House Human Services Committee
Testimony on House Bill 44.

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March 1, 2007

Chairman Pugh and members of the Committee:

My name is Dr. Ira Byock. I am licensed to practice medicine in Vermont.

I am the Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center and a professor at Dartmouth Medical School. However, I am testifying this morning as an individual. The testimony I will provide is solely my own. My views do not necessarily represent those of Dartmouth-Hitchcock or Dartmouth Medical School.

I have been asked to testify on this bill by the Vermont Center for Independent Living and do so with some reluctance. Although for reasons that will be clear, I am testifying in strong opposition to this bill, I enter this fractious debate with mixed feelings. Allow me to explain.

I have been involved in hospice and palliative care since 1978. For many years, I was an active, vocal opponent to the movement to legalize physician-assisted suicide, including standing alongside pro-life groups in opposition to the bill which eventually became law in Oregon. Several years ago, I realized that the debate over physician-assisted suicide had, itself become a distraction from the problem it purports to address. As it is doing in Vermont today, this debate threatens to hijack public attention and precious legislative energy and keep us from taking truly bold and constructive actions that could actually fix the problem.

On one point I fully agree with the proponents of this bill. A public health crisis surrounds the way we care for people and the way many Americans die. The Institute of Medicine has pointed out serious deficiencies in clinical education and training, common errors of omission and commission in medical practices, as well as systemic legal, organization and economic barriers that result in needless suffering.

A large volume of research confirms what many of us know from our personal lives. Too many people needlessly suffer in pain. Many people are bewildered by the health care system. By the end of a long illness, people are commonly devastated, not only physically, but emotionally and financially. Most of us want to spend our final days at home, in comfort, surrounded by people we know and love, and who love us. Instead, 80% of Americans die in institutions, either hospitals or nursing homes. Nearly 20% of Americans spend their last days in an ICU. Dying is inherently hard, but it doesn’t have to be *this* hard.

Some causes of this crisis are easy to identify. Today, we still educate every medical student as if it was 1950. In medical schools across the country, students are required to take classes and rotations in obstetrics amounting to nearly 200 hours of training. Of course, it’s not the middle of the 20th Century. These days very few doctors deliver babies in their practices and every doctor who does has completed a post-graduate residency in Obstetrics or Family Medicine. At the same time, required training in communication, pain assessment and management, ethics of decision-making and guidance for people facing life’s end is scant and has increased only marginally in recent years. Most graduating students and licensed physicians have never been taught to assess and treat cancer pain, know little about hospice care and have not been trained in ways to counsel a person with advanced illness who worries about the future or has begun to feel that life is not worth living. Today’s young doctors are bright, caring, committed and generally well-trained professionals, but they weren’t born with the aforementioned skills, nor have they been taught them.

While problems of medical education, practice and our health system are big parts of the problem, this crisis is fundamentally social and cultural. We are fixated on youth, beauty, vitality and independence. Frailty and dependence on others seems somehow undignified. We want to die with our boots or our makeup on.

As a society we are focused on remaining active and independent and psychologically -- and too often literally -- tend to avoid anything that threatens to remind us of physical dependence, dying and death. The things we avoid include ill and old people. It’s easy to do. Contemporary America is so mobile and fast-paced that without a car, or the ability to drive, a person’s world rapidly shrinks. Seriously ill or simply frail, elderly people often describe feeling isolated. Gradually add the accumulated effects of cancer pain, shortness of breath or just arthritic hips, failing eyesight and imperfect balance, and it’s easy to see how living alone can feel isolated. Studies confirm that elders living alone are at high risk for falls and unwitnessed health problems that can result in needless suffering.

I know a lot of people in these situations who struggle to find alternatives. A majority of adults with children simply cannot stop working (sometimes two jobs) to care for their frail aging or ill parents. And even in New England, many of my generation have ended up living quite a distance from our parents. Similarly our own adult children have moved away in pursuit of education, careers and their own families.

Assisted living facilities are in short supply and too expensive for many people. Nursing homes likewise can easily bankrupt a couple, leaving a surviving spouse with very few assets. Even if that wasn’t the case, it’s an open secret that many people would choose to die instead of going into a nursing home. I have lost count of the times a patient has told me that they would rather commit suicide than enter a nursing home.

Correspondingly, people my age (56) are often mortified when they search for a nursing home for a parent. They confide to me that they feel ashamed of being unable to care for their mother or father at home and of having to put them in a nursing home, yet they don’t know what else to do. Thankfully, some truly wonderful nursing homes exist, but unfortunately they are rare. These days when someone my age finds a really terrific nursing home for a parent, they report the news to extended family and friends with an exuberance once reserved for a child’s admission to the college of his or her choice.

I don’t say any of this as a criticism of the professionals and staff who work in nursing homes. Quite the contrary, they are heroic and among the most committed caregivers I know. I am proud to consider them colleagues. But the long-term care system is broken. Short staffing is endemic; a fact that has been repeatedly documented in academic and government studies. It doesn’t matter how well-trained, caring, and compassionate a facility’s staff is, if there is one nurse for 30 or more residents and one aide for 15 people. None of that matters, if there is no one to answer the bell when a person needs to get to the bathroom or is lying in a wet bed. In 2002 a large federal study concluded that 90 percent of the nation's nursing homes have too few workers to take proper care of patients. A 2001 Commonwealth Fund study estimated that 30 percent of nursing home residents are malnourished because they do not receive enough help in eating from aides, who must assist as many as 15 patients at mealtime. All of this has been reported in the newspapers, but little has changed. What improvements that have occurred have been incremental. Budget cuts have made services for frail elders, seriously ill people of any age and family caregivers ever-more-meager.

The thing patients with advanced illness tell me they fear most is being a burden to their families. In opinion surveys, being a burden on one's family is consistently the first or second most common reasons people cite for wanting to have the option of assisted suicide. Yet in fact, in the current situation too many people conclude that they have become a burden to their families. Caregiving is always hard, but it doesn't have to be *this* hard.

Today, a seriously ill person's decision to commit suicide may be entirely rational. But doesn't that make it all the more tragic? I would never presume to judge an individual's decision to end his or her life. But as a physician and as a responsible member of my community, I can not and will not contribute to this social catastrophe.

As stark as the current situation is, these may be the good old days. Consider that the national nursing shortage is already severe and is likely to get a lot worse in the next decade. Budget deficits show no sign of abating and cuts in health care and social services seem destined to continue. It is sobering to think that the nursing homes of tomorrow may make the nursing homes of today seem luxurious.

One need not invoke moral considerations, to conclude that giving physicians the authority to write lethal prescriptions in this social context is not sound public policy. Simply put, it would solve nothing. The day after this bill were to become law, medical education would still be seriously lacking in attention to communication, pain assessment and management, counseling of patients and families during this difficult time of life, medical and social services would still be woefully inadequate, Medicaid and insurance payments would still incentivize doctors and hospitals to provide aggressive treatments, while inhibiting them from providing palliative care and hospice services, staffing in many nursing homes would still be insufficient to provide the level of medical and nursing care we desperately want for our parents.

The crisis is national but we all know that its manifestations are felt close to home. In Vermont, as in other states, it is difficult to recruit and retain adequate staff for nursing homes. Some skilled nursing facilities are still not staffed with registered nurses overnight.

Some insurance companies legally sell health policies to Vermonters that do not provide anything close to adequate coverage for hospice care. Such policies inflict needless practical and emotional suffering on patients, contributing to the sense of being burden to others that they may feel.

There are only a small handful of Vermont physicians who are certified in Palliative Medicine. Vermont hospices frequently have difficulty attracting certified medical directors, as well as hiring sufficient numbers of experienced nurses. Too few Vermonters are referred to hospice care and when they are, they are often referred late in the course of illness, often within days of their deaths.

Clearly all of us have work to do. As medical professionals, medical educators, as legislators and leaders and members of our neighborhoods, faith communities and workplace communities we must commit to care well for our family members, clients, friends and neighbors.

I urge a do not pass vote on House Bill 44. If, however, the committee does vote to approve this bill, I respectfully ask that the following two amendments be considered. First, a section that requires the University of Vermont, College of Medicine to ensure that every medical student has significant training in palliative and end-of-life care. As a benchmark I suggest that the amount of curriculum time be proportionate to the time of class room study and clinical rotation devoted to pregnancy, childbirth and neonatal care, including a mandatory clinical rotation in hospice and palliative care equal in length to that required for obstetrics.

Second, a section that mandates the Vermont Medical Board to impose on a requirement that physicians must demonstrate command of basic knowledge of pain assessment and treatment and similar fundamental principles of palliative care as a condition for obtaining a license to practice medicine. Standardized tests have been developed and could be applied. This requirement could be implemented in a manner that is budget neutral and not unduly burdensome for physicians.

Neither of these statutory changes would require new revenue. Both of them have the potential to dramatically improve care and the quality of patients' lives. I hope that proponents of legalizing physician-assisted suicide would embrace these amendments.

I am aware that a small number of Vermont physicians have written letters to the editor or given testimony in support of legalizing physician-assisted suicide. I particularly hope that any physician who supports the current bill will speak and write in support of these proposed amendments.

In summary, I ask you to not pass this bill. But please don't turn your back on this crisis. I urge you to address to the issues of aging, dying and caregiving with careful deliberation and fierce determination. This is one crisis we can fix.

People of good will and intentions will continue to disagree about whether or not physician-assisted suicide should be legalized. But while disagreeing on that point, there is so much we could accomplish together to substantially improve medical and nursing education, mandate adequate insurance coverage for hospice and palliative care, double or even triple the staffing of nurses aides in long-term care (which would approach recommended standards.) I hope that the proponents of House Bill 44 will join with those of us in the palliative care and aging services communities to advance a robust public policy agenda that will finally address the roots of this crisis.

Passing House Bill 44 would not correct the crisis that surrounds the way people are cared for through the end of life. But making lethal prescriptions legal might subtly reduce pressure on the medical profession, the health system and this legislature to address the shameful deficiencies in care and support for the most ill, elderly and vulnerable among us.

The people of the state of Vermont have an opportunity to take far more socially progressive and culturally constructive actions. Together we can build a truly enlightened community in which to care well for one another.