



# We Must Earn Confidence in End-of-Life Comfort Care

## CLINICAL AND CULTURAL LEADERSHIP IN TUMULTUOUS TIMES

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**W**e live and practice in challenging times. Thanks to advances in public health and treatments for hitherto swiftly fatal conditions, people in developed countries are living longer than ever before. However, during those extra years, people commonly accumulate multiple chronic medical conditions along with the need for expert health care and supportive services.

Fundamental social and clinical ethics, and basic human values, suggest that seriously ill people deserve reliably skillful, coordinated care to optimize their comfort and quality of life, as well as support for their families. By this benchmark, we are failing. Dying in America remains a public health crisis.

Despite decades of efforts and significant progress in hospice and palliative medicine, many Americans continue to die badly. Every year, thousands spend their last days in circumstances they wanted to avoid — either in hospitals and ICUs, being subjected to overly aggressive, inevitably futile treatments, or in long-term care facilities or at home with their physical distress inadequately treated, their emotional and spiritual suffering unaddressed, feeling undignified and a burden to those they love.

For anyone who believes that it is medically and ethically wrong for doctors to intentionally end a patient's life — and I count myself among them — the growing political, cultural and clinical acceptance of physician-assisted suicide and euthanasia constitutes a conjoined crisis.

### ASSISTED SUICIDE

Physician-assisted suicide is now legal in Oregon,

Washington, Vermont, California, Colorado and Montana. Each year in states across the country, political battles are waged over new bills or citizen initiatives. In 2016, Proposition 106 passed in Colorado with 65 percent of the vote, and in Washington, D.C., a Death with Dignity Act passed the City Council by an 11-2 vote. The mayor signed it into law.

In 2017, a string of 23 similar state bills were defeated, tabled or withdrawn due to strong, principled opposition, bolstered by evidence of dangerous consequences. However, the political movement to legalize physician-assisted suicide and euthanasia is well-funded and tenacious. Public opinion polling and the number of planned or pending bills suggests that its long-range strategies are working.

In Canada, the political question was settled in 2015 by the Supreme Court's decision in *Carter v. Canada*, declaring that the Canadian Charter of Rights and Freedoms includes a right to have a physician prescribe lethal medications or administer lethal medications if the person has a "grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition."<sup>1</sup>



A decade ago, virtually all mainstream medical organizations opposed legalization of physician-assisted suicide. In recent years, some health professional associations, including hospice and palliative care associations, have adopted positions of “studied neutrality” and others of support for legalization.

Proponents cast the legal hastening of death as an expansion of personal freedoms. To many opponents, physician-hastened death is wrong on principle and, in this contemporary context, represents a failure of medical care and basic social responsibilities. The voter initiatives, laws and court decisions that made intentionally ending people’s lives legal have left unaddressed the deficiencies in care and the unmet needs of vulnerable people, and the untenable choices they face.

#### **CHANGE IN STRATEGIC APPROACH**

Opposition to assisted suicide and euthanasia must continue in legislatures, courts of law and the court of public opinion. However, to be both effective and socially constructive, the opposition’s strategic approach must change.

To this point, those of us in opposition have remained confined to the national conversation framed by proponents of physician-assisted suicide. The single question “Should physician-hastened death be legal?” is the topic of endless columns, interviews, radio talk shows and public forums. Our editorials, testimonies and *amicus* briefs point out fallacies and dangers of proponents’ positions, but most often without also articulating proactive, practical and viable alternatives to people dying badly. The public knows what we are against, but they can be forgiven for wondering what we are for.

In the face of the endemic deficiencies and needless suffering that define the public health crisis surrounding dying in America today, opposition to hastening death is only half a stance. To voters who have yet to make up their minds, opposition alone can sound sanctimonious and insensitive to the plight of dying people.

It’s time for us to expand and reframe the national conversation. Many Americans perceive only three ways for themselves, or someone they love, to die: suddenly, through suffering, or by suicide. Most people literally cannot imagine how someone with brain cancer, or ALS, or dementia, could possibly die well.

This lacuna was apparent in the news coverage

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surrounding Brittany Maynard, a vibrant 29-year-old woman with an incurable glioblastoma. She feared losing her dignity and dying in pain, and therefore moved to Oregon to legally receive a lethal prescription, and she ended her life in 2014. Maynard described her fear of facing a gruesome death, a phrase that was often repeated by usually careful journalists and commentators.

Had they fact-checked this assertion, they would have found that people with glioblastomas and similarly devastating conditions are cared for every day in the best hospice and palliative care programs, in ways that ensure that their symptoms are well controlled; that they are able to live as fully as possible, their dignity intact; and, when death approaches, are able to drift from life gently, surrounded by their family and friends.

The widespread inability of people to imagine such alternatives to dying badly contains its own solution. The leadership of health systems, faith communities and consumer rights groups must correct this glaring imaginative deficit.

How? First and foremost, by making reliably excellent care routine within every one of our affiliated clinical programs and settings. People of all ages, races, ethnicities, religions and walks of life need to feel confident that they and those they love will be well cared for through the very end of life. It is essential to make visible the personal stories of people who died well under our care. These stories will re-seed communities’ collective imagination and raise people’s expectations about the quality of care they deserve.

Second, bold, proactive, constructive public policy agendas will inspire people to think more broadly. Policies can teach, informing patients and their families about the quality and range of services they should expect and, if not forthcoming, demand. On a societal level, muscular policy proposals that are designed to correct



entrenched deficiencies in care can redirect voters' frustrations.

Catholic health care by its history, mission and core values is well positioned to assert clinical, social and cultural leadership in this realm of human caring. Rooted in core values and an unwavering commitment to provide the best care possible for people who are seriously ill, Catholic health care also must extend to supporting the families who share in their loved ones' illnesses, care for them and, ultimately, grieve their deaths.

Clinically, our principle-based refusal to participate in legal physician-hastened death must be matched with major, well-funded clinical programs of health systems to dramatically improve care for ill and vulnerable people and support for their families, making assisted suicide and euthanasia progressively irrelevant.

Politically, continued opposition to legally hastened deaths must be balanced with equally dramatic public policy initiatives to correct persistent deficiencies that underlie needless suffering of dying Americans and their families. Only by being bold can these twin strategies transform the landscape of dying in America.

In the near term, the media attention earned by the extent and courage of these programmatic and policy agendas would shift the national discourse. Instead of "Should we legalize physician-hastened death?" people would begin asking, "Why are so many people still dying badly?" and "Who is accountable?" and "What will it take to fix this situation?"

#### CONSISTENTLY GIVING THE BEST CARE POSSIBLE

For the collective voices of Catholic health care to effectively lift the national dialogue on dying and end-of-life care, the continuum of our services must be best in class.

This continuum includes hospital and community-based palliative care, hospice, long-term care, PACE (programs for all-inclusive care of the elderly) and dementia care. Exceptional programs already exist that have proven that much better care and outcomes are both feasible and affordable.<sup>2,3,4,5,6,7</sup>

For instance, each year, the American Hospital Association's Circle of Life Award recognizes programs that deliver the best palliative and end-of-

life care. The Catholic Health Association and the Supportive Care Coalition are two of the award's sponsors. In aggregating the lessons and implementing key characteristics of Circle of Life finalists, high performing programs could become the norm, rather than the exception.

While poised to succeed, bringing these models to scale would require extraordinary commitment. Although the prevailing quality of programs and services of nonprofit home health, hospice, palliative care and long-term care services, including Catholic health programs, is generally higher than their for-profit counterparts,<sup>8,9,10,11,12</sup> the magnitude of quality advantage is modest. For these purposes, modest is not good enough.

To effectively assert clinical and cultural leadership, Catholic health's palliative care programs would need to routinely meet or exceed National

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Consensus Project and The Joint Commission guidelines.<sup>13,14</sup> Each palliative care program would encompass the full complement of professionals that make up an interdisciplinary palliative care team — medical, nursing, social work and chaplaincy. Staffing levels would ensure that palliative care expertise is available to patients throughout a hospital (including the emergency departments and ICUs), and can respond to urgent needs during nights, weekends and holidays. Palliative care teams would contribute to the care for patients after discharge from a hospital and see new patients in consultation in ambulatory clinics, assisted living and long-term care facilities, or at home.

Similarly, hospice programs and long-term care facilities affiliated with Catholic health systems would have active involvement by specialist geriatric or palliative care physicians, far exceed-



ing Medicare's minimum oversight requirements.

As a quality standard, every person cared for by a Catholic health palliative care, hospice, PACE, geriatric long-term care and dementia care program or facility must have individualized contingency plans for any foreseeable symptom emergency. Analogous to refresher courses and recertification for advanced cardiac life support, clinical protocols for managing pain, dyspnea, seizures, severe anxiety and agitated delirium need to be regularly rehearsed and clinical staff regularly skill-tested.

In terms of steps, evidence-based symptom management protocols must extend to proportionate sedation under direct physician supervision. Palliative sedation should be a treatment of last resort, but it must be available when less intensive treatments have failed to alleviate persistent suffering. Emergency symptom relief kits must be readily accessible in residential settings, enabling family caregivers or providers at a suffering patient's bedside to administer initial doses of symptom-relieving medications.<sup>15</sup>

Such commitment to clinical excellence must be supported by the monitoring of quality data. The Triple Aim of health care reform can guide the choice of metrics.<sup>16</sup> Health systems must optimize the electronic health record to document person-centered components of care and devote sufficient information technology resources to collect, analyze and display data in ways that clinicians can apply in real time to care planning and managers can use in continuous program improvement.

#### **A POLICY AGENDA — DEMANDING AND ACCEPTING ONLY THE BEST**

The coalitions of health care, disability rights and faith-based groups that coalesce in each state to defeat each new bill or voter initiative to legalize physician-hastened death typically disband once Election Day is over or the legislative session ends. Our political efforts must not end there. Our voices must remain forceful and resolute.

It is important, however, for the tone of our voices to shift from angry and defensive to hopeful and loving. Motivated by *caritas*, our opposition to intentionally ending patients' lives can be accompanied by offering proactive, affirmative policy initiatives devised to dramatically improve care and quality of life for seriously ill people and their families.

Public policy agendas from the fields of hospice and palliative care, as well as those of Catholic health care, largely have been reactive, supporting or opposing proposals put forward by others. Even when proactive, the policy initiatives from those in the caring community have been modest, confined to what seems politically practical in the short term.

Proponents of physician-assisted suicide and euthanasia long have eschewed such self-constraints. They understood that bold policy proposals do more than enact new statutes. Well-crafted proposals, including those that seem initially out of reach, sketch potential futures in ways that command public discussion and shape collective thought.

Proposals that effectively address the entrenched causes of suffering among ill and dying Americans would challenge and encourage to think again those who currently assume that the enlightened path is for doctors to end life.

Specific proposals could hold medical schools accountable for turning out physicians unskilled at treating pain and uncomfortable talking with — and listening to — their patients, particularly those who are scared, sick and dying.<sup>17</sup> State or federal funding could be tied to major improvements in curriculum and testing within a short, two- or three-year time line.

A citizen initiative could impose a surtax on pharmaceutical companies that arbitrarily set exorbitantly high prices, bankrupting those whose lives depend on their drugs, while earning extraordinary profits each quarter for their shareholders and their executives. The proceeds of such a surtax could be directed to expand the National Institutes of Health budget.

Lawmakers could levy stiff fines on nursing homes that don't maintain sufficient staff to help frail residents eat or to answer the bell rung by a bedridden elder who needs help getting to the bathroom before becoming incontinent. Those fined that fail to immediately correct their deficiencies could lose their licenses. Statutes could ensure that quality data is freely available to consumer groups and industry watchdog agencies and posted on government websites.

Such sites should list the ownership of health care programs. Patients, their families, as well as care coordinators, care managers and discharge planners deserve to know, especially since available evidence suggests that nonprofit hospitals,



nursing homes and hospice programs tend to deliver higher quality services than their for-profit counterparts.<sup>18, 19, 20, 21, 22</sup>

Similarly, the annual turnover rates of employed nurses and aides is another important but infrequently reported quality metric in long-term care. It is reasonable to assume, in places where the turnover rate exceeds 70 percent each year, that something unwholesome is occurring.

By law and regulation, Medicare and Medicaid payments for invasive or high-risk interventions for specific conditions should require consultation with a palliative care specialist or documentation of thorough shared decision-making between patients and their doctors. Such conditions include: surgery or chemotherapy for pancreatic cancer, liver cancer, glioblastoma and any stage IV cancer; stem cell transplants; kidney dialysis; aortic valve replacement or transcatheter aortic valve replacement procedures; and organ transplantation.

While hardly exhaustive, these examples illuminate the potential direction of policy planks and political debates. Proposals would not need to be tethered to defeating “death with dignity” or “aid-in-dying” measures to broaden the public discourse and affect voters’ opinions in positive ways.

Strenuous objection to these proposals would be expected from medical schools and training programs, including the Association of American Medical Colleges and for-profit nursing homes and hospice chains. In fact, the strategy relies on their response. The controversy would play out through open forums, town hall meetings, committee hearings and testimonies, editorial board meetings and opinion pages, turning public attention to the potential of transforming care for and the personal experience of people with complex needs, including those who are approaching the end of life.

**THE COSTS OF INACTION**

The idea of pairing programmatic and policy agendas will strike some as overly lofty, costly and politically beyond reach. “Who is going to pay for all this?” is the reflexive question that skeptics ask.

Cost is not a credible obstacle to these or similarly ambitious programmatic or public policy agendas. The changes in health care financing — from volume to value — and the emphasis on Triple Aim goals of improving quality of care and the health of populations, while controlling runaway costs, present opportunities to accelerate adoption of highly personalized, goal-aligned

**WHAT TO SAY TO PATIENTS WHO ASK ABOUT LETHAL PRESCRIPTIONS**

I often am asked by doctors who are personally opposed to, or who work in institutions that do not participate in, acts that intentionally end patients’ lives, “How can I reply to requests to hasten death?” and “What can I say besides, ‘We don’t do that here?’”

My answer is that we can always respond with compassion, with a willingness to ask why a person is making the request — and we can listen to the answer. We can bring our own clinical expertise in caring, along with that of our team, and consultants, including palliative care specialists, to explore the person’s fears, and, together, develop plans to effectively alleviate the person’s suffering and replace anxiety with confidence in our collective ability to meet his

or her future needs.

We can be unapologetic in explaining that we cannot write a lethal prescription or give a patient a lethal injection. We can explain that our refusal to intentionally cause a person’s death comes from understanding that, even where these actions are legal, they are beyond the ethical boundaries of medical care. In respectfully declining to participate in ending a person’s life, we need not inhibit, but instead can invite open conversation about his or her feelings and worst fears. We can reaffirm our commitment to accompany the patient and the patient’s family in the days ahead.

Not every patient will be satisfied with this response. Even with the best palliative and hospice care, some people will

choose to end their lives. There are two moral agents in every clinical relationship. As clinicians, our responsibility is to do everything we can to make the best of the patient’s condition and quality of life. The patient has a right to decide whether, and to what extent, our services are of value to him or her.

In exercising our legal right to decline taking part in legally hastened patient deaths, we can recognize the moral agency of others. Doctors’ offices and patients’ bedsides are not political arenas but places for clinical expertise and compassion. We need not obstruct people from their legal abilities to request, be prescribed, or receive lethal drugs from willing providers.

— Ira Byock, MD

care that includes reliably excellent care for dying people in our nation. Better communication, routine advance care planning and shared decision-making, effective treatment of symptoms and seamless coordination of services and handoffs reliably result in less unwanted treatment, fewer emergencies and hospitalizations and lower costs.<sup>23, 24, 25, 26, 27, 28, 29</sup>

From an economic perspective, not acting represents a tacit decision to continue spending much more money than necessary while accepting lower quality care and unnecessary suffering.

There also is a moral cost to inaction. Western society is sliding into acceptance of voluntary death as a response to an ever-wider range of maladies and life situations. In finding that the right to physician-assisted suicide or euthanasia was not restricted to terminally ill people, but instead included those who are "...enduring suffering that is intolerable to the individual in the circumstances of his or her condition," the Supreme Court of Canada confirmed that the slippery slope is real.

Canada follows the precedent of the Netherlands, Belgium and Switzerland. In the Netherlands, voluntary euthanasia now comprises 4.5 percent of deaths, which includes a steadily increasing proportion of people with non-life-threatening physical conditions and those who are not physically ill, but suffering from depression or other psychiatric conditions.<sup>30</sup>

## CONCLUSIONS

The next chapter of human history is being written. The story of physician-hastened death is not over. The current social narrative predicts that the movement to legalize hastened death will gradually overcome principle-based resistance and evidence of harms, eventually becoming available to people who wish to end their lives for a broad range of reasons.

There is still time to write a narrative in which hastened death progressively fades from relevance as American society courageously owns up to long-standing failures in basic medical care and social responsibilities, builds programs and adopts policies that make dependably excellent care routine. We can earn people's confidence in being well cared for, their comfort assured, their loved ones supported and their dignity and worth affirmed through the end of life. The pen is in our hands.

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## QUESTIONS FOR DISCUSSION

Ira Byock, MD, has long offered eloquent resistance to the growing initiatives around physician-assisted suicide. In this article, he urges the Catholic health ministry to complement continued opposition to physician-hastened death with emphasis on what we are *for*, including excellence in hospice and palliative care, as well as becoming national leaders of bold public policy initiatives to improve care for seriously ill people and their families.

- How has your ministry shaped its practice to deliver excellent care for people through the end of life? What procedures are in place that guarantee communication among care professionals, patient and loved ones is at an optimal level for the information patients and families need?
- Byock is concerned that much of the opposition to physician-assisted suicide can sound sanctimonious and insensitive to the concerns and suffering of people who are dying. In what ways can palliative care open conversations about suffering, pain relief and worry about those left behind? Who on your staff is able to have those conversations? Who else should be?
- How do you think Byock's dramatic policy proposals to markedly enhance physician training in communication and palliative care, and to demand nursing home accountability, could change the way we care for people who are dying and their loved ones? Do you have any policy suggestions to add?



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