

A COMMUNITY-BASED CONVERSATION ABOUT THE MASSACHUSETTS DEATH WITH DIGNITY ACT

This November, a Ballot Initiative will ask citizens of Massachusetts if the General Laws of our State should be amended to include the “Death with Dignity Act.” This legislation would declare:

“...that 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 humane and dignified manner....such a process [will] be entirely voluntary on the part of all participants...”

The Community Ethics Committee (CEC) is a diverse group of 18 Boston-area residents which meets regularly to study and advise the Harvard-affiliated hospitals regarding a community perspective on bioethics policy questions. In the spring of 2012 the Committee engaged in an extended study of the Death with Dignity Initiative. Our goal was to understand the proposal ourselves in order to help citizens of the Commonwealth become educated voters in November. Our efforts resulted in a White Paper about what we called “Choosing Medically induced Death”. The Paper 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 reflected within our own group, we sought to clarify the issues rather than take positions. We did achieve clear consensus in two areas – the extraordinary value to suffering patients of palliative care services and the extraordinary value to our communities of a reasoned and open conversation about end-of-life decisions.

WHAT IS THIS INITIATIVE ALL ABOUT?

Is Choosing Medically Induced Death a good thing or a bad thing?

It’s good if you think granting a patient the right to choose how, when, and where to die is paramount in relieving a patient’s suffering at the end of life. It’s bad if you think the unintended consequences of altering the profound and historical relationship of physician and patient based upon healing will cause distrust and uncertainty among many, including those who may be most vulnerable to abuse (the disabled, frail elders, and costly patients).

Who would benefit if this Initiative passes?

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.

Who could be harmed if this Initiative passes?

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. Another concern raised about the Initiative was that many patients 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.

How is Choosing Medically Induced Death different from other End-of-life Treatment Options?

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, pain is well-managed, and familial and community supports are in place. Care of all patients is immeasurably enhanced by the presence of medical care teams trained in palliative care. Specialists in palliative care have well-developed skills in conducting constructive dialogs with patients and families about end-of-life issues and they bring needed expertise in pain management. Choosing Medically Induced Death may become a less attractive option when easily accessed palliative care is in place, including palliative sedation (also known as continuous deep sedation to unconsciousness as comfort care until death).

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 a non-medical 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.

How should I vote?

The concerns about who could be harmed by allowing patients to choose a medically induced death are balanced by concerns 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, when, and where to die is not their choice; and the rest of us who are defined by how we protect the weakest among us.

Our White Paper can be found at medicalethicsandme.org under CEC Publications. We hope you will read it and discuss what you think about the Initiative with family, friends and colleagues. It will be important for you to know what you think before you vote!