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BY EMAIL

Representative Jeffrey Sánchez
(Jeffrey.sanchez@mahouse.gov)
House Chair
Joint Committee on Public Health
Room 130
State House
Boston, MA 02133

Senator John F. Keenan
(John.Keenan@masenate.gov)
Senate Chair
Joint Committee on Public Health
Room 413B
State House
Boston, MA 02133

Re: Written testimony OPPOSING H1998, "An Act affirming a terminally ill patient's right to compassionate aid in dying."

Dear Chairman Sánchez and Chairman Keenan, and Members of the Joint Committee on Public Health:

Thank you for hearing testimony today regarding **H1998,** "An Act affirming a terminally ill patient's right to compassionate aid in dying."

My name is Eileen Feldman. I was born with an organic condition that is still defined as a terminal condition. As an adult I continue to outlive my prognosis and daily manage this rare condition along with a set of accumulated multisystem disabilities, each of which tends to deepen the user's respect for Mortality.

I strongly oppose H1998, which subverts progressive healthcare initiatives striving to enhance the best care possible for dying people; and instead, equates a "right to compassionate aid in dying" with being offered an easy pathway to deliver such patients from the trials of living.

I believe that H1998 is regressive public health policy and Ought Not to Pass. Here's why:

Public health policy needs to be supported by facts, evidence, indicators, studies, research, knowledge-based decision making.

This bill's target population is "capable terminally ill patients" whose stated wish to hasten their deaths is normalized as understandable; and, distinguished from "incompetent" patients, whose stated wish to hasten their deaths is presumed to be suicidal.

Yet, our most up to date evidence proves that individuals with life-limiting medical conditions are explicitly one of the 11 populations at increased risk for suicidal wishes- and *especially in the first*

few months after diagnosis.[i]

Relevant findings, from the 2012 Report by the U.S. Surgeon General and the National Action Alliance for Suicide Prevention conclude:

- ❖ While suicide risk tends to be highest in the first few months after diagnosis, risk remains elevated in the first 5 years.[ii]
- ❖ Fear associated with how the disease is perceived and managed, rather than the fear of death itself, is a frequent precipitator of suicidal behaviors.[iii]
- ❖ The consequences or side effects of treatment can also result in psychological problems.[iv]
- ❖ Fatigue and/or exhaustion, some of the most frequently reported side effects of cancer treatments, can be a risk factor for suicidal behaviors.[v]

And here are 5 specific ways in which this bill would put presumably-competent terminally ill patients at increased risk of acting upon suicidal wishes - with gratitude to Rita Marker [vi] for her generous analysis:

H1998:

- has a provision permitting a physician to dispense a lethal prescription without requiring a second physician to affirm the patient's diagnosis and prognosis. [Section 7 (2) (a)]
- does not require that the prescribing physician refer a depressed or mentally ill patient for a psychiatric or psychological consultation unless the physician believes that the patient's depression or mental illness is causing impaired judgment. [Section 8]
- does not require any waiting period between the time the patient is diagnosed with a terminal condition and the time the lethal dose is prescribed. It requires only one written request without any mandated oral requests. [Section 3]
- requires two people to witness the written request. However one of those witnesses can be a relative, an heir, or the employee of a health care facility where the patient is receiving medical care or is a resident. [Section 3 (3)]
- may permit an appointed health care agent to request the lethal dose on behalf of the patient. Massachusetts law provides that a health care agent "shall have the authority to make any and all health care decisions on the principal's behalf that the principal could make." [M.G.L.A. 201D § 5]

Nothing in the bill explicitly prohibits a health care agent from making the written request on behalf of the patient.

By the way, medical conditions which are found to increase suicide wishes in the general population include: cancer, traumatic injuries of the spine and central nervous system, chronic and severe kidney disease, traumatic brain injury (TBI), degenerative diseases of the central nervous system, and HIV/AIDS.[vii]

H1998 is substantially equivalent to MA 2012 Ballot Question 2, which has already been given a thumbs down by constituents who require increased social and health equity initiatives.

In 2012, 1,516,584 Massachusetts voters said NO to Ballot Question 2 (Q2), the Doctor-assisted suicide question, which can be summarized as follows: " Should a doctor be legally allowed to prescribe medication, at a terminally ill patient's request, to end that patient's life?"

Q2's defeat was driven by the constituents of Suffolk, Bristol, Essex, Hampden, Norfolk, Plymouth and Worcester Counties.[viii]

With the exception of one county, this listing corresponds to the Massachusetts communities with the highest clusters of low-income and minority residents.[ix]

It is puzzling why this bill which is substantially equivalent to last year's defeated Ballot Question 2 would be resubmitted one year later for reconsideration to the members of the General Court of Massachusetts.

End of life public health policies should be targeted towards optimizing healthcare practices rather than concretizing social-bias constructs.

Take the drastically negative prophecies made by the loved ones of Tim Bowers, a 32-year old newlywed and father-to-be who sustained a spinal injury last month:

> "The last thing he [would have]wanted was to be in a wheelchair" (stated one of his best friends to *The Indianapolis Star)*. "To have all that stuff taken away would probably be devastating. He would never be able to give hugs, to hold his baby. **We made sure he knew that, so he could make a decision.** Even if he decided the other thing, the quality of life would've been very poor..."[ix] [bolded words by me]

Mr. Bowers was influenced by his loved ones to remove himself from life supports within 24 hours of his accident, rather than being steered towards optimal future medical supports.

It seems clear that guidance offered to Mr. Bowers was based on traditionally constricted social-bias constructs which continue to link attributes of dis-ablement with "loss of dignity." Like H1998 does.

The general public lacks awareness about the possibilities of long-term quality of life medical supports and technologies available in the 21st century.

Pain management and best care practices for end of life care have also improved since proponents of doctor-assisted suicide began their crusade some 50 years ago.

As the Massachusetts Commission on End of Life Care noted, in its 2005 report to the legislature:

> "Despite the inevitability of death, many Massachusetts residents are not aware of the health care and other options available to them as they approach the end of life. Critical conversations regarding home care, palliative care, hospice care, pain management and symptom control are often delayed until it is too late to address the needs and wishes of the dying patient."[xi]

H1998 suggests that "guiding" patients and their healthcare associates towards the fatally constrained option of doctor-assisted suicide is a compassionate "best practice."

Massachusetts can choose to be in-step with best practices public health and medical interventions which strive to institutionalize life-affirming and quality-affirming end of life care, technologies, and health practices instead.

As a constituent who lives with conditions defined as life-limiting, I'm submitting this testimony with the hope of encouraging Massachusetts political leadership to focus on supporting, increasing, maximizing and maintaining quality of life healthcare options into the future.

Please do not abandon terminally ill patients to futility practices and discouraging predictions. Best- care options are best.

I hope you will agree that H1998 ought not to pass.

Thank you,

Sincerely,

Eileen Feldman, Somerville MA

Endnotes

[i] 2012 National Strategy for Suicide Prevention: GOALS AND OBJECTIVES FOR ACTION
A report of the U.S. Surgeon General and of the National Action Alliance for Suicide Prevention.
Appendix D. http://www.surgeongeneral.gov/library/reports/national-strategy-suicide-prevention/full_report-rev.pdf

[ii] Lonnqvist JK. Physical illness and suicide. In: Wasserman D, ed. *Suicide: an unnecessary death*. London: Martin Dunitz; 2001:93-98.

[iii] DeLeo D, Meneghel G. The elderly and suicide. In: Wasserman D, ed. *Suicide: an unnecessary death*. London: Martin Dunitz; 2001:195-207

[iv] Schlebusch L. Suicide risk and cancer. In: Berman AL, Pompili M, eds. *Medical conditions associated with suicide risk*. Washington, DC: American Association of Suicidology; 2011:59-74.

[v] National Cancer Institute. PDQ depression: assessment, evaluation, and management of suicidal patients. Bethesda, MD: National Cancer Institute; 2011. Available at www.cancer.gov/cancertopics/pdq/supportivecare/depression/HealthProfessional/page5. Accessed June 30, 2011.

[vi] Thanks to Rita Marker, Executive Director of Patient's Rights Council since 1987; and author of the critically acclaimed book, Deadly Compassion (Wm. Morrow & Co., 1993; Harper/Collins, 1994; Avon Books, 1995) - for the pith analysis of certain deficiencies in H1998.

[vii] Medical Conditions Associated With Suicide Risk, Edited by A.L. Berman & M. Pompili, 2011. American Association of Suicidology.

[viii] http://www.politico.com/2012-election/results/ballot-measures/massachusetts/

[ix] See MASSACHUSETTS OPPORTUNITY COMMUNITIES INITIATIVE by The Kirwan Institute for the Study of Race and Ethnicity at http://kirwaninstitute.osu.edu/massachusetts-opportunity-communities-initiative/ . For a summary of these findings , see MA DHCD ConPlan 2010, at http://tinyurl.com/kaq4u9h DHCD says for example: "The state's minority homeowners – particularly its black owners – remain geographically concentrated in a handful of communities, the majority-minority neighborhoods of Boston foremost among them. [For example,] Between 2000 and 2006: 74.4% of black home buying took place in just six municipalities (Boston, Brockton [Plymouth], Springfield [Hampden], Worcester, Randolph [Norfolk], and Lynn [Essex]); 52.2 % of Latino home buying took place in just six municipalities (Boston, Lawrence, Springfield, Lynn, Worcester, and Revere)..."

[x] Tim Bowers, Newlywed and Dad-to-Be, Dies After Taking Himself Off Life Support By ASSOCIATED PRESS 11/07/2013 http://www.people.com/people/article/0,,20753329,00.html

[xi] http://www.endoflifecommission.org/download/Executive_Summary_Key_Findings_2005.pdf