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## THE RIGHT TO DIE AND THE RIGHT TO HEALTH CARE

**ABSTRACT:** Two central issues that shape contemporary medical ethics are, on the one hand, the nature and basis of rights to health care, and, on the other hand, the rights of the dying and the role of the physician when death is imminent. The right to health care and the right to die are typically treated as two distinct sets of issues. These issues, however, are not distinct. As we shall see, if there is a right to die, which I argue there is, then there is also a right to health care. In particular, I argue that respect for the autonomy of persons requires that we respect a person's informed and considered request to hasten death but that concern for persons also supports strong procedural safeguards governing assisted dying. In addition to the normal conditions limiting physician assisted suicide and active euthanasia, I also argue that the right to die provides a justification for a right to health care services.

**KEYWORDS:** Right to die, Right to health care, Physician assisted suicide, Euthanasia, Double effect, Right to hasten death

Two central issues that shape contemporary medical ethics are, on the one hand, the nature and basis of rights to health care, and, on the other hand, the rights of the dying and the role of the physician when death is imminent. The right to health care and the right to die are typically treated as two distinct sets of issues. These issues, however, are not distinct. As we shall see, if there is a right to die, which I argue there is, then there is also a right to health care.

End of life issues in medical ethics usually focus on how to respect patient autonomy and yet still act with concern for the best interest of the patient; or at least, to act so as not to directly harm the patient. As the ancient oath famously says, above all first do no harm. These are the three core principles of clinical medical ethics: beneficence, non-maleficence, and respect for patient autonomy. The ideal patient-physician relationship must honor and sometimes balance these core principles. More specifically, the nature of the right to die and the correlative responsibilities of the physician involve day to day issues that emerge between a particular patient and physician in a clinical setting. Health care justice, by contrast, focuses on the health care delivery system rather than the clinical setting of the patient-physician relationship. The principles in question here are matters of distributive justice, efficiency,

and fairness. This division is, of course, overly simplistic. The health care system is the context in which clinical questions occur, and the system is often a constitutive part of a moral problem or dilemma. Indeed, health care systems may be more or less justified, in part, because of the problems they resolve or cause. In general, if a basic part of the social structure of a society contributes to the violation of fundamental rights, that is a good (*prima facie*) reason to modify the structure in question.

At present in the United States, the main obstacle to the acceptance of a broader right to control the manner and time of one's death is the combination of unequal access to basic health care services and the inadequacy of the care of the dying in this country. In the context of the United States health care delivery system, decisions about death may reflect the economic costs of continued care or the inadequacy of palliative and comfort care provided, rather than the deeper values of the patient. Remarkably, rather than recognizing this as a compelling reason to provide both better end of life care and universal access to this care, irrespective of financial considerations, the inadequacy of medical care has been used as a basis to inflict further indignities on dying patients by restricting their right to die as they see fit.

In addition, arguments which focus on inadequate end of life care provide a similar rationale for limiting or prohibiting the now routine decisions to let patients die. The decision to withdraw (often very expensive) life-prolonging care is surely as subject to subtle or explicit coercive pressures as the decision to end one's life when one is not dependent on life support and so must do so by more active means. Yet the opponents of a more expansive right to die (including the AMA) seem to ignore the apparent inconsistency in their position. If lack of access to high quality end of life care is grounds for doubting the autonomy of decisions to actively end one's life, it is also equally an argument against the autonomy of decisions to passively end one's life. The inconsistency here reveals, I believe, an important problem with the current state of thinking about end of life decision making.

In what follows, we first look at the basic rationale for a right to die. More specifically, the right in question is a right to hasten one's death in such a manner that one dies sooner in order to die better. The qualities that make a death a good death or at least a better death are determined by the person's individual conception of the good and also broader religious or spiritual imperatives. The focus is on the character of the death, however, and not simply the decision whether to live or die when the death of person is not already imminent. A right to die, as I conceive it, in no way diminishes the value of each person's life. After looking at the basic rationale for a right to die we turn to familiar objections to taking more active means to hasten death, including physician assisted suicide (PAS) and voluntary active euthanasia (VAE).



Throughout, I argue that pragmatic considerations, and not basic principles, are the primary remaining objections to actively hastening one's death; that these practical objections apply equally to passively hastening death by letting underlying diseases kill people; and I conclude that the appropriate moral and practical response to the practical objections clearly is not prohibition of physician assisted suicide (PAS) and voluntary active euthanasia (VAE), but instead an expanded right to high quality end of life health care services. As a corollary, it also follows that high quality end of life care should be an essential part of basic health care services.

#### AUTONOMY, BATTERY, AND PUBLIC POLICY

Although reasonable people may disagree about the nature and extent of a right to die, as a matter of public policy in a secular democracy, there is an overwhelming case for a broad and expansive right to die. Clearly, one of the most powerful sources of opposition to a right to die is based in particular religious beliefs and a more general belief that life and death questions are a matter for the divine will and not human choice. Religious doctrines and the judgment of religious authorities are powerful and important determinants of individual moral belief. In a society committed to religious freedom and a doctrine of free faith, however, religious authority does not provide a reasonable basis for public policy or state coercion. Choice about how to die is analogous to the pro-choice position over the decision whether or not to carry a pregnancy to term. The fundamental liberty principle set out by the United States Supreme Court in the *Casey* abortion decision clearly applies equally to end of life decisions:

It is a promise of the Constitution that there is a realm of personal liberty which the government may not enter ... Men and women of good conscience can disagree about the profound moral and spiritual implications of *actively hastening a death or letting a person die, even by withholding treatment*. Some of us find *assisted suicide and euthanasia* offensive to our most basic principles of morality, but that cannot control our decision. Our obligation is to define the liberty of all, not to mandate our own moral code. The *patient facing death* is subject to anxieties, to physical constraints, to pain that only *he or she* must bear. The suffering of *patients* is too intimate and personal for the state to insist upon its own vision of the *end* of life, however dominant that vision has been in the course of our history and our culture. The destiny of *terminal patients* must be shaped by *their* own conception of *their* spiritual imperatives. (from *Casey* US SC 1992: italicized changes are alteration from the original to apply to end of life decisions. For original

unaltered text see footnote #1)<sup>1</sup>

Although many constitutional principles are controversial, there is indeed a widespread overlapping consensus embracing the principle of freedom of conscience, especially on fundamentally personal, spiritual, and religious matters. There is thus a strong presumption in favor of a fundamental right of self-determination at the end of one's life. Furthermore, since, unlike the abortion controversy, the right to die does not involve any issue of the potential life of another, the right of self-determination should be even clearer in this case.

It should be clear to all that respect for autonomy, that is, individual self-determination, provides a clear basis for the individual's right to refuse life prolonging medical care. Some, however, have argued that the right to refuse care is based instead on right to be free from battery and other assaults on one's bodily integrity. This more limited right, it is argued, does not include a right to control the manner and nature of one's death. Persons have a general right to be "let alone" unless they violate the rights of others, and this negative right is the basis for the right to refuse treatment but it is not a sufficient basis, it is claimed, for a positive right to hasten one's death.<sup>2</sup> This argument is puzzling. Granted that battery is wrong, but so too is restricting liberty. Persons have a fundamental interest in determining how they die, and this provides a clear basis for a basic right to hasten death.<sup>3</sup> We need some competing essential government purpose for any state actions that aim to restrict this liberty, and this includes attempts to restrict the liberty of others who are willing to help hasten my death. Both sides of this debate recognize the importance and centrality to a person of the manner of their own death. Indeed the debate is over how one shows due respect and compassion for the dying person. So, as an issue of public policy, limits on the right to die need to focus on legitimate protections of the dying person's own interest, or alternatively on distinct and assignable harm to others in society. The rest of our discussion will focus on these types of concerns.

#### THE PRIORITY OF PERSONS OVER MERE PREFERENCES

First, we need to get clearer about the nature of respect for a dying person. It is argued by some that the intentional destruction of an innocent person is always incompatible with respect for the dignity of that person. Indeed, the argument goes, it is always wrong to kill oneself merely to avoid suffering because one's value and dignity as a person transcends the mere value of pleasure and pain. It is thus never permissible to kill oneself because one's future promises more misery than benefit



because doing so violates the fundamental moral requirement to treat oneself as an end and not a means only. Each person has a special value, a dignity that cannot be exchanged for mere benefit or to avoid some harm. Just as it is wrong to sacrifice someone in order to promote the pleasure of others, so too it is wrong to sacrifice oneself merely to avoid pain. The self-destructive act of suicide treats oneself as a thing and thus fails to recognize the inner value and dignity of oneself as a person.<sup>4</sup>

The idea behind this principle of prohibition of all suicides does have some appeal. Consider a case where a person whom one cares about is acting on self-destructive preferences: Normally, if we care about people, then we also care about their happiness and we thus also want them to realize their projects and to live up to their ideals. Our concern for the ends of others, however, is based on our concern for them. When we act in ways that promote the ends of another, it is because we think that that person matters. If not, then their ends would not matter. So there is something incoherent about caring about the subjective ends of another and not caring about that person. In general, the ends of another person matter because the person matters. The value of a person is prior to the value of the person's preferences — so far so good.

The argument for the prohibition on suicide next assumes that one's continued existence as a person always takes priority over one's conception of one's own good. Here is the idea: My conception of the good matters only if I matter, so my conception of the good cannot provide a justifying basis for destroying myself. Suicide for the sake of benefit is thus never justified. Despite its apparent logic, this just does not seem right. It seems clear that death can be a release and a benefit for a dying person. So what has gone wrong?

We need to distinguish two senses in which we might be concerned for a person, and not simply the preferences of the person. The argument for prohibition assumes that concern for a person necessarily involves concern for the continued existence of a person. Concern for a person, however, involves concern for the person's integrity and character, not the person's mere existence. The object of respect and the basis of human dignity is autonomy: the capacity to set oneself ends and pursue a conception of the good that gives one's life meaning and purpose. We thus respect human dignity by endorsing and following procedures that allow each person to reflectively endorse and to pursue a substantive conception of the good.<sup>5</sup> We respect the dignity of ourselves by living *and dying* in accordance with the values and principles that we reflectively endorse. Respect for others also involves a similar respect for their values and principles. And, of course, respect for dignity, in this sense, may include assisting them in dying, in a manner that reflects the values and principles that con-

stitute their conception of the good. Helping someone die may be fully consistent with respecting the dignity of that person.<sup>6</sup>

The choice here can be limited to how to die when death (or loss of personhood) is imminent. Controlling the timing and method of one's death in no way compromises the value of life itself. One can continue to view life as a priceless gift and to honor the dignity of all persons, including one's self, and yet also realize that one's life as a person is now done. The acceptance of death is compatible with the valuing of life. After all, it is not as if how long one lives determines the intrinsic value of one's life. Furthermore, I believe that clinging to every minute of life, simply because it is more life, fundamentally misconceives the nature of the intrinsic value of a human life.

Let us pause for a moment and notice, however, that the argument so far does not imply that one should honor all requests to die. The decision to die must be informed and considered and it must actually reflect the values and principles of the person in question. Respect for a person does not require respect for uninformed or reckless or irrational decision. I have argued that the primary object of respect is the person and not simply the person's preferences. We honor preferences because they reflect the character and values of the person. Especially in cases where the consequences are serious and irreversible, it is reasonable to have procedures and policies that help demonstrate that the preference in question is indeed informed and that it reflects the values and principles of the person. The decision to die clearly should be based on a stable and enduring principled preference. It follows that safeguards that try to insure that the decision to die does indeed reflect the person's values and principles are called for. We want to make sure that a request to die sooner is not simply the result of depression, panic, or coercive social pressure. Procedural safeguards reflect a commitment to respect the person, and not just passing or distorted preferences, and thus these types of safeguards are not unduly paternalistic and disrespectful of the person. The exact nature of these safeguards will be discussed more explicitly below.

#### THE ROLE OF THE PHYSICIAN

Assisting someone to die strikes many physicians as contrary to their fundamental role as healers. The role of the physician is to save lives, not end them, it is argued.<sup>7</sup> Some physicians (still) think of death as an enemy, an evil foe to be conquered and defeated and, since this is in the end impossible, to be fought by every means necessary to that bitter end. Of course, few physicians really hold this extreme view (although the above is almost a direct quote from a physician on a medical ethics



committee). Patients clearly cannot always be cured and the physician's role includes caring for patients who cannot be cured. Indeed, before the great successes of modern medicine, easing the suffering of illness and dying was a primary focus of much medical care.

Yet once we acknowledge, as surely one must, that caring for the dying is a constitutive part of the role of a physician, it is unclear why helping someone die cannot be an act of care that is done for the sake of the patient in question. Since the fundamental values and principles of a particular patient determine what is a good death for that patient, the patient's values, not the physician's, should be sovereign. Since caring for a person includes respecting their values and perspective, helping a patient to die sooner so that they die better can be a way of caring and showing compassion for the dying. Compassion towards the dying is indeed a medical imperative, and compassion in dying can involve hastening the death of the person. When this is so, there is nothing in the role of the physician that is intrinsically inconsistent with helping a person die in a manner that reflects the dying person's values and perspective.

Furthermore, physicians do let patients die, in a compassionate and caring way, all the time. It is now commonplace to withdraw life-sustaining treatments at the request of patients or their surrogates. Clearly, when such decisions are made, the physician role does not end; it is instead transformed. The standard of reasonable care of the dying includes continuing to care for the patient, to respect the wishes and values of the patient, and striving to make their passing as comfortable and painless as is possible. Why then does this role not also include respecting a terminally ill patient's considered and informed request to hasten death? In short, hastening a patient death is inconsistent with the role of the physician only if it is wrong for some other reason. It is a dodge, and ultimately also disingenuous, to appeal to the "essential healing" role of the physician. Caring for those who cannot be cured is and ought to be part of the mission of medicine.

The substantive objection behind this misleading appeal to the ends of medicine, I suspect, is the concern that it is always wrong to intentionally end life. What is truly difficult in these controversial cases is quite simply the individual's recognition of the weighty responsibility for helping to actively end a life. This is not a decision or action to be taken lightly. In the Netherlands, whenever possible, physicians always try to ease a patient's death by euthanasia at the end of the day and on a Friday.<sup>8</sup> It is too hard to go on as usual afterwards. Even with the conviction that the action is compassionate and justified, hastening a death is still a trying and difficult thing to do. It is no wonder that physicians do not seek this weighty responsibility.<sup>9</sup>

### INTENDING AND FORESEEING DEATH

At the heart of much opposition to actively hastening death is the assumption that the intentional taking of human life always violates the sanctity of life. This type of concern is not new. Over the past 40 years, the progress of medical science and technology has forced us to continually rethink and consider the meaning of the prohibition on taking human life. First, the ability to keep the body functioning when the brain is dead changed the focus from cardio-respiratory function to brain function in the determination of the death of the person. Next, the New Jersey Supreme Court case that involved Karen Anne Quinlan (in 1976) focused attention on the permissibility of withdrawing life support for persons in a persistent coma with irreversible loss of consciousness. Although at the time the hospital and doctors argued that the act of withdrawing life-sustaining care is an intentional action that causes death and so is an act of wrongful killing, it is now almost universally agreed that such actions are not wrong. It is also argued that, in withdrawing life-preserving treatment, the physician is not killing the patient but is simply letting the patient die. It is the underlying disease, and not the physician, they say, that causes the patient's death. Although this claim is a commonplace, it is curious. As we have just discussed, the opponents of actively hastening death have also argued that curing disease and preserving life is the primary role of the physician. We are thus owed some explanation for why it is ok to just let patients die when life-sustaining care is available. Of course, if the patient is not facing a terminal condition and has not consented, it would be truly surprising if this omission were consistent with the ends of medicine and the role of the physician! It seems clear that what distinguishes permissible and impermissible cases of letting someone die is in part the consent of the patient or a surrogate, or, when the patient's wishes are not known, a judgment that the continued life prolonging treatment is not in the patient's best interest. The patient's consent, fundamental values, and best interest play a crucial role in deciding whether or not continued life-prolonging care is called for.

So, what importance, if any, is there to the fact that the disease is necessary in these cases as the underlying cause of death? The opponents of more active measures to hasten death, when the death is equally consistent with the patient's wishes, fundamental values, and best interest, place tremendous importance on whether the underlying disease kills the patient or whether instead an additional cause is introduced to intentionally cause the death. Clearly many people *feel* that there is a personal responsibility for the death if more active measures are taken, even when the death is just as certain a result in both cases. But what is the morally relevant difference



between intentionally withholding or withdrawing care that will result in the death of the patient and intentionally introducing a cause that will result in the patient's death? Why is the former a case of permissibly letting a patient die and the latter a case of (supposedly) impermissibly killing the patient?

The typical, but mistaken, answer to this question appeals to the supposed different intentions in the two types of cases.<sup>10</sup> The moral principle that is supposed to mark the difference here is called the doctrine of double effect. Roughly, this principle distinguishes actions that directly aim at harm from actions that cause, as a foreseeable effect, a similar harm but which do not directly aim to cause harm. Fortunately, we do not need to consider the soundness of this controversial principle, for it simply does not even apply to the types of cases that we are considering.<sup>11</sup>

The doctrine of double effect prohibits intentionally aiming at evil (or harm to the innocent) so that good may be done. The principle is familiar in discussion of just war theory and terrorism. One way of distinguishing acts of terrorism focuses on the wrongness of directly harming or killing the innocent as a means to even an otherwise legitimate goal. On the other hand when in war, for example, one may foresee that innocents will be killed as a result of an otherwise justified bombing of a military target. Foreseeing that innocents will be killed is morally different than targeting the innocent. It makes a difference if one is aiming at the harm to innocents, that is part of the plan one might say, or whether it is an unintended result of what one intends. Although the principle itself is controversial, let's assume that it is sound. The problem is that this principle simply does not apply to the types of cases which we are interested in here. The doctrine of double effect presupposes that the patient is being harmed and seeks a context in which the outcome is not a wrongful harm. Yet the reason why it is permissible to intentionally let a patient die, in some situations, is that we are respecting the patient's considered preference or fundamental values, and thus not letting the patient be harmed (all things considered) at all — or, alternatively, the death in question is judged to be in the patient's best interest and thus simply is not a harm. As these judgments about the permissibility of letting a patient die concede, death is not always an evil or harm to a person. In some cases the body lives on but the person is already lost and thus intentionally acting in ways that are meant to let the body die manifest no intention to allow a harm at all. In other cases, death can be a release from great suffering and thus something the person legitimately deems good. Indeed, if letting a person die involves foreseeing that the patient will be harmed, it is not clear *why* the physician does not do wrong by letting patients die. At the very least, if the death is a harm, the physician should do all they can to discourage patients from intentionally harming themselves in this way. Clearly, it is hard

to see how it could ever be permissible for a proxy to harm a patient in this way. And of course, the best interest standard of proxy decision-making would simply never apply. The point here, however, is that we rightly judge that death is not always a harm. But if the patient is not really harmed, then so too actively hastening death also does not necessarily intentionally harm the patient. In point of fact, the doctrine of double effect, as used in these types of cases, illegitimately assumes what is in question — namely, that the act of ending a life in accordance with the considered wishes of the patient is always wrong and thus evil. It assumes what is supposed to be shown and thus does no independent work in distinguishing actively hastening death from letting a person die.

As a last point, we need to briefly consider the case of “terminal sedation.” As a result of Cruzan (1990), it is permissible to withdraw nutrition and hydration and sedate a patient and let them die. This practice of “terminal sedation” is now also common in the United Kingdom and many other countries. How the doctrine of double effect here applies is especially curious. Although the sedation does indeed often treat pain and suffering, the lack of nutrition and hydration serves no palliative function. The reason for the withdrawal of nutrition and hydration is to let the patient die. This is the end and goal just as clearly as in the case of a lethal injection. No additional causal agent is introduced and thus the process is slow rather than swift, but the end is just as certain. One hopes that this type of decision is not treated lightly; that safeguards would be in place to prevent abuse; and that all other options are first explored. Yet I fear that a clear negative side effect of the comforting use of the idea that it is an underlying disease, and not the physician, causing the death is that decisions to end a patient’s life by withdrawal of life prolonging care are not adequately scrutinized and given the attention that they deserve.

#### LIMITS AND SAFEGUARDS

The principles of respect and concern that I have been defending are focused on a person’s *informed* preferences that *reflect the person’s basic values*. Decisions at the end of life, however, are difficult decisions influenced by fear of suffering, fear of death, and perhaps even clinical depression. Patients also often have unrealistic fears and concerns about loss of independence. It is thus necessary to be cautious in responding to a person’s desire to die. We need to know if the expressed preference to die is a considered, informed preference that reflects the person’s values or whether it is a suicidal impulse, which simply reflects fear and depression. To overcome these difficulties, yet still respect the right to choose death, assisted dying statutes in Oregon



(and proposed statutes in other states), include mandatory waiting periods, second opinions, counseling about palliative care and hospice care options, possible psychological evaluation for clinical depression, and a provision to try to include family members in the discussion and thereby get a fuller sense of perspective on the patient's preferences. If one includes appropriate *safeguards*, then I believe that the benefits of honoring basic rights overrides these otherwise legitimate concerns about hastening death.

The standard conditions and safeguards that are now incorporated into statutes permitting actively assisted dying, and which I would support, typically include:

- (1) A voluntary request initiated by a competent individual
- (2) A mutual, informed decision-making process
  - including an understanding of the reason for the request
- (3) A critical and probing consideration of alternatives
  - including curative, comfort, hospice, and palliative care options
- (4) Consultation with others
  - including an independent physician, perhaps a psychological or psychiatric consult, and perhaps family consultation.
- (5) A continued, expressed, preference for death
  - including an explicit written request and a mandatory waiting period
- (6) An irreversible condition causing the permanent loss of self
  - terminal illness
  - perhaps, and more controversially, significant dementia

These procedural safeguards clearly can have an impact. In the Netherlands, although about 25,000 patients per year seek assurances of the option of an assisted death and 9,000 patients make an explicit request, only 2,320 result in active euthanasia and 400 choose assisted suicide. In the state of Oregon, palliative care and hospice use has improved significantly since the legalization of assisted suicide. It is likely that this is the result of a more open system that allows patients to speak more freely with their physicians and thus become better informed about their options. Nonetheless, even with excellent palliative and hospice care, some patients still want the options to hasten their death, if their condition becomes intolerable.

It is important to realize that physical pain alone is rarely given as the only reason for wanting the option to hasten one's death. Even with high quality palliative care, many patients still want to control the manner and time of death. Therefore, it is a consequence of a prohibition on assisted dying that we use the force of law in an attempt to compel fully competent informed adults to die in a manner that is contrary to their values and principles. This is not something to be done lightly. Imposing, in

a coercive and paternalistic fashion, one's own conception of how one should die on another person is fundamentally disrespectful and a basic affront to the dignity of that person. The opponent of assisted dying chooses to force people to die in a manner that offends the person's preferences and principles.

We can, of course, foresee that even with safeguards some people will choose to die for irrational reasons. We must thus decide how we should balance rights of self-determination and duties to prevent unintended and indeterminate harm. In answering this question, the doctrine of double effect provides guidance. Other things equal, it is wrong to intentionally infringe on the rights of some because we foresee that other persons may be harmed. The proper response is instead to honor individual rights and to also strive to minimize any foreseeable harm. Indeed, the procedural safeguards outlined above aim to balance respect for individual self-determination with our legitimate concern to protect the vulnerable.<sup>12</sup> There is a big difference, however, between procedures that aim to promote an informed, voluntary choice and outright prohibitions that paternalistically assume that dying patients are uninformed or incompetent.

#### THE RIGHT TO DIE AS A BASIS FOR HEALTH CARE RIGHTS

Many people still oppose any form of active assistance in dying in the United States simply because of the unequal access to high quality end of life care in the United States. This is a bad argument despite its popularity. First, the conclusion that follows from concerns about inequalities in access to health care is that we should be fighting for universal access to a basic health care package that includes high quality end of life care. One can only wonder at those who have opposed and continue to oppose universal coverage but who then use the lack of universal coverage to deny people basic rights to self-determination at the end of life. Second, if I am faced with a system that has inadequate end of life care, then it may well be the case that I prefer to die sooner in order to die better. That I would not have this preference if there were better end of life care available in no way undermines the soundness of my preference given the real life options that I face. Surely I would also not choose to die if presented with a cure for my disease, but fantasy options do not change my considered preference given my actual situation. Third, why would the fact that I am denied basic rights to health care services provide a reason for also infringing on my basic right to control the manner of my own death? It is strange logic indeed that uses the violation of one right as the basis for the violation of another right.

The proper response to the inadequacy of health care services is clearly to strive to provide better health care services. Furthermore, as a general principle if right B



is necessary to secure a fundamental right of type A, that is a clear basis for protecting right B. For example, the right of free association (right B) is a necessary social precondition for the right to assemble and petition one's government for grievances (right A). Even though only the right of assembly is enumerated in the Constitution, the right of association is also a constitutionally guaranteed right simply because it is necessary to protect the enumerated right of assembly. Since we have a fundamental liberty right of self determination in dying (right A), and if a right to health care services (right B) is a social precondition for the safe exercise of this fundamental liberty right (right A), then we have a social responsibility to provide health care services (right B), especially high quality end of life care. The fundamental right to die is thus itself a basis for recognizing a right of universal access to basic health care services.

Finally, opponents of assisted dying need to explain why the allegedly coercive context of US medicine does not provide an equally sound argument for prohibiting physicians from withholding and withdrawing care and "letting people die." The economic and social pressures here are as great, and usually in fact much greater, than in the case of patients that are not life-support dependent. Clearly, there will be countless cases where the withdrawal of care from a patient in an ICU is many times more cost effective than the cost of home care or hospice care for a cancer or AIDS patient. The argument from social pressure and economics is relevant to all end of life medical decisions. We should be more concerned with insuring that the decision to die, whether it involves passively letting someone die or more actively hastening death, is fully informed and truly voluntary. Given the clear inequities in our health care system, for millions of people the decision to die must surely be affected by the economic consequences of the decision. So here again we have an overwhelming reason to provide universal access to high quality health care.

#### CONCLUSION

The right to die and the right to health care are indeed connected. Contrary to the arguments of many, however, the connection does not provide a basis for limiting the right to die to passive cases of withholding and withdrawing care and thereby letting patients die. First, pragmatic arguments that focus on the coercive force of socio-economic considerations apply equally to all end of life decisions. Second, the proper conclusion is not that there is no right to actively hasten death. Instead, the right to die provides an additional reason (as if we do not already have enough) for universal access to health care services. Finally, as long as millions are denied the right to health care, the less risky practice of physician-assisted suicide increases the self-

determination of competent patients facing death without undue risk. If we are to show due respect for patients facing death, we should show them concern and compassion but the final decision about how to die must be theirs.

#### NOTES

<sup>1</sup> Italics indicate passages altered above so as to apply to the end of life cases: "It is a promise of the Constitution that there is a realm of personal liberty which the government may not enter ... Men and women of good conscience can disagree about the profound moral and spiritual implications of *terminating a pregnancy, even in its earliest stage*. Some of us find *abortion* offensive to our most basic principles of morality, but that cannot control our decision. Our obligation is to define the liberty of all, not to mandate our own moral code ... The *mother who carries a child to full term* is subject to anxieties, to physical constraints, to pain that *only she* must bear. *Her* suffering is too intimate and personal for the state to insist upon its own vision of the *woman's role*, however dominant that vision has been in the course of our history and our culture. The destiny of the *woman* must be shaped ... by *her* own conception of *her* spiritual imperatives." (from "*Casey v. Planned Parenthood of Pennsylvania*" US SC 1992)

The constitutional argument for the right to hasten death is developed in "The Philosopher's Brief," by Ronald Dworkin, et al., *New York Review of Books*, 44.5 (March 27, 1997).

<sup>2</sup> This commonplace argument can be found in the influential New York Task Force on Life and Law, "*When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context*," Supplement to Report, April 1997. For a good response to this argument, see G. Dworkin p.69 in *Euthanasia and Physician Assisted Suicide: For And Against*, Gerald Dworkin, R.G. Frey, and Sissela Bok (Cambridge: Cambridge University Press, 1998).

<sup>3</sup> An fundamental liberties based argument for the right to die is developed in "The Philosopher's Brief," which is an amicus curiae brief of six moral philosophers to the United States Supreme Court pertaining to the cases of the *State of Washington v. Glucksberg* and *Vacco v. Quill*. For the main idea, see Dworkin's "Assisted Suicide: The Philosopher's Brief, Introduction" in *The New York Review of Books*, 44. 5 (March 27,1997).

<sup>4</sup> Kant's example of a suicide maxim in the *Grounding for the Metaphysics of Morals* is often taken to support this type of position. Kant's discussion of maxims of suicide in the *Metaphysics of Morals*, however, is subtler. Leon Kass asserts this type of position in "Neither for Love or Money: Why Doctors Must Not Kill," *The Public Interest* 94 (Winter 1989). The best fleshing out of this position is found in David Velleman's article, "A Right to Self Termination," *Ethics* 109.3 (April 1999): 606-28.

<sup>5</sup> The understanding of respect for persons and human dignity here is, of course, heavily influenced by John Rawls.

<sup>6</sup> In the quite different context of his defense of the death penalty, Kant recognizes that respect for human dignity does not always require that we preserve life. So in fact he does not unequivocally endorse a substantive interpretation.

<sup>7</sup> This is the position of the American Medical Association and the British Medical Association. It is also defended by Leon Kass in "Neither for Love or Money: Why Doctors Must Not Kill," *The Public*



*Interest*, 94 (Winter 1989), and in "Is There a Right to Die?" *Hasting Center Report*, (Jan 1993): 34-43. Also see Edmund Pellegrino "Doctors Must Not Kill" in *The Journal of Clinical Ethics*, (Summer 1992): 95-102. Despite the position of the medical associations, this does not seem to be the position of many and perhaps most doctors. Many doctors support physician assisted suicide and many who oppose it do so for the more pragmatic policy reasons discussed below. For a quite different view of the role of a compassionate and responsive physician, see Timothy Quill, "Doctor I want to Die. Will you help me?" *Journal of the American Medical Association*, (August 1993): 870-73, and *Death and Dignity: Making Choices and Taking Charge* (Norton, 1993). Also see Gerald Dworkin and R. G. Frey excellence response to Kass in *Euthanasia and Physician Assisted Suicide: For And Against*, Dworkin, Frey, and Bok (Cambridge, 1998).

<sup>8</sup> Liesbeth (Elisabeth ) Kalff, NVVE, The Dutch Voluntary Euthanasia Society, presentation on euthanasia in the Netherlands, Amsterdam, March 2003.

<sup>9</sup> There are also conceptual limits on how we think about hastening death. Margaret Battin has pointed out the interesting difference in this respect between attitudes towards hastening death in Germany and the United States (see her article, "Euthanasia: The Way We Do It, The Way They Do It," *Journal of Pain and Symptom Management*, vol. 6 no.5, 1991; pages 298-305). She argues that German cultural history and linguistic resources have given root to a somewhat unique position on physician-assisted "rational suicide." First, the German language, and thus also thought, distinguished different kinds of acts we call suicides with different words which carry distinct denotations and connotations. The German *Selbstmord* means "self-murder" which connotes a desperate and wrong action; *Selbsttötung* literally means self-killing and is a neutral scientific term; the Latin construction *Suizid* is used for a suicide which results from psychiatric pathology; and *Freitod* means "free death" and connotes a voluntary individual choice which is an expression of deeply held values or ideals. One commits *Selbstmord* but one chooses *Freitod*. These distinct linguistic categories have made it comparatively easy for Germans to distinguish a free death from unacceptable suicide. The United States on the other hand, has struggled with the confusion generated by using one word for similar actions motivated by such different contexts and reasons. Second, in Germany, a "freely chosen death" or rational suicide — that is, a voluntary, reflective choice to end one's life, which is not rooted in despair, clinical depression, or mental illness — has been decriminalized since 1751. So in addition to a richer linguistic conceptual scheme, the evolution of German practice has been unencumbered by either a legal prohibition or an unclear common law traditions.

As a result, medically related assisted "suicide" is quite common in Germany. The German Society for Humane Dying (which is similar to the Hemlock Society) lends out a booklet under control condition on "A Dignified and Responsible Death" which details how to acquire and take drugs so as to produce a painless and nonviolent death. The society reports between 2,000 and 3,000 suicides a year among its more than 50,000 members (as of 1991). The problem with the German approach is that with no physician involvement or statutory procedural safeguards one is likely to have a significant number of cases where the patient in question is not adequately informed about other medical options. In addition, since initial requests to die are often a result of unwarranted fear or treatable clinical depression, physicians could play an important role in ensuring that patients requesting death are making an informed, reflective, and uncoerced decision.

<sup>10</sup> See, for example, Edmund D. Pellegrino, "The Place of Intention in the Moral assessment of Assisted Suicide and Active Euthanasia," in *Intending Death: The Ethics of Assisted Suicide and Euthanasia*,

edited by Tom L. Beauchamp (Englewood Cliffs, NJ: Prentice Hall, 1996).

<sup>11</sup> For the best discussion of the doctrine of double effect and its problems, see Shelly Kagan, *The Limits of Morality* (London: Oxford, 1991). Also see Timothy E. Quill, M.D., "The Ambiguity of Clinical Intentions," in *The New England Journal of Medicine*, 329.14, (September 1993): 1039-40.

<sup>12</sup> Can a policy of assisted dying provide adequate safeguards against involuntary euthanasia? The Rummelink study has suggested to some that an unacceptable level of misuse is unavoidable. What the Dutch classify as involuntary euthanasia occurred in 0.8% of all deaths. Somewhat triumphantly, many have announced that this is powerful evidence that significant abuse is impossible to avoid once a policy of allowing euthanasia is set in place. This conclusion, however, is overly hasty.

First, voluntary euthanasia in the Netherlands is taken to require an explicit, informed, and persistent request to die. All of the cases without an explicit request involved mentally incompetent patients. On average, the specialist involved in these cases knew their patients for 2.4 years and the general practitioners for 7.2 years. In 60% of the "involuntary" cases the physician had clear evidence of the patient's preferences for death, either from earlier discussions or from family members. In 83% of these controversial cases, the physician had the consent of a relative. In the remaining cases, the patients were incompetent and suffering from uncontrollable convulsions and significant pain and life was probably shortened by a few hours or days at most.

The physicians in these cases were attempting to act in the best interest of their patients and agonized over their decisions. This is a far cry from the reports of physicians killing patients against their will that have been reported by overzealous critics. In the United States all such surrogate decision-making is considered a natural extension of autonomy and it is now routine in cases of passive euthanasia. Once we distinguish Voluntary, Non-Voluntary (no explicit request), and Involuntary (contrary to known preferences of the patient) cases, all of the problematic cases are properly classified as non-voluntary – there is no evidence in any of these cases that the action was contrary to the preferences or principles of the patient. By US standards, these are all cases of legitimate proxy judgment by a surrogate acting on a prior directive (even if not an explicit specific request), or trying to determine the preferences and best interest of the patient. (see L. Pijnenborg, van der Mass, et al., "Life Termination Acts Without Explicit Request of Patient," *The Lancet* 341 (1993): 1196-99.)

The Netherlands seem to demonstrate that it is indeed possible to practice institutionalized voluntary euthanasia without sliding down a slippery slope to either euthanasia on demand or the involuntary killing of the sick and the elderly. We also learn that the healing ethic of the medical profession is alive and well in the Netherlands.

<sup>13</sup> I would like to thank Sarah Conly, Tom Tracy, Michael Boylan, and the students of my Colby, Bates, and Bowdoin comparative medical ethics and justice program for helpful comments and discussions.