

Testimony on House Bill 304

February 19, 2009

My name is Dr. Ira Byock. The testimony I give today is solely my own. I am the Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center and a professor at Dartmouth Medical School. My views do not necessarily represent those of Dartmouth-Hitchcock or Dartmouth Medical School.

I have been involved in hospice and palliative care since 1978. For many years, I was a vocal opponent to the movement to legalize physician-assisted suicide. But several years ago, I realized that the debate over physician-assisted suicide had, itself, become a distraction from the very problems it claims to address. Since then I decided to focus on correcting the deficiencies that cause people to believe that assisted suicide is necessary.

As it is doing in New Hampshire today, the debate over legalizing assisted suicide hijacks precious legislative energy from taking truly bold and genuinely constructive actions that could actually alleviate suffering among dying people.

I fully agree with the proponents of this bill on one point. Too many Americans suffer as they die. People deserve to feel confident that they or their loved one's suffering will be alleviated. Instead, at present, a true crisis surrounds the way many people are cared for in the last months, weeks and days of life. 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. Although some progress has been made, much of it is confined to grant-funded research or a relative few, progressive medical centers and long-term care programs.

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, often sedated or with their arms restrained so they will not pull out breathing tubes, intravenous lines or catheters. Pain commonly remains undertreated, even in otherwise excellent medical centers and by otherwise excellent physicians. Dying is inherently hard, but it does not have to be *this* hard.

Some causes of this crisis are easy to identify. Even today, in medical schools across the country, minimal training is required in communication, pain assessment and management, ethics of decision-making and guidance for people facing life's end. And these topics are virtually absent in postgraduate training residency and fellowship training for internists, surgeons and other specialists.

It is not surprising that most graduating medical 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 most are never taught the aforementioned skills, so it is no mystery that they don't have them.

Medical school deans claim that there is simply not enough time in four years to teach all that doctors need to know. That is certainly true; however, it is not a viable excuse. For instance, every medical student is still required to take nearly 200 hours of classes and clinical rotations in obstetrics as they were in the 1950s. But 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.

While problems of medical education, practice and our health system are big parts of the problem, this crisis that surrounds the way Americans die is fundamentally social and cultural.

We are fixated on youth, beauty, vitality and independence and committed to remaining active and independent. Frailty and dependence on others seems somehow undignified. Americans tend to actively avoid anything that threatens to remind us of physical dependence, dying and death. That is why we tolerate woeful deficiencies in our health care and social services for frail elders and dying people. We don't want to think about it – so we don't. 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. Consider that nearly half of all women over the age of 75 and a quarter of all men over 75 live alone. It is not only isolating, but dangerous. Studies confirm that elders living alone are at high risk for falls and unwitnessed health problems that can result in needless suffering.

Over time, the accumulated effects of aging – arthritic pains, poor eyesight or hearing, imperfect balance, shortness of breath from emphysema or heart problems – all constrain a person's mobility and erode quality of life. This may seem dramatic, but in reality it is ubiquitous. Every day in my practice I meet New Hampshire citizens in these situations. If they have a common diagnosis, such as heart, lung or liver failure, or prostate, breast or lung cancer, every one of them would qualify for physician-assisted suicide under this bill. Medicare, Medicaid or their insurance drug plan would likely pay for the lethal drug.

The alternatives to living alone are difficult for frail elders and their families to find. Assisted living facilities are in short supply and too expensive for many people to afford. Nursing homes can easily bankrupt a couple, leaving a surviving spouse with very few assets. Personal finances aside, many patients have told me that they would rather die than end up in a nursing home.

As stark as the current situation is, these may be the good old days. The national shortage of nurses and nurse aides 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.

The crisis is national but we all know that its manifestations are felt close to home. In New Hampshire, 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 New Hampshire residents 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 New Hampshire physicians who are certified in Palliative Medicine. New Hampshire hospices frequently have difficulty attracting certified medical directors, as well as hiring sufficient numbers of experienced nurses. Too few New Hampshirites 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.

HB 304 offers a simple and cheap solution to this social dilemma, by providing legal means for people to practice "self-deliverance," as proponents like to call the act of killing oneself. The bill has the veneer of respecting individual rights. But as a physician and citizen who takes social responsibility seriously, the idea of dispensing lethal prescriptions seems eerily macabre. It smacks of science fiction, not responsible social policy.

In the context of uncontrolled pain, social isolation, financial devastation and the toll that an individual's illness takes on his or her family, a 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 citizen of New Hampshire and the United States, I can not contribute to this social catastrophe.

As an elected, representative body, it seems important for the legislature to know what New Hampshire citizens think about these issues.

During 2007, in the midst of the Presidential primaries, colleagues and I convened forums with citizens in 8 towns across New Hampshire asking them to think and talk about their and their families' needs and values in facing the last chapters of life. More than 450 New Hampshirites participated.

I am appending to my testimony an academic paper and a monograph, both of which report the findings of these forums. The results were striking. People of our state feel passionately about problems they perceive in medical care and basic support for daily life, both for their loved ones and for themselves. They are frustrated by gaping holes in the health care and in basic social services for people who are elderly or ill.

With characteristic common sense these New Hampshire citizens voiced reasonable expectations. As they contemplate “the waning phase of life” over 90% said it is very to extremely important for their pain to be controlled, their choices for care honored, and their dignity respected. They want timely referrals to hospice and palliative care and adequate insurance coverage for their needs. They want their families to be supported in caregiving and protected from debt. They expect doctors and nurses to be well-trained and skilled in care of elders and dying people. Most want to stay home. Notably, not a single participant would choose to spend their last days in a nursing home.

During the second half of each forum, participants’ were asked what they want policy makers to know as our elected officials deal with issues of aging, family caregiving, serious illness and dying. Overwhelming majorities said that medical and nursing schools should be required to teach future doctors and nurses basic knowledge and skills of pain management, addiction medicine, geriatrics and palliative care. As an indication of how strongly people feel about these issues, more than 90% agreed that passing tests of basic knowledge and skills in pain management should be a condition for doctors, nurse practitioners and physician assistants to be issued a license to practice medicine.

It is not necessary to invoke moral considerations to conclude that HB 304 should be rejected. Giving physicians the authority to write lethal prescriptions in this social context is not sound public policy. Simply put, it would solve nothing.

If HB 304 were to pass, the day after it became 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 reward doctors and hospitals for providing aggressive treatments, while not supporting access to palliative and hospice care. Staffing in many nursing homes would still be insufficient to provide the level of medical and nursing care we desperately want for our parents, siblings, children, and neighbors.

House Bill 304 would not correct the deficiencies that surround 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.

For all these reasons, I urge a do not pass vote on House Bill 304.

If, however, the committee votes to approve this bill, I respectfully request that the following two amendments be considered:

First, a section should be added requiring every medical student in New Hampshire to have adequate 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, the New Hampshire Medical Board should impose a requirement that New Hampshire physicians must demonstrate command of basic knowledge of pain assessment and treatment and the fundamental principles and skills of palliative care as a condition for obtaining a license to practice medicine. Standardized tests exist and can be readily adapted to this purpose. 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 HB304 would embrace these amendments, and support such measures whether or not this bill is advanced.

In summary, I urge you to vote down this bill. But please do not turn your back on the plight of frail elders, dying people and their families in New Hampshire. As difficult as the challenges are, this is one social crisis we can fix.

People of good will and intentions will continue to argue about whether or not physician-assisted suicide should be legalized. 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 304 will join with those of us in the hospice and palliative care and aging services to advance a robust public policy agenda that will finally address the roots of this crisis.

Clearly all of us have work to do. As clinical 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. The people of the state of New Hampshire 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.