

CHOOSING MEDICALLY INDUCED DEATH

COMMUNITY ETHICS COMMITTEE

A White Paper on Massachusetts Petition 11-12 on the subject alternatively known as Death with Dignity and Physician Assisted Suicide

July 2012

The Community Ethics Committee was created under the auspices of the Harvard Ethics Leadership Group and functions as a part of the nonprofit, Community Voices in Medical Ethics, Inc. The Committee was developed to serve both as a policy-review resource to the teaching hospitals affiliated with Harvard Medical School and as an educational resource to the varied communities from which the members come.

The volunteer members of the Committee are diverse as to age, socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds.

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INTRODUCTION

Who are we and why are we issuing this White Paper?

The Community Ethics Committee (CEC) is a group of eighteen volunteers living in the Boston metropolitan area who are members of the various populations served by the Harvard-affiliated teaching hospitals. The CEC's members are diverse as to age, socio-economic status, religious affiliations, cultural and language groups, and educational backgrounds. Eleven of the members are women and seven are men; we range in age from twenties to seventies. Some have advanced degrees and some have high school diplomas. Among the members are a high school administrator and a high school teacher; a rabbi, a Muslim female attorney, and a professor at a Protestant seminary; and some of us are individuals with disabilities and parents with disabled children. Two are retired, one from a large Boston law firm. We are students and writers and small business owners. We volunteer in our local communities, including on an Institutional Review Board and in local health care facilities. We belong to eight different religious traditions, including atheism, and we are fluent in seven different languages. Many of us were able to attend the Harvard Bioethics Course in June of 2007, where the CEC first met and began the conversation as the Community Ethics Committee.

On Election Day 2012, Massachusetts registered voters will be asked whether to adopt an Initiative Petition called the Death with Dignity Act. The Initiative, if passed, will become law in the Commonwealth, affecting the health care rights of all Massachusetts residents. The CEC thought it was important to discuss the statute from a community point of view and share that dialogue with the broader public. Although we usually present a recommendation or report, the Committee is issuing this "White Paper" instead. A "White Paper" is described as an "authoritative report or guide that helps solve a problem. White papers are used to educate readers and to help people make decisions." In this case, it is the record of a dialogue about a pressing societal matter, reviewing the details of proposed legislation presented in the Initiative for Death with Dignity, as well as sharing the Committee's thoughts about the broad range of health care options available to patients at the end of life. (The Committee is in the midst of discussing end of life care options within the topic called "Medical Futility" and this Initiative sits squarely within those discussions.)

The Initiative, as it will be presented to the voters, is provided as a website reference at the end of this White Paper. The Attorney General's office has provided a summary of the Initiative as a descriptive aid to voters which is also cited. If sufficient votes are obtained for its passage, the Initiative will become law, subject to the rights of voters to litigate and the rights of the Legislature to repeal the law. If the Initiative fails, Massachusetts law will be unchanged, and it will remain illegal for physicians to prescribe a lethal dose of medication upon a patient's request.

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PROCESS

Although the usual source of questions for our review comes from hospitals, the CEC felt strongly that we have developed a certain expertise in addressing end of life issues from our past consults, including a recent focus on topics involving Medical Futility (what we are currently calling Intractable Disputes at End of Life). We believe we are particularly well-equipped to address the Initiative Petition. The Committee met throughout the Winter of 2011 and into the Spring of 2012 to educate ourselves about the Initiative - reading articles, attending conferences and educational seminars, and familiarizing ourselves with the Oregon Death with Dignity Act (ORS 127.800 to 127.897) which has been in effect for over ten years. We came to the topic with no preconceived notions of its rightness or wrongness, but instead approached the topic as we have other ethical dilemmas – with an open mind and a willingness to engage in the conversation. We understood the task before us would be potentially divisive and we agreed that, being representative of the wider community, we would likely not come to a consensus of opinion about the topic.

As much as any other topic the Committee has addressed to date, the issues raised by this ballot Initiative brought out most vividly the differences of our varying religious, ethnic, and cultural backgrounds and of our diverse perspectives on what constitutes a dignified death, whether individual choice should be protected, and what societal burdens and benefits would accompany such a law.

Based on our group discussions and in order to obtain everyone's viewpoints, a survey was distributed that elicited individual Committee members' views on the Initiative. Some of the comments from that survey are included as a Point/Counterpoint dialogue provided at the end of this White Paper. In addition, a public survey was distributed informally and the results of that survey will be attached as the results are compiled.

Among CEC members, opinions about the Initiative range from vigorous support to strong opposition. Even in the presence of widely divergent views, we are in complete agreement about two things - the value of a robust and reasoned **conversation** on these challenging issues and the need for **compassionate care** for patients who are nearing the end of life, especially for the relief of their pain and suffering. The Committee was unanimous in: (a) its support for the expansion of palliative care services throughout the entire health care system; (b) its encouragement of the early use of hospice services; and (c) its reinforcement of its Report recommending patients be made aware of the treatment option we called "Continuous Deep Sedation as Comfort Care until Death." The Committee recognized that patients may seek lethal prescriptions based on fear of dying in intractable pain and we are convinced no one should make such an irrevocable decision based on fear. We trust this White Paper will provide the voters of Massachusetts and the patients treated in Massachusetts with information that will assist them in making good decisions both in the ballot booths and on their death beds.

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RESPONSES and COMMENTS

The Committee focused on three questions which arose in connection with its review of the Initiative. In brief, those questions were:

1. What is the language that should be used in this discussion?
2. What aspects of the Initiative became the focus of the Committee's discussion?
3. What are the areas of end-of-life decision-making about which the Committee is in complete agreement?

The responses set forth below are necessarily condensed and cannot completely reflect the richness of the Committee's discussions or the care with which we wrestled with these issues.

1. What is the language that should be used in this discussion?

We all recognize that the language we use in our conversation is critical to our ability to discuss the issue effectively. Those CEC members who are proponents of the Initiative argue that the phrase "Death with Dignity" (DWD) is the fairest and least judgmental way to describe a compassionate option in promoting choice for those who are dying. After all, who would want to oppose dignity in death? The dignity of one's death notwithstanding, the clearest and most widely understood term for the choice to take one's own life is "suicide." The particular act of suicide permitted under the Initiative is accomplished through the use of a lethal dose of medication which can only be obtained with a doctor's prescription, and so it has come to be known as Physician Assisted Suicide (PAS). Many on the Committee felt this was the best phrase to use because of its specificity and transparency. Whichever position the Committee members espoused, almost all of us acknowledged that linguistic euphemisms did not serve the discussion well nor did the use of the word "suicide" which is immediately prejudicial.

As the CEC pursued the dialogue over the course of several months, we all recognized that whatever the Initiative is called – Death with Dignity or Physician Assisted Suicide - neither term is both precise and fair. We wrestled with finding terminology that is more precise and balanced, striving for a way to discuss this topic that is both accurate and nonjudgmental. We briefly considered the unwieldy phrase "Patient-Requested Medically Facilitated Death by Lethal Prescription" and have concluded the best way of describing what we are talking about may be "Choosing Medically Induced Death."

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The CEC was particularly sensitive to the fact that the language used in this White Paper might frame the underlying rationale for accepting or rejecting the Initiative and we have concluded the phrase “Choosing Medically Induced Death” contains the direct and unambiguous language we required. The choice to be made is the patient’s; how the choice is accomplished is through the use of a medical agent and not the patient’s underlying disease; and, in the end, death is the choice being made. “Choosing Medically Induced Death” was the most coherent way to describe what we were talking about.

In coming to this conclusion, the Committee grappled with the implications and assumptions pervading many of the phrases and ideas that underlie any and all discussions in this area. We thought it would be helpful to set forth in a concise way some of those phrases and ideas:

- a. Medically induced – in addressing what is done and how, we understood that a physician writes a prescription for a medication, the type and dosage of which will result in the patient’s death. We also understood that the data in Oregon suggests many prescriptions are written that are never filled, supporting an underlying assumption that comfort was given to the patient by the possession of the prescription itself.
- b. Physician intent – for those on the Committee who found Choosing Medically Induced Death to be ethically justified, reliance upon the concept of “double effect” was helpful. The Rule of Double Effect focuses on the intent behind an action to determine if it is ethically supportable. If the intent is to accomplish a good, even though the result may be bad, the action may still be good. For example, when morphine is given to a patient at the end of life with the intent to reduce pain, caregivers know that sometimes the morphine will also suppress breathing to the point the patient will die. The Rule of Double Effect supports the giving of morphine in that circumstance. In situations addressed by the Initiative, the physician intends to provide the patient with relief from suffering by writing the prescription. It can be argued that the physician does not intend to cause death but rather is responding with compassion to the request of a terminally ill patient to orchestrate their own death with dignity, however they may define that for themselves. The patient is the one who chooses to take the medication or not. The physician’s intent is to relieve suffering and to facilitate a patient’s choice through the writing of a prescription for a lethal dose, which might be an ethically supportable action. Needless to say, a physician retains the right to conscientiously object and not facilitate a patient’s choice to pursue a medically induced death.
- c. Continuum of Disease – it was necessary for some members on the Committee to differentiate among diseases and to identify where along a continuum of disease a particular patient might be, recognizing that although the Initiative applies only to those who are terminally ill (within six months of death), the prognosis of terminal illness is an uncertain science. Among those patients who were chronically ill, progressively ill, and terminally ill, differences in diseases led to differences in conclusions about Choosing Medically Induced Death.

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- i. For those patients who are chronically ill, we came to the conclusion that Choosing Medically Induced Death is not a justifiable option – by taking this position, Committee members felt those who are in vulnerable populations (the disabled, frail elders, and costly patients) would be more protected from abuse.
 - ii. For those patients who are progressively ill, we came to the conclusion that Choosing Medically Induced Death might be a justifiable option – the actual time of the patient’s progression to death is often prognostically uncertain and a prescription to induce death could be unnecessary and premature. On the other hand, there are diseases with a known course of progressive loss of function and a prescription to induce death could be the only form of relief available to a patient experiencing prolonged suffering. (The Oregon law has most frequently been used by cancer patients who know the progressive course of their disease and who want to choose how, when, and where to die.)
 - iii. For those patients who are terminally ill, when death is expected within six months, we came to the conclusion that Choosing Medically Induced Death may well be a justifiable option – the fact that death is both imminent and certain means that the choice of how, when, and where death arrives may be perceived as “rightly” in the control of the dying patient.
- d. Continuum of Treatment – it was helpful to some on the Committee to differentiate among the kinds of treatment options we were discussing, to obtain as much clarity as possible.
- i. Allowing death – occurs in the decision to forgo (withhold) certain medical treatment options that might be available but which would not accomplish the patient’s overall goals of care (health). An example of this would be a decision not to insert a feeding tube in someone with advanced Alzheimers.
 - ii. Allowing death – also occurs in the decision to stop (withdraw) certain life-sustaining medical treatments that have already begun and which are not accomplishing the patient’s overall goals of care. An example of this would be a decision to withdraw a feeding tube in someone with advanced Alzheimers. (In the academic world of ethics, there is no moral difference between withholding and withdrawing when a treatment is no longer accomplishing the patient’s overall goals of care. Even so, withdrawing a treatment that has already begun is much more difficult emotionally for many patients and families to do.).
 - iii. Prolonging dying – occurs in the decision to continue medical treatments, even when those treatments may be invasive, painful, and ineffective in accomplishing the patient’s overall goals of care. This category of “prolonging dying” is the central pivot point of a discussion about medical futility.

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- iv. Causing or inducing death – occurs in the decision to take a new action that will lead directly to death. An example of this would be a patient choosing to ingest a medication that is of a type and dosage that is meant to be lethal.
- e. End-of-life Treatment Options – based upon a prior in-depth review of these topics, the Committee found it helpful to provide a description of the various end-of-life treatment options available, including Choosing Medically Induced Death.
 - i. Palliative Sedation – what we termed “Continuous Deep Sedation to Unconsciousness as Comfort Care until Death” (CDS) is a medical treatment option available to terminally ill patients who are suffering from intractable untreatable pain, either physical or existential (psychological, emotional, or spiritual). In providing CDS, the physician administers the least amount of sedative necessary to render the patient unconscious and therefore out of pain. Under that sedation, the course of the patient’s disease usually progresses to death in a fairly short period of time. Death, however, is not necessarily hastened by CDS – sometimes a patient’s life is prolonged due to the body’s response to the relief from incessant pain. The palliative care that is provided by CDS is its primary goal – the relief of the patient’s pain and suffering.
 - ii. Hospice Care – a holistic caregiving model for those who are terminally ill, hospice addresses the multifaceted distress that dying patients and their friends and families are experiencing providing extensive palliative care, expert pain management, and extraordinary social and spiritual supports. Even though hospice services are widely available, they are infrequently accessed. The Committee uniformly encourages patients and families to avail themselves of hospice services as soon as they become available.
 - iii. Choosing Medically Induced Death – what the Initiative calls Death with Dignity and what is often termed Physician Assisted Suicide will only be available to adult, mentally competent, physically able, terminally ill patients who have repeatedly requested a lethal dose of medication. The physician is, by law, authorized to write and deliver such a prescription to a qualified patient. That is the full extent of the physician’s involvement and explicit legal protections are provided to the physician who writes such prescriptions. It is under the patient’s control whether to fill the prescription and whether and when to take the lethal medication and die. The societal good that may be provided by the Initiative is in granting a patient the right to choose how, when, and where to die – thereby relieving a patient’s suffering at the end of their life. The societal harm that may be caused by the Initiative lies in the unintended consequences of altering the profound and historical relationship of physician and patient based upon healing – thereby causing distrust and uncertainty among many, including those who may be most vulnerable to abuse (the disabled, frail elders and costly patients).

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- iv. Suicide – although it cannot be considered a medical treatment option, there are many non-medical ways to commit suicide and the result is the same. In contrast to choosing medically induced death, choosing self-inflicted suicide can result in distinctly undesirable consequences. Unfortunate insurance exclusions are triggered by suicide and tragically bad outcomes can be caused by failed suicide attempts. There is some sense that condoning medically induced death will avoid the undesirable consequences of self-inflicted suicide, at least for those patients who are qualified under the Initiative.
- v. Voluntary Euthanasia – this is a medical intervention that, for many people, crosses an ethical “line.” Voluntary euthanasia allows a surrogate to act on behalf of a terminal patient who has made the choice of how, when, and where to die. The support for voluntary euthanasia lies in the observation that, if a terminally ill patient has the right to choose how, when, and where to die – if there is a right to die with dignity – then that right should not be denied based upon physical or mental infirmity.
- vi. Involuntary Euthanasia – this is a form of killing that is not generally considered ethically supportable. Involuntary euthanasia allows a person to decide when another’s life should not be supported or when affirmative actions are taken to cause a person to die. Sometimes termed “mercy killing,” involuntary euthanasia is illegal and, when prosecuted, falls within the definition of murder.

2. What aspects of the Initiative became the focus of the Committee’s discussion?

The Committee has found, in discussing ethical dilemmas, it helps to be specific about what we are talking about. In order to provide in this White Paper a sense of our dialogue, we will frame our discussion around who it is we are talking about when we speak of patients choosing medically induced death; what we are talking about in the choice; how that choice is made and accomplished; and why that individual choice may be a good or bad societal choice.

Who

The Initiative is directed to terminally ill patients – those who have received a medical diagnosis of less than six months to live. They are those who are most profoundly affected by issues of death and dying and it is their particular sense of the values they bring to that final human experience that should govern the medical options available to them. They are dying – or, in the alternative, they are living with the extraordinary awareness of the shortness of time left to live that life. The choices surrounding how they live that terminal life are significant and should be honored and respected.

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The Initiative is also directed to physicians – those who would be authorized to write prescriptions for lethal medications. Concern was expressed about the profound changes to our health care system that would result, changing historic assumptions underlying the physician-patient relationship. The unintended consequences of such a radical shift within the medical profession were deemed to militate against the Initiative. (It was not lost on some Committee members that physicians were the professionals most involved at the beginning of the German eugenics movement that led to the Nazi Holocaust.) Committee members were careful to note that physicians will always have the right to conscientiously object and not participate in the writing of prescriptions for lethal medications. Others argued that providing such prescriptions to suffering terminal patients was the height of compassionate care.

Two concerns were voiced about the terminal diagnosis. The inability of physicians to accurately prognosticate the timing of death is renowned and so provides an uncertain basis upon which to grant this right to choose a lethal prescription. The other concern lies in the observation that those who receive a terminal diagnosis and then choose a medically induced death are necessarily suffering from emotional turmoil and yet no mental health evaluation is required under the Initiative's provisions. While some felt that mandated mental health services are a necessary protection against abuses, others felt that such a requirement was patronizing and unnecessary. Concern was also voiced that, given our fragmented health care system, the physician who is evaluating mental competency may not be someone who has known the individual for any length of time. Without continuity of caregivers, there is no likelihood of a continuity of knowing who this individual is and what values frame their choices for a death with dignity. In all events, the choice must be made by one who is mentally competent.

For some, support for the Massachusetts Initiative is bolstered by the actual experience of citizens in Oregon, where the practice of terminal patients Choosing Medically Induced Death has been legal for over ten years. The data from Oregon shows that the number of patients actually taking lethal doses has been quite small (less than 0.2% of the entire population) and the public's support for the practice has been largely positive. Those who have taken advantage of the law's provision, those who have chosen to obtain a prescription and have self-administered the lethal dose, are statistically Caucasian, college-educated, covered by health insurance, not suffering from physical pain but rather suffering from psychosocial burdens, and are more likely than not cancer patients enrolled in hospice.

There were some on the CEC, however, who cannot support a law that carries the potential for far-reaching societal consequences when it provides benefits to so few. A troubling aspect of who is protected by the proposed Initiative is the reality that many who would most benefit from the ability to exercise the choice to end life and die with dignity are precisely the ones who are not qualified to choose under the law's provisions. Examples of this excruciating dilemma are most notably found in those patients with ALS (at the time the choice makes the most sense, they lack the physical ability to self-administer the medication) or those with advanced Alzheimers (by the time they are terminally ill, they lack the mental capacity to make

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the choice). Both patients know the terrible and sure progression of their disease and both are excluded from exercising their right to die with dignity solely because of the cruel twist of fate that they become “terminal” too late to do anything about it. The proposed Initiative offers them no comfort or relief.

To those who support the Initiative, the narrow scope of who may choose a medically induced death is necessary for its passage at this time. Acknowledging the fact that the State’s grant of permission to physicians to prescribe a lethal dose upon a patient’s request to die is a highly charged and controversial practice in the public’s eye, proponents argue change must be incremental. Change must start with small steps - providing the choice to patients who are adult, physically able, mentally competent, and terminally ill gives them one more option to address their personal suffering and to self-determine their own “good death.”

Some on the Committee argued that, in order to attain its passage by the public vote, the Initiative is purposefully engaged in “compassion rationing.” Those who benefit from the law’s protections are those who, although terminally ill, still have the widest range of medical and personal options available to them. They are mentally competent and physically able. They are typically not suffering from unremitting physical pain. They can benefit from the whole panoply of end of life care options, running the gamut from hospice and palliative care services to Continuous Deep Sedation as Comfort Care until Death. Yet those patients who have the “wrong diagnosis,” who are not yet terminal, must live without relationship or with ongoing intensive medical interventions. They do not have the choice to stop their suffering and they are completely unprotected by this particular Initiative. The subtle and unspoken rationing of compassion-based options is troubling to some.

In the end, we are talking about terminally ill patients. We are talking about people who have received the news that they will not live another full year. We are, as a society, trying to find a way to honor their choices while protecting those others also involved in this process of death and dying – the medical community who have committed themselves to the healing arts; friends and families who must come to terms with the fact that a loved one’s choice of how and when to die is not their choice; and the rest of us who are defined by how we protect the weakest among us.

What

What we are really talking about is the grant to a physician of legal permission to write a prescription for a lethal dose of medication. The prescription is delivered to a qualified terminally ill patient who then makes the decision whether to fill it and whether to take the medication. If the patient fills the prescription and takes the medication, he or she is choosing a medically induced death. That choice inherently involves rejecting a medically prolonged life.

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Another way of framing what we are really talking about is the legal protection of a patient's choice to control how, when, and where death occurs. The fact that death is looming underlies this whole discussion – the patients who are going to benefit from the Initiative are terminally ill and will die within six months. The question of when death occurs is posed within the context of that short six months. Terminal illness robs individuals of many of those things which give life value and meaning and it is the cumulative loss of dignity, autonomy, choice, and control of the most basic bodily functions that underlies a patient's drive to choose how to die. Lastly, survey after survey indicate that most people desire to die at home and yet death in our culture has been medicalized and more often than not occurs in a hospital. An individual's desire to control where he or she will die is only accomplished through the choice protected by the Initiative. Many on the Committee felt that, when a patient's illness has already made death inevitable, providing this medical treatment option to patients can be a profound act of true compassion.

Even so, referring to Choosing Medically Induced Death as a “medical treatment option” was problematic for some on the Committee. The Committee in its prior work validated and even encouraged the medical community's provision of continuous deep sedation to unconsciousness for those terminal patients who were experiencing unremitting, unresolved, untreatable, intractable pain. In its earlier Report (which can be found at the website medicalethicsandme.org), the Committee strongly supported use of a medical treatment option that would be available to those with both physical and existential pain and the Committee even supported that option for those who are minors. In those discussions, the Committee made a strong distinction between palliative sedation being a caring response to a patient's pain and the prescription given in the context of Choosing Medically Induced Death being a direct cause of a patient's death. We noted that “Continuous Deep Sedation to Unconsciousness as Comfort Care until Death” is a medical treatment option provided in response and in titrated amounts necessary to alleviate a patient's pain, recognizing that the patient's death was inevitable. Skirting the line toward Voluntary Euthanasia, the prescription of a lethal medication does not seem to be a “medical treatment” as much as a “medical intervention.” In its prior work, the Committee found this to be an important distinction - finding Continuous Deep Sedation to Unconsciousness as Comfort Care until Death to be compassionate care that stops short of intentionally causing death - short of crossing an ethical line that some on the CEC feel has both protected suffering patients and served the professional practice of medicine well.

That being said, many current members on the Committee felt the earlier discussion about CDS did not address Choosing Medically Induced Death sufficiently to distinguish the benefits and burdens of both. For terminally ill patients in intractable physical, psychological and/or existential pain, some Committee members concluded CDS should be presented to patients as a valuable medical treatment option. But what if an individual is experiencing significant existential suffering about when, where and how they will die? What if an individual's greatest fears are being incapacitated rather than being in control, and/or dying in an institutional setting rather than home? When the relief of suffering provided by the Continuous

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Deep Sedation actually contributes to those particular patient fears, then Choosing Medically Induced Death may be an important option to retain. Data from Oregon show that the primary fear most people cited as being addressed by Choosing Medically Induced Death was the loss of autonomy at the end of life, followed by a reduced ability to engage in activities making life enjoyable, and then the loss of dignity. None of these fears would be addressed by CDS.

For some on the Committee, however, it was extremely important to note that the deficiencies in the scope of the Initiative are addressed and satisfied by CDS. One of the deficiencies that troubled some on the Committee focused on the lack of required mental health counseling prior to the physician's writing of a lethal prescription. The protections afforded to clinically depressed patients by CDS lie in the fact that, in order for the pain and suffering to be determined "intractable," everything medically appropriate must have been done. If CDS is determined to be a medically indicated treatment option, the patient has received extensive mental health counseling beforehand. Additional deficiencies in the Initiative lie in those who are qualified or disqualified to benefit. Those patients who are no longer mentally competent to choose or those who are no longer physically able to administer a lethal medication have no protected rights under the proposed Initiative but those same individuals may find relief for their intractable pain and suffering in the medical treatment option of CDS.

How

How the Initiative works out practically was also a focus on the Committee. Some Committee members expressed concerns about several particular aspects of the Initiative – most particularly, how the medications are monitored and administered; how the cause of death is characterized; and how the option of Choosing Medically Induced Death is communicated to terminally ill patients.

As we have noted earlier, patients who are given prescriptions for lethal medications are not required to fill those prescriptions. Nothing in the Initiative monitors the use of the prescription for a lethal agent – how long the prescription may be held, who may fill the prescription, or what is done with the medication once it is delivered. Controlled substances are left uncontrolled and some Committee members were quite concerned by that fact.

In addition, some Committee members were troubled by the explicit provision in the proposed law that states, in those cases where a patient chooses to take the lethal dose, the cause of death on the Death Certificate would be the patient's underlying disease and not the lethal dose of the prescribed medication. This apparently is an effort to afford legal protections to the physicians who prescribe the lethal dosages so that otherwise sympathetic physicians would not avoid the practice. In addition, attributing the cause of death to the underlying disease may help to preserve the patient's Estate's access to insurance claims and benefits, claims which are denied in the event of suicide. Even so, this legally required maneuvering on the Death Certificate strikes some on the CEC as absurd and troubling. The law's creation of a falsehood plants its own seed of public distrust. A lie for compassionate reasons rings no less false.

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Communicating what medical options are available to terminally ill patients is of great concern. The Committee's Report on Continuous Deep Sedation strongly encouraged the medical community to communicate the fact that CDS is a medical treatment option that is readily available. We concluded that providing information about a treatment option that could alleviate intractable pain was a physician's duty and we recommended such information be provided early in the therapeutic relationship. Interestingly, the Committee was less encouraging and more concerned about how the option of Choosing Medically Induced Death would be communicated to terminally ill patients. Two facets of this concern were raised – physician communication skills and patient's perceptions of coercion. Even the best and clearest communicators among the medical community are often misunderstood, especially by terminally ill patients in emotional or physical distress. The CEC imagined a scenario where a physician, with a patient's best interests at heart, dutifully communicates the option of Choosing Medically Induced Death to a patient with poor English skills. The combination of power imbalance and language deficit most assuredly has the potential to cause serious misunderstanding. Were the physician to repeat the information to improve the patient's understanding, the effect might well be perceived as coercion.

Why

If the proposed Initiative were to pass, concerns were voiced that what may start out as a positive opportunity can end as a negative obligation. The positive opportunity which the Initiative grants to a limited number of patients – those who are mentally competent, physically able, terminally ill adults – an opportunity for a patient to exercise free choice by asking a physician for a lethal dose of medication – may, in a society strangled by rising healthcare costs, morph into a negative obligation – coercing a costly or vulnerable patient to choose death. That is, by subtle or outright pressure, a costly or vulnerable patient may be coerced to choose death. Some on the Committee were concerned that as soon as the State establishes an affirmative principle - choosing to die is a reasonable thing to do - then the societal realities can soon result in a negative principle - not choosing to die is an unreasonable thing to do. Especially in light of cost containment measures that are absolutely necessary in our current economic climate, how will cost not be a central issue in the decision-making process in deciding a patient's eligibility and suitability for Choosing Medically Induced Death? Will the ranks of the most vulnerable patients be widened to include those who are receiving costly care and what protections will be in place for them?

Many CEC members saw within the narrowly written language of the statute, a tacit nod to "slippery slope" concerns. Protections and restrictions should be in place for the most vulnerable among us – those who are disabled, frail elders, or perhaps those who are the recipients of unusually expensive medical care. Some Committee members cautioned that protections can also become barriers and those who are within vulnerable populations should not be completely without access to this otherwise legally available choice for "death with dignity."

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Another concern expressed by Committee members was that the current measure could be seen as a “first step,” to be followed sooner or later by a broadening of a physician’s role in hastening death, moving into the territory of voluntary euthanasia without much of a stretch of the imagination.

Both dilemmas present an opportunity to slide down extremely dangerous “slippery slopes” – undue barriers to a perceived public good and uncomfortable pressures toward a perceived public harm. The hazards of both slopes are best navigated when the actions of physicians are focused on providing multi-faceted and skilled palliative care.

Finally, an ironic and dichotomous struggle was experienced by some of those Committee members who oppose Choosing Medically Induced Death. They wrestled with two irreconcilable conclusions - the statute goes too far, crossing an ethical line that currently serves well both vulnerable patients and the medical profession; and the Initiative does not go far enough, limiting access to a perceived good to a privileged few. That is, if Choosing Medically Induced Death is truly a compassionate and valid medical treatment option, why are so many excluded? Why are the ALS patients and the dementia patients and the chronically ill but not terminal patients in merciless pain – why are they outside the scope of this compassionate public good? The fact that this group of citizens is excluded from the benefits of the law and burdened with continuing and costly care seems particularly odd in Massachusetts, which has led the nation in the effort to ensure all residents have access to medical care. If Choosing Medically Induced Death is legislated to be good and reasonable end-of-life care, why limit it so severely?

3. What are the areas of end-of-life decision-making about which the Committee is in complete agreement?

This Conversation involves an irresolvable dilemma. How does our society honor the choice of a terminally patient who wants to control the when, how and where of that most personal expression of a life – choosing a “good death” - while at the same time how does our society protect those among us who are most vulnerable from societal pressures to choose death and “so decrease the surplus population.” Even though we were unable to reach a consensus on the Initiative, the Committee was in complete agreement on the broader topic of end of life care – we are all driven by compassion for those in our midst who are in pain and are suffering. We cannot stress enough our belief that the medical system and our society at large must attend to providing compassionate care for patients who are nearing the end of life, especially for the relief of their pain and suffering.

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One last observation which the Committee felt compelled to make has to do with encouraging institutions to develop a strong palliative care specialty service. The literature that the Committee reviewed repeatedly made the point that the care of patients at the end of life is immeasurably enhanced by the involvement of medical care teams who are trained in palliative care – both in their particular skill in conducting constructive dialogs with patients and families about end-of-life issues and in their expertise in pain management. It is probably fair to say the goal of everyone is a “dignified death” or perhaps more universally, a “good death” – one in which the dignity of the person is maintained, when pain is well-managed, and familial and community supports are in place. To the extent palliative care specialists can be made available to provide such specialized care, the patients and their families benefit and that is a good thing.

As stated at the beginning of this Conversation, even in the presence of widely divergent views, we are in strong agreement about the value of a robust and reasoned conversation on these challenging issues. It is the dialogue that matters. With such a divisive, controversial question as whether we should ask physicians to become central and intentional participants in the death of patients; with staunch proponents arguing for compassion, choice and dignity, and opponents, issuing dire warnings of a “slippery slope” into perdition. Given the relatively few individuals in Oregon who have taken their own lives with legally prescribed lethal doses of medicine, the passage or defeat of Choosing Medically Induced Death is perhaps of less consequence to our society than the conversation the ballot measure might inspire in Massachusetts. The Conversation is the thing of most value and it is a Conversation that ought to continue long after the heat of this election season cools.

The topic of how we die, and how we wish to die, is well worth engaging. Massachusetts already is rolling out a MOLST program -- Medical Orders for Life Sustaining Treatment -- which is an admirable effort to improve the likelihood that a person’s advance directive, a statement of specific end-of-life wishes, will follow them through the medical system -- ideally, even to emergency care, where a patient’s wishes so often fall victim to uncertainty and urgency. The CEC wholeheartedly, and by consensus, endorses the MOLST program, as well as the growing movement to establish the end-of-life expertise of palliative care into the medical mainstream. MOLST and integrated palliative care are a potent combination for compassion and choice, and dignity at the end of life.

A true conversation requires deep listening, and respectful, open-minded attention even to views that are not one’s own. That the CEC achieved no consensus on the central question of the propriety of Choosing Medically Induced Death is perhaps predictable; the public itself is far from any consensus. The CEC’s conversations about Choosing Medically Induced Death were often heated but always respectful and, as in previous studies, saw individual members come to opinions they could not have envisioned before the conversation was begun. On some questions we simply “agreed to disagree,” not thinking less of each other in the disagreement.

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In the voting booth this November, each Massachusetts voter will make up his or her own mind on the Initiative question, expanding a patient's end-of-life choice by including a physician in a patient's decision to die. If this White Paper is to have any value in the debate that precedes that vote, it will be to guide voters to their own best decisions.

The CEC, Religion and Politics

The separation of church and state is a highly-treasured Constitutional principle that underlies our political process. And it might be considered a guiding value in CEC conversations. No matter one's beliefs, it is a common understanding that no single religion should dictate the law. In questions concerning the beginning and ending of life, however, it is especially vexing to separate the two – to separate religious and cultural views of death and dying from the law's protections of those who are dying. As challenging as it was, the CEC undertook to address this topic with the goal of not allowing any one religious or cultural viewpoint to overtake the Conversation. The CEC includes people of faith in all major religions, ethical humanists, and atheists. Even within any single, mainstream religion, when sacred teachings may provide a significant degree of moral clarity, there exists a full range of beliefs among the faithful.

Although there is no overarching religious consensus on the Committee on questions of end-of-life medical care, perhaps the closest to interfaith consensus we found was provided to us within the basic teaching of several religions – while the hastening of death is not allowed, there is no obligation to actively prolong pain or suffering, or to lengthen a patient's life. This principle underlies the Committee's strong consensus that strong palliative care specialty services must be developed to provide compassionate end-of-life care that competently and thoroughly addresses patients' pain and suffering.

Among some CEC members with values shaped by religious faith, there is a cautionary aspect to Choosing Medically Induced Death. For some of them, this is not an incremental, "baby" step. Instead, in expanding a patient's choice to include death and by granting the physician a role beyond healing to include intentional participation in killing, the Initiative obliterates a moral/ethical line. However, a strong sentiment exists among several CEC members, who consider the highest societal values to be the right of a patient to autonomous choice and that doctrinal religious teachings have no place in society's decision-making regarding how best to honor the desire of citizens for a dignified death. For others on the CEC, there is useful clarity found in the duality of the religiously based teaching against hastening death and prolonging dying, and there is a sense that, to remove the source of one's religious values from an individual's socio-political decision-making is to remove values/morals/ethics from the decision. It is precisely in the ethical/moral tug-of-war between the two that the fate of the Death with Dignity Initiative will be determined.

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It is our highest hope that this White Paper will encourage you to engage in this important Conversation among your friends and family, in your communities, for our common good.

The Attorney General's website provides the text of Petition 11-12 along with a summary. Those citations are provided here:

<http://www.mass.gov/ago/docs/government/2011-petitions/11-12.pdf>

<http://www.mass.gov/ago/docs/government/2011-petitions/11-12-summary.pdf>