

## ***DEATH WITH DIGNITY: A COMMUNITY-BASED CONVERSATION***

*Written and compiled by Herman Blumberg, Rabbi, and a founding member of the Community Ethics Committee, with excerpts from the Massachusetts Death With Dignity Act and the CEC's White Paper regarding the act.*

This November, a Ballot Initiative will ask citizens of Massachusetts if the General Laws of our state should be amended to include the "MA Death With Dignity Act." This legislation would declare:

"that the the public welfare requires a defined and safeguarded process by which an adult Massachusetts resident who has the capacity to make health care decisions and who has been determined by his or her attending and consulting physicians to be suffering from a terminal disease **that will cause death within six months** may obtain medication that the patient may self administer to end his or her life in a human a dignified manner....such a process [will] be entirely voluntary on the part of all participants."

The Community Ethics Committee (CEC), part of the nonprofit organization Community Voices in Medical Ethics, is a diverse group of 18 Boston-area residents which meets regularly to study and advise the Harvard-affiliated hospitals regarding bio-medical questions.

In Spring 2012, the CEC engaged in an extended study of the Initiative. Our goal was to fully understand the proposal and to help citizens of the Commonwealth clarify their response to the proposal. Our efforts resulted in a White Paper which is a *record* of our discussions, carefully presenting balanced arguments on every aspect of the Initiative. Sensitive to the complexity of the question before us, and the reality of widely divergent opinions within the community -- as well as in our CEC -- we have sought to elucidate the issues rather than take positions, except where we achieved clear consensus.

Using a questionnaire-type format, we present here the primary questions discussed and invite you to choose your responses. Following each question, we offer **(in bold type)** a digest of our discussions. In this way we hope to bring you into our dialogue and assist you in forming your opinion regarding the legislation to vote upon it in November.

## 1. UNDERSTANDING THAT MOST OFTEN LABELS CARRY A BIAS, WHAT SHOULD THIS ACT BE CALLED?

Death With Dignity  
Physician Assisted Suicide  
Medically Assisted Suicide  
Choosing Medically Assisted Death  
Voluntary Euthanasia  
Aid in Dying  
Other

**CEC DISCUSSION: Those 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.**

**Many felt that Physician Assisted Suicide (PAS) was the best phrase to use because of its specificity and transparency.**

**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 description may be “Choosing Medically Induced Death.”**

## 2. WHAT DIFFERENCES, IF ANY, DO YOU SEE BETWEEN PAS/DWD AND OTHER END-OF-LIFE TREATMENT OPTIONS?

Hospice Care and Palliative Medicine – a holistic caregiving model for those who are terminally ill. Both Palliative and Hospice Care address the multifaceted distress that dying patients and their friends and families are experiencing. They offer expert pain management, and extraordinary social and spiritual supports.

Suicide – Self-inflicted death.

Voluntary Euthanasia – Voluntary Euthanasia allows a surrogate to act on behalf of a terminal patient who has made the choice of how and when to die, but who is not physically able or currently mentally competent to take a lethal medication on their own.

Involuntary Euthanasia – 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," this is a form of killing that is not generally considered ethically supportable. Involuntary euthanasia is illegal and, when prosecuted, falls within the definition of murder.

**CEC DISCUSSION: Palliative Care: 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. Care of patients is immeasurably enhanced by the presence of medical care teams 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.**

**Hospice Care is a form of Palliative Care employed during the last six months of life. Even though hospice services are widely available, they are infrequently accessed. The CEC uniformly encourages patients and families to avail themselves of hospice services as soon as they become available and for the health care systems to expand both affordability and availability to all patients.**

**The CEC affirmed that Involuntary Euthanasia is a form of killing that is not generally considered ethically supportable. It is illegal and, when prosecuted, falls within the definition of murder.**

**The CEC observed that although Suicide 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.**

**The CEC observed that Voluntary Euthanasia, for many people, crosses an ethical "line." The support for it lies in the observation that, if a terminally ill patient has the right to choose how and when to die – if there is a right to die with dignity – then that right should not be denied based upon physical or mental infirmity.**

3. WHAT DO YOU BELIEVE IS THE DIFFERENCE, IF ANY, BETWEEN CHOOSING MEDICALLY INDUCED DEATH (PAS/DWD) AND PALLIATIVE SEDATION?

Palliative Sedation - 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 palliative sedation, 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 palliative sedation – sometimes a patient's life was prolonged due to the body's

response to the relief from incessant pain. The palliative care that is provided by palliative sedation is its primary goal – the relief of the patient’s pain and suffering.

Choosing Medically Induced Death – 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.

**CEC DISCUSSION: The CEC, in a previous study, endorsed the use of palliative sedation, what we called “ Continuous Deep Sedation as Comfort Care Until Death,” which should be available to patients who are within six months of dying and in intractable pain, which cannot be relieved by other medical interventions. The Committee was unanimous in reinforcing this recommendation.**

***Choosing Medically Induced Death:* 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 his/her 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).**

4. WHO SHOULD BE ALLOWED TO CHOOSE THE TIME AND MANNER OF THEIR DEATH, USING A PRESCRIBED LETHAL DOSE OF MEDICINE? (Check off as many categories of patients you think should be allowed to choose. \* are included in Massachusetts Initiative.)

*S/he must be both physically capable and mentally competent to self-administer the lethal dose. \**  
*S/he must have received a psychological evaluation.*  
*S/he must have received psychological and/or spiritual counseling.*  
*S/he must be physically disabled, but is otherwise mentally competent and able to speak for themselves.*  
*S/he must be terminally ill or actively dying.\**  
*S/he Must be an adult.\**  
*S/he must have a diagnosis of a terminal disease.\**  
*S/he must be able to speak for self.\**  
*S/he may have a surrogate decide.*  
*S/he must be experiencing physical pain or suffering.*  
*S/he must be experiencing documented psychosocial pain or suffering.*  
*Other*

**CEC DISCUSSION: 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 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. These concerns were voiced about the terminal diagnosis: The ability 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.**

**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 were a necessary**

**protection against abuses, others felt that such a requirement was patronizing and unnecessary. Finally, 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 Alzheimer's (by the time they are terminally ill, they lack the mental capacity to make the *choice*). Both patients and their families 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 law offers them no comfort or relief.**

**These concerns are balanced by ultimate concern for 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.**

**5. WHO SHOULD BE THE ONE TO PRESCRIBE THE LETHAL DOSE?  
(\* Massachusetts Initiative)**

*A physician \**

*Any medical professional with authority to dispense controlled substances*

*A palliative care physician\**

*A family physician who has known individual at least a year*

**CEC DISCUSSION: Concern was voiced that, given our fragmented health care system, the physician 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.**

6. WHERE DOES DWD/PAS FALL IN RELATIONSHIP TO THE RULE OF DOUBLE EFFECT, INVOKED BY BOTH PROPONENTS AND OPPONENTS OF DWD/PAS, AND WHICH PROVIDES THAT AN ACTION WITH BOTH A GOOD AND A BAD EFFECT/RESULT IS ETHICALLY PERMISSIBLE IF THE FOLLOWING CONDITIONS ARE MET:

- a. The action itself is morally good or at least indifferent.*
- b. Only the good result is intended.*
- c. The good result must not be achieved by way of the bad result.*
- d. The good result must outweigh the bad result.*

**CEC DISCUSSION: 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 PAS as a "medical treatment option" was problematic for some on the Committee. The CEC made a strong distinction between palliative sedation being a caring response to a patient's pain and PAS being a direct cause of a patient's death. We noted that "Continuous Deep Sedation 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**

**as Comfort Care until Death to be compassionate care 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.**

7. WHAT, IF ANYTHING, HAPPENS TO THE MEDICAL PROFESSION IF DOCTORS ARE PERMITTED TO PRESCRIBE A LETHAL AGENT WITH THE ACKNOWLEDGED PURPOSE OF CAUSING DEATH?

**CEC DISCUSSION: 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.**

8. ARE THERE "SLIPPERY SLOPE" ARGUMENTS THAT THIS INITIATIVE WILL LEAD TO FURTHER END-OF-LIFE MEASURES RADICALLY DIFFERENT THAN CURRENT MEDICAL PRACTICE?

**CEC DISCUSSION: 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 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 by subtle or outright pressure or “duty” to die.**

**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.”**

**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.**

9. ARE THERE RELIGIOUS OR CULTURAL INFLUENCES THAT CAUSE YOU TO CONCLUDE ONE WAY OR THE OTHER ON THIS ISSUE? IF SO, WHAT ARE THEY?

**CEC DISCUSSION: 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 patient’s pain and suffering. Among those CEC members with values shaped by religious faith, there is a cautionary aspect to Choosing Medically Induced Death. For 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 value 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.**

10. THE CEC'S DELIBERATIONS YIELDED THE FOLLOWING ARGUMENTS IN SUPPORT OF AND IN OPPOSITION TO THE INITIATIVE. THIS SUMMARY IS PRESENTED HERE AS YOU CONCLUDE YOUR PERSONAL STRUGGLE AND PREPARE TO VOTE.

***Issues/reasons/values which incline proponents to support the PAS/DWD legislation:***

1. The highest societal value is the right given a patient to exercise autonomous choice at a critical life moment.
2. The compassion afforded terminally ill patients, suffering painful and undignified end of life situations.
3. For some patients the extreme suffering about how, when and where he/she will die is not adequately addressed by palliative measures, including Continuous Deep Sedation.
4. The carefully worded safeguards in the legislation against abuse.
5. The largely-positive experience with such legislation in Oregon and other states, including the fact that for a significant percentage of suffering patients, securing the lethal medication itself has been helpful.
6. The DWD/PAS act provides physicians with another ethically sound vehicle -- within the boundaries of the Rule of Double Effect -- to extend compassionate care to patients in contrast to Voluntary Euthanasia or Suicide which cross ethical and legal lines.

***Issues/reasons/values which incline proponents to oppose the PAS/DWD legislation:***

1. The high regard for the sanctity of life informed by religious and cultural values.
2. DWD/PAS measures are virtually the same as Voluntary Euthanasia, obliterating the boundary established by the Rule of Double Effect.
3. The law provides relief for a relatively small number of patients who are cognitively and physically able to self-administer the lethal medication. Societal energy is better expended to bring compassionate Palliative and Hospice Care to a much larger number of patients at the end of life.
4. The "slippery-slope" argument: Will our society be inclined to extend DWD/PAS interventions to a larger group of patients who lack any relational capacity or who endure expensive and burdensome medical interventions? And, paradoxically, perhaps unjustly, excludes others who might benefit from it.
5. 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 well-established moral/ethical line.
6. The act directs that the Death Certificate indicate that the terminal disease and not the lethal dose of medication is the Cause of Death, creating a falsehood. A lie for compassionate reasons breeds public mistrust.

#### Resources:

1. Massachusetts Death With Dignity Act  
<http://www.sec.state.ma.us>
2. Community Ethics Committee "White Paper"  
[https://docs.google.com/open?id=0B-ehSSMbV\\_I6Rjh1U000YmITR3M](https://docs.google.com/open?id=0B-ehSSMbV_I6Rjh1U000YmITR3M)