balance} 194-95 (1990) (describing social policies that could support a commitment to control pain and address suffering); see also du Bois-Pedain, supra note 3, at 297 (arguing that the duty of care “should be understood as giving rise to a distinct moral, and consequently also to a distinct legal regime”); \textsc{Herring, Caring and the Law}, supra note 3, at 88-101 (considering the role of the state in providing care). See \textit{generally} \textsc{Nancy K. Knauer}, \textit{Aging in the United States: Rethinking Justice, Equality, and Identity Across the Lifespan}, 21 TEMP. POL. & CIV. RTS. L. REV. 305 (2012) (discussing University of Virginia Professor Lois Shepard’s view that on end-of-life medical care should be “approached . . . with consideration to patient’s wishes, values, interests, and relationships—and without special laws”).

\textsuperscript{131} \textsc{Thomasma}, supra note 130, at 194. This duty should be triggered when one is diagnosed as terminally ill, has made a determination (or executed an advance directive) that, because of medical conditions, life no longer has personal meaning, or when, even though no such decision has been made by the patient and there is no advance directive, there is nonetheless a medical realization that the terminal illness is “in its imminent phase and the patient is no longer able to participate in the spiritual and material goods of human life.” \textit{Id.}

\textsuperscript{132} See \textsc{Pellegrino & Thomasma}, supra note 89, at 26-27, 32-35 (explaining that beneficence acts towards the best interests of the patient).

\textsuperscript{133} See \textsc{Eric J. Cassell}, \textit{The Nature of Suffering and the Goals of Medicine} 275-76 (2d ed. 2004) (discussing “[t]he progression of suffering” and noting that “the experience of illness of which the pain in part is fed by external events such as unhappy interactions with physicians, medical, care, or institutions, the injury to the patients begins to broaden”); see also \textsc{Jeffrey T. Berger}, \textit{Rethinking Guidelines for the Use of Palliative Sedation}, HASTINGS CTR. REP., May/Jun. 2010, at 32, 32-33 (2010) (explaining that palliative sedation can provide relief for patients at end of life).

\textsuperscript{134} See \textsc{Epstein}, supra note 18, at 311 (describing “the needless amount of suffering that” takes place at the end of life without assisted suicide); \textsc{Charles Foster}, \textit{Human Dignity in Bioethics and Law} 170-72 (2011) (discussing the concerns of dignity in end-of-life scenarios and various British cases involving such situations); \textsc{Posner, Aging and Old Age}, supra note 98, at 260 (advocating for a right of physician-assisted suicide for the terminally ill); see also \textsc{Henig}, supra note 21, at 42 (discussing Professor Margaret Battin’s notion that two essential moral constructs must be operating in tandem before physician assistance at death should be allowed: namely, autonomy—with a sincere patient acknowledgment of a wish to die—and mercy, a medical conclusion that death assistance is the only way in which intractable pain and suffering can be abated).