

State of Vermont
Senate Committee on Health and Welfare
Hearing on End of Life Choices
January 31, 2013
Testimony of Ira Byock, M.D.

Chairman Ayer, and Members of the Committee. Thank you for allowing me to come before you this morning.

I am Dr. Ira Byock. I am a practicing palliative care physician and direct the palliative care program at Dartmouth-Hitchcock Medical Center in Lebanon, NH. I am a professor in the Department of Medicine at the Geisel School of Medicine at Dartmouth.

I give testimony today as an individual, not on behalf of any institution or organization.

I have an active Vermont medical license and although I live and practice in New Hampshire, as many as 40% of the patients I and our team serves live in The Green Mountain State.

My clinical experience of over 30 years of practice informs my approach to care for people through the end of life. Of course, my personal understanding of society and my political beliefs also influence my testimony today. I am a proud lifelong social and political progressive. I support universal health care, disability rights, voting rights, women's rights, Planned Parenthood, gay marriage, alternative energy, nuclear disarmament and gun control.

Proponents assert that the death with dignity bill is about an individual's right to die. To political progressives, this is an attractive approach. What could be more personal than a right to control one's own body?

As a physician I have devoted myself to advocating for the rights and wellbeing of seriously ill and dying people and their families. If legalizing physician-assisted suicide represented an authentic extension of personal freedoms, I would be an ardent advocate. In reality, giving doctors the authority to write lethal prescriptions represents acquiescence to well-documented social failures and unmet needs of ill people and their families. While masquerading as progressive politics - "the right to die" is an effective slogan – legalizing physician-assisted suicide is regressive social policy.

Lawyers and legislators will recognize that no right to suicide can be found in any social compact; not in the Magna Charta, the Declaration of Independence or the U.S. Constitution. The United States was founded on certain unalienable Rights, "that among these are Life, Liberty and the pursuit of Happiness."

Consistent with these rights, I believe that there is a right to basic health care,

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including palliative and hospice care when someone has a life-threatening condition and complex needs. Thanks to Governor and this legislature, Vermont has made important strides toward improving health care for the residents of the state. I applaud and support your efforts. However, we have a long way to go toward achieving the goal of honoring this right for all seriously ill Vermonters.

Responding to Suffering

One thing on which good people on both sides of this issue agree is that far too many people suffer needlessly as they approach the end of life.

If I thought lethal prescriptions were necessary to alleviate suffering I would support them. In 34 years of practice, I have never abandoned a patient to die in uncontrolled pain and have never needed to hasten a patient's death. Alleviating suffering is different from eliminating the sufferer. Allowing a person to die gently is importantly different from actively ending the person's life.

The real question for this Committee – and by extension for all us – is how can we take the best care possible of seriously ill Vermonters and the families who love and care for them?

The Role of Doctors and Health Care Professionals

The health care system and health professionals in general, and doctors in particular, have important roles to play.

The ancient professions developed as repositories of specialized expertise and services to members of society. From antiquity, the medical profession was developed to protect, save or sustain life, and to enhance quality of life, including alleviating suffering.

Today, America's health care system is really a disease treatment system. We have more power to diagnose and treat disease and to save and extend life than ever before in human history. Until the latter part of the 20th Century, people with conditions such as kidney failure or heart failure died abruptly but today they may live for many years – for most of the time quite well. Throughout history, cancer was a brief illness. We are now able to cure nearly 60% of cancers and many cancers we cannot also become conditions that people can live with, often for many months if not years.

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For all the progress and power of medicine, we have yet to make even one person immortal. Instead we have invented chronic illness and we have inadvertently made dying much harder than it used to be – or needs to be.

I'm proud of being a doctor, but it is undeniable that our health care system, including many of my fellow doctors, are not caring well for dying people.

It is not because doctors are callous or insensitive to people's suffering. As a medical educator, I can say that despite modest improvements in medical school curriculum, in our zeal to fight disease, we are neglecting to train doctors to care well for the people *living with* disease. Stated differently: We are still setting new doctors up to fail, not just themselves, but also their patients and, collectively, the very society that trains and pays them. Hospice and palliative medicine are given short shrift in medical training. Only small amounts of curricular time are devoted to symptom management, communication, and the ethics of decision-making. Little if any time is invested in teaching young doctors how to counsel patients and families who are living with life-limiting illness. Less time still is spent building skills of working in teams with hospice and palliative care clinicians or of coordinating care for patients. We teach minutia of biochemical pathways, but not eligibility criteria for accessing vital services such as home health and hospice,

Persistent Health Care Deficiencies

Vermont is rightly proud of the health care that it provides to residents. But as this Committee knows, serious challenges remain.

Few of Vermont's hospitals have palliative care services, including most of the critical access hospitals that serve small communities in this state. And in those hospitals where palliative care does exist, it is typically a threadbare service that leaves many patients and families with unmet palliative needs.

Hospice penetration among Medicare enrollees in Vermont has improved slightly in recent years, but lags far below the national average. Nationally, in 2010, 63% of Medicare beneficiaries who died had hospice care, but in Vermont only 36% of Medicare patients received hospice care before they died.

When the Medicare Hospice Benefit was established by Congress in the early 1980s, it was intended to be available for the last 6 months of people's lives. But median length of hospice service nationally is just 19 days before death, despite perennial efforts to educate doctors and the public to access hospice earlier.

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Under regulatory scrutiny from Medicare, patients who are admitted to hospice have to continue to decline or they risk being discharged from hospice care. Of course, although hospice care rarely cures anyone, it often makes people's conditions better. Indeed, in 2010, over 10% of hospice patients in Vermont were discharged from hospice because they were not dying quickly enough.

Vermont's hospice programs are also challenged by their small sizes and geography, including our rural roads, northern weather and long distances between patients. Hospices in rural communities often have difficulty incorporating the rapid advances in the field of hospice and palliative care. As a practicing physician, I often encounter hospice programs in our region which cannot accept patients whose treatment plans include medically administered nutritional support, injectable medications for pain or other symptoms, or IV fluids for comfort, or wound care with vacuum dressings.

The medical directors of many hospice programs in the state typically work for hospice only a few hours a week – it is a community service rather than a vocation for most. Few hospice medical directors are specialists in the way we think of specialists in cardiology, oncology, or critical care. When a hospice medical director is out of town or otherwise unavailable, medical supervision for hospice patients and afterhours calls typically reverts to each patient's own primary physician or that physician's associates. But those physicians may have no interest or expertise in this realm of practice. So specialty level care for pain or other symptoms, counseling and family support becomes unavailable.

In addition to the discomforts and exhaustion of illness, seriously ill people often suffer from a sense of being a burden to those they love. That is one of the main reasons that people in Oregon request lethal prescriptions under that state's Death With Dignity Act.

In America today – including in Vermont – we inadvertently make that burden heavier than it needs to be. In the fight against disease, cost is no concern, but our system pauperizes people for being seriously ill and not dying quickly enough. Inadequate staffing in assisted living and long-term care makes frail elders feel undignified, often because there is simply no one to answer the bell when someone's grandmother or grandfather needs help in getting to the bathroom.

Dying will always be hard, but it doesn't have to be this hard.

Reasons for Limiting a Doctor's Role

There are limits to a doctor's role. From earliest beginnings of the profession of medicine, society gave physicians special authority and privileges – to touch people in intimate ways and talk about highly personal matters that would otherwise be inappropriate. Correspondingly, society imposed clear limitations on a doctor's role. Chief among them was the principle that doctors must not kill patients.

This prohibition extends beyond assisting in suicide or performing euthanasia. Doctors are disallowed by the profession from participating in capital punishment, even in jurisdictions in which it is legal and court ordered. Similarly, doctors must not participate in torture or “forcible interrogation”, even when police or military authorities order us to do so. These proscriptions were not put in place to protect the sensibilities of practitioners, but to protect the public and vulnerable people from misuse of medical power.

Those in favor of legalizing physician-assisted suicide point out that many people want to be comfortable AND alert and interactive to the very end. It's true that while I can assure people of being reasonably comfortable as they take their last breaths, the “cost” of comfort may well require them to be sleepy.

Proponents suggest that having to be sedated and having to be turned and cleaned by others is an assault to a person's dignity. But this notion of dignity seems self-fulfilling, setting the bar for dignity so high that few people at the far end of life will qualify.

People who are seriously ill should not have to die with their boots or their makeup on to feel dignified. They already ARE dignified. This is a settled matter of social ethics. In 1948 United Nations Universal Declaration of Human Rights begins with the stipulation:

“Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.”

If dignity is an inherent feature of human life, our collective responsibility is to care for one another in ways that allow people who are aged, ill or otherwise frail to see their *inherent dignity* reflected in our eyes. Each of us, as members of society, should expect that degree of sensitivity from the doctors, nurses and

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others who are caring for our loved ones – our mothers, fathers, grandparents, spouses, siblings, children and friends.

The Power of Words

It is not my place to judge the suicide of any individual. Suicide may be a personal and private act. But physician-assisted suicide involves two people, one of whom was trained and licensed by society and is compensated by society. The legalization of physician-assisted suicide is social policy.

Recognizing the serious deficiencies of care and family support that continue to plague incurably ill people and their families, the drift toward embracing physician-assisted suicide feels Orwellian. George Orwell understood the power of language to reshape moral thought.

Today we know that branding matters. That is why the Hemlock Society morphed into Compassion and Choices, which promotes “death with dignity” and objects to the word “suicide,” preferring “aid-in-dying” or “self-deliverance” or “hastenings.” These terms sound benign, but the undisguised act they describe remains a morally primitive, socially regressive, response to basic human needs.

Proponents of adopting an Oregon-style act in Vermont emphasize safeguards in the law and assert that Oregon’s experience proves that worries about a slippery slope are unfounded. However, a recent PBS Frontline documentary, *The Suicide Plan*, shows unambiguously that the leaders of Compassion and Choices and the Final Exit Network truly believe that the right to self-deliverance must not be abridged, nor should it be dependent on physical ailments or the willingness of a prescribing doctor. (www.pbs.org/wgbh/pages/frontline/suicide-plan/) The filmmakers did not take sides, adopting an unblinking approach to the topic. I encourage any legislator who feels drawn to vote for legalizing physician-assisted suicide to see this documentary.

Suspicion of Hospice and Palliative Care

Although the hearings this week respond to citizens who support legalizing physician-assisted suicide, there is a significant portion of the public who worry that they or their relatives’ or friends’ lives might be prematurely shortened by doctors. I am not aware of any formal surveys or studies, but both as a doctor and as someone who talks with the lay audiences about these issues on a

regular basis, I would estimate that 25% or more of the public would have difficulty distinguishing between hastening death and hospice and palliative care.

Some people worry that palliative care is a euphemism for euthanasia. In my experience such fears are more common among people with long-standing disabilities, people of color, and self-identified social conservatives. In a single day at the hospital recently, I encountered two separate families who were hesitant to allow me to consult on their loved one's care. In each case, they wanted to know how palliative care was different from Jack Kevorkian or euthanasia.

The inflammatory characterizations of advance care planning discussions with one's doctor as "death panels" and accusations of "killing granny" were entirely unfounded, and yet have left a lasting impression. Although the large majority of social conservatives applaud and support hospice and palliative care programs and professionals, a vitriolic fringe accuses our field, along with medical ethicists, of promoting a "culture of death" and representing "stealth euthanasia." I would simply ignore such nonsense, were it not for the tangible consequences it has in sowing suspicion and limiting my and my colleagues ability to serve people who need our help.

Hospice and palliative care professionals feel responsible for serving all of the population of our region. Many people will not allow us to care for their mother or father if they think we might surreptitiously end their loved one's life. Therefore, it is essential to reaffirm the distinction between hastening death and allowing people to die gently with medical competence, social support, tenderness and love.

A Progressive Agenda to Improve Care and Quality of Life

An authentically progressive agenda for improving the way we die would include the state of Vermont making use of the Medicare waiver mechanism within the state's health plan to dissolve the arbitrary requirement that incurably ill people give up treatment for their disease to receive hospice care for their comfort and quality of life and support for their families.

The Vermont legislature could preserve the dignity of frail elders and physically ill and dependent people by ensuring that there sufficient staff in long-term care facilities to answer the bell when Vermont's mothers or fathers, grandmothers or grandfathers, need help in getting to the bathroom. Nothing assaults an ill or demented person's dignity more than being unable to get help when needed.

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It is past time for every state legislature to insist that every medical student receives adequate training and passes competency tests in basic palliative care knowledge and in the skills required for effective symptom management, communication, shared decision-making, and counseling related to serious illness and dying – skills that too many physicians lack today.

Summary and Conclusion

Despite all the collective efforts of Vermont's health care community and government, including this body – and the significant incremental progress being made – we are failing people who are facing the end of life and those who love and care for them.

The bills being considered would not address the root causes of suffering. Nothing in an Oregon-style Death With Dignity Act would change serious curriculum deficiencies or ameliorate the impact they have on the public health. It would simply give licensed physicians in this state authority to write lethal prescriptions – nothing more.

Nothing in the legislation would protect a terminally ill Vermonters who legally obtains a lethal prescription from being denied hospice care because he wants to continue disease treatments, nor from being subsequently discharged from hospice care if his condition slightly improves. The message from state and federal government will be clear: We may not be able to afford hospice care for you, but your legal right to “self-deliverance” remains available.

The day after the new law took effect, hospice length of service would still be shrinking, hospice would still have limited ability to serve people undergoing active treatments. Staffing in long-term care would still be woefully inadequate. And we would still be graduating and licensing new physicians who have been inadequately trained and are demonstrably unprepared to care well for dying patients.

Rather than representing an extension of our rights, granting physicians the authority to write lethal prescriptions feels like capitulation to our failures. We are better than that. Physician-assisted suicide is not a right; it is a wrong.