

Patient-Centered Care and Human Mortality

The Urgency of Health System Reforms to Ensure Respect for Patients' Wishes and Accountability for Excellence In Care

Report and Recommendations of the
Massachusetts Expert Panel on End-of-Life Care

Submitted to:

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“Something deep and sanctifying takes place when people who belong to each other share the thought that every day, each coming hour, may separate them. In this awareness we always find that the initial anxiety gives way to another deeper question: Have we given each other everything we could? Have we been everything we might have been to one another? Thinking about death in this way produces true love for life.”

Dr. Albert Schweitzer

October 2010

To The People of the Commonwealth:

In our richly pluralistic nation and Commonwealth, we have many—and sometimes passionate—differences about important issues, including the most profound moral questions regarding life and death. Nonetheless, we have found that there is deep and widespread agreement in the Commonwealth about the following principles:

- 1. The life of every person is of incalculable value, through the very end of life.*
- 2. Medical decisions require the informed consent of the patient (or appropriate surrogate), and must always be anchored in the patient's own values and preferences.*
- 3. While we all share in common the fact of our mortality, our individual values, priorities, and preferences regarding death and dying are highly variable.*
- 4. Care for patients with serious, advancing illness must therefore always be individualized, with patients supported in making well-informed choices from among the full range of options for their care—whether aggressively life-prolonging, or entirely comfort-focused, or some balance of the two.*
- 5. An ethical health care system—one committed to universal patient-centered excellence—would ensure that patients receive the care they want and need near the end of life.*

In preparing this report, we found substantial, convincing, and often deeply disturbing evidence that today's health care system is poorly designed to ensure that these basic principles are respected. Every day in the Commonwealth, seriously ill patients and their families confronting questions of life and death are being failed—at exactly the time when they are most vulnerable and in need of help.

This report describes the many gaps in care we have identified, and recommends both immediate and long-term steps that must be taken to address them. For virtually every failing, proven examples of how to do better already exist. There is no justification for further delays in addressing these known shortcomings.

Once the steps we recommend are implemented, we are convinced that when each of us confronts a serious advancing illness, and one day the inevitable fact of our own mortality, we and our loved ones can know that we will be cared for with the respect, the compassion, and the excellence that we want, need, and deserve.

Achieving this will require our united efforts. We look forward to working with all of you, beginning today.

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EXECUTIVE SUMMARY

Background: The Massachusetts Expert Panel on End-of-Life Care was established in 2009 by the Executive Office of Health and Human Services, as directed by the Massachusetts Legislature,ⁱ to “identify best practices for end-of-life care...[and] present recommendations for any legislative, regulatory, or other policy changes necessary to implement its recommendations.”

Despite extraordinary advances in medical care, each of us—and everyone we love—remains mortal. While in our richly pluralistic Commonwealth we have widely diverse views about how best to confront and respond to the possibility of approaching death, the Massachusetts Expert Panel on End-of-Life Care found unity about the importance of respecting the personal values, goals, and treatment preferences of individual patients and their families.

Much of the news about care near the end of life in the Commonwealth is positive, including life expectancy that is nearly two years longer than the national average and declining death rates from cancer, heart disease, and other serious illnesses. But the Expert Panel found many disturbing failures in the way our current system cares for patients and their families confronting ultimately fatal illnesses. Health care providers do not routinely discuss preferences about end of life care with their patients. While most residents of the Commonwealth would prefer to die at home, too few actually do. Too many patients suffer from inadequate treatment of pain and other physical symptoms, and too few patients and their families receive the emotional and spiritual support they need. Existing financial incentives and payment mechanisms do not support excellence in providing individualized, patient-centered care that meets the needs of patients and families confronting serious advancing illness.

Fortunately, national standards for excellence in end-of-life care are now well established, and within the Commonwealth and in other states the Expert Panel found examples of how excellence can be achieved.

The Panel determined that achieving excellence in end-of-life care will require Massachusetts to create much more reliable and accountable systems of patient- and family-centered care; ensure that health care providers reliably elicit patients’ wishes and ensure that those wishes are respected; build up a work force skilled in eliciting patients’ preferences and in delivering palliative care and hospice services, should this be the patient’s preference; provide better access to these services; and reform the payment structure to support these systems.

With nearly 1,000 residents of the Commonwealth dying each week, and with countless other family members also affected, the urgency of achieving transformational change in the quality of care near the end of life is clear. Recommendations for how this can be achieved fall into six categories:

1. Inform and Empower Residents of Massachusetts
2. Support A Health Care System that Ensures High-Quality Patient-Centered Care
3. Ensure A Knowledgeable, Competent, and Compassionate Workforce
4. Create Financing Structures that Promote Patient-Centered Care
5. Create A Responsible Entity to Ensure Excellence and Accountability
6. Employ Quality Indicators and Performance Measurement

Implementing these recommendations will require the united efforts of health care professionals and organizations, community and business leaders, and the general public—exactly the collaborative approach that has been so successful in the first phase of health care reform in the Commonwealth, achieving near-universal insurance coverage.

1. Dying In Massachusetts

A Snapshot

On an average day in Massachusetts, 144 people die. One is an infant. A few are children. Some are middle-aged, most are over 75. More than half die after a period of predictably declining health from conditions such as heart disease, cancer, or chronic lung disease.¹ Countless additional family members are also affected, and are left with memories that range from gratitude for the care their loved ones received, to confusion, depression, and even anger about what happened.

Most of us try not to think too much about when, how, or where we will die, even though we all know that one day death will come for each of us and for everyone we love. We just hope it will not come too soon.

And in that sense, the news in Massachusetts is good: life expectancy in the Commonwealth is nearly two years longer than the national average; the overall mortality rate is about nine percent lower; and the rates of death from the most common causes—including cancer, heart disease, stroke, diabetes, and chronic lower respiratory disease—have all fallen in recent years. While up to 45,000 Americans die each year because they are uninsured,² groundbreaking reforms in Massachusetts have already addressed this problem by achieving health insurance coverage for nearly every citizen of the Commonwealth.

But there is disturbing news as well. Massachusetts residents who are nearing the end of their lives often do not receive the care they want and need. Many receive inadequate pain relief and symptom control. There is wide variation in patterns of medical treatment in the last year of life—such as rates of admission to Intensive Care Units (ICUs) (Figure 1)—with no evidence that this variation is based on patient preferences.

Figure 1: Percent of Patients Ages ≥80 with Any ICU Admission during their Terminal Hospitalization, by Hospital, FY04

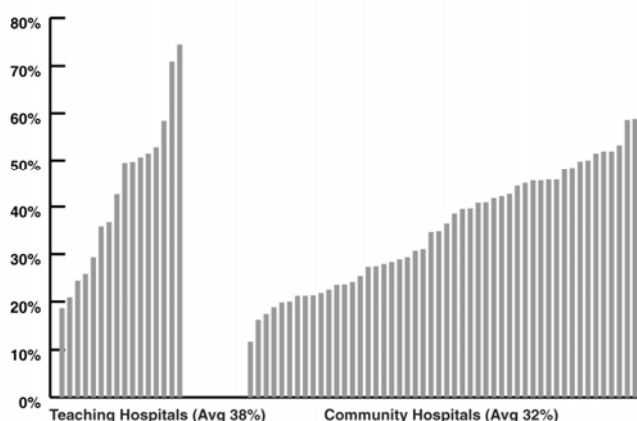


FIGURE 1: Patterns of care for patients near the end of life vary enormously by hospital in the Commonwealth, even after adjusting for differences between teaching and community hospitals, with no evidence that this is based on differences in patient preferences. *Source: Massachusetts Division of Health Care Financing and Policy, 2006*

And while nearly 70 percent of Americans say they wish to die at home, surrounded by family,³ in

Massachusetts the reality is exactly reversed: More than 70 percent die in hospitals or nursing homes, often spending their last days or weeks attached to high-tech life-support machines. Fewer than 25 percent actually die at home (Figure 2). Despite many efforts to improve care near the end of life, since 1991 the percentage of patients dying in the home has not increased significantly.

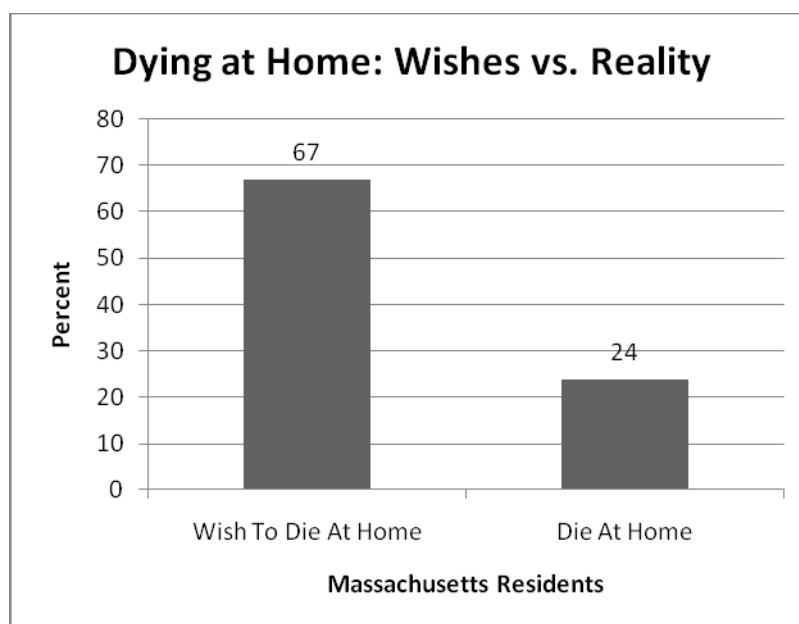


FIGURE 2. Dying at home: wishes vs. reality. Sources: *Massachusetts Commission on End of Life Care and MA Chapter AARP, End-of-Life Survey, 2005*; and *Massachusetts Department of Public Health, Massachusetts Deaths 2007*

What Do Patients Really Want?

When people say they “want to die at home,” almost all have more in mind than the physical location of their last breath. Regardless of the care setting, what people want and need as the end of life approaches are things that have mattered to them throughout life, often now more intensely than ever: that their wishes and values are respected; that their symptoms are well controlled; that their dignity is maintained; and that they can spend as much meaningful time as possible with those they most love.⁴ A health care system that understands and meets these needs will always be fundamentally *life affirming*, even—or especially—when the end of life is near.

The choices that patients and their families make about care at this stage of life are extremely personal, but can only be made well if the full range of options is presented, explored and considered with each patient individually. For some people, end-of-life care will include the use of advanced medical technology that attempts to extend life even if the burdens of treatments increase and the odds of success diminish. Others will prefer, as their illness advances, that their care prioritize comfort and time with family in their own homes. Many will choose aspects of both, varying over the course of their illness.

Unfortunately, even when patients are well informed about their care options, their choices are not always fulfilled. Some patients undergo more intensive medical interventions than they want, some less.⁵ Many feel abandoned by their long-term caregivers as they are sent to unfamiliar settings and

cared for by teams they do not know in the last days and weeks of life.⁶ This mismatch between preferences and actual care is sometimes the result of unavoidable circumstances. But too often, it results from inadequate communication. A 2005 study by the Massachusetts Commission on End of Life Care and AARP found that the two most important and frequent concerns of those surveyed regarding end of life care of those surveyed were "honest answers from MDs" and "understanding treatment options."⁷

Meeting Patients' Needs and Preferences: Three Essential Concepts

The Commonwealth's world-renowned hospitals offer an extraordinary range of life-prolonging and sometimes potentially curative interventions. Panel members agreed that the first phase of health care reform in Massachusetts has been enormously successful in ensuring that people have insurance that covers essential life-prolonging measures, and in providing information about how to access those services.

To ensure that Massachusetts residents understand the full range of choices that are available to them, and to ensure that health care decisions in the face of serious illness are anchored in each individual patient's goals and values, three concepts are essential: advance care planning, palliative care, and hospice.

Advance Care Planning

Health care professionals cannot fulfill patients' wishes regarding care if they don't know what those wishes are. This sounds elementary, but in the case of serious, ultimately fatal illnesses, it is too often the case. In the Commonwealth, in the event that a patient cannot make decisions for him or herself, decision-making authority rests with the patient's legally designated health care agent, sometimes called a health care proxy. This person is empowered to make decisions that are—ideally—based on meaningful conversations with the patient about his or her care preferences.

Research supports the idea that this type of meaningful communication is crucial. Written documents that attempt to spell out specific instructions for end-of-life decisions (such as a "living will") are often by themselves inadequate. These documents are especially insufficient if they are prepared in the absence of other communications with loved ones or one's physician, and in part because exact circumstances and decisions are not always foreseeable.

Advance Care Planning (ACP), then, refers to a more comprehensive approach to priority setting for patients who have or may develop serious advancing illness. It involves conversations between the patient, family members, friends, and providers about the patients' values, goals, hopes and wishes, as well as a mechanism for documenting those conversations and for updating the information as priorities or conditions change. There is growing evidence that ACP can improve end-of-life care—not just ensuring that patients' wishes are more often followed, but also reducing stress, anxiety and depression in surviving family members.^{8,9} For ACP to fully achieve its potential, it must take place within a health care system that not only consistently elicits and documents a patient's wishes, but where there is also accountability for seeing that those wishes are fulfilled.

One approach designed to ensure that ACP discussions are appropriately implemented in actual care is known as MOLST (Medical Orders for Life-Sustaining Treatment). A completed MOLST form, signed by the patient (or surrogate) and the patient's clinician, is a transferable medical order that is designed to ensure that the preferences of patients with serious advancing illness are respected across

care settings. Systematic use of MOLST in other states (including Oregon, West Virginia, Washington, and Wisconsin) has been associated, for example, with a significant decrease in hospitalization of dying nursing home patients.¹⁰ The Massachusetts Legislature has already initiated a MOLST pilot program in the Commonwealth. The MOLST pilot began in April 1, 2010, in Worcester, with enormous enthusiasm and support from both professional and community partners, under the guidance of Commonwealth Medicine, the Executive Office of Elder Affairs, and the Department of Public Health.

Palliative Care

Palliative care refers to medical and other efforts to relieve suffering and improve quality of life for patients with serious advancing illness, including efforts that are provided at the same time as curative or life-prolonging treatments. The first hospital-based palliative care programs were created in the late 1980s, and today palliative care is a formally recognized and rapidly growing medical subspecialty. Since 1996, the American Board of Hospice and Palliative Medicine has certified over 750 physician graduates of more than 50 approved hospice and palliative medicine training programs, many from programs within the Commonwealth. Palliative care is generally provided through an interdisciplinary team, usually including at least physician, nursing, and social work staff, with pastoral care, psychiatry, physical therapy, and other disciplines often involved.

A substantial number of scientific studies have clearly demonstrated multiple benefits of palliative care services for patients with serious advancing illness and their families, including reductions in pain and other symptoms, improvements in communication, better emotional and spiritual support, and receipt of care in a setting preferred by the patient.¹¹ For hospital-based palliative care services, these benefits in quality of care are also associated with reductions in hospital and intensive care unit days, and in the use of burdensome diagnostic or therapeutic interventions of marginal or no benefit to patients.^{12,13} A recent Massachusetts-based randomized controlled trial demonstrated that patients with advanced lung cancer who were offered palliative care services at the time of diagnosis, rather than waiting until later in their illness, not only had fewer depressive symptoms and improved quality of life, but also longer survival.¹⁴

Given these proven benefits, patients with serious advancing illness cannot be considered well-informed about their options for care unless they have a clear understanding, as early in the trajectory of their illness as possible, of the potential contributions of palliative care services, and how to access them.

Hospice

Hospice programs in the U.S. grew out of work in England in the 1960s by British physician Dame Cicely Saunders, who pioneered methods of improved symptom management and emotional and spiritual support for dying patients and their families. A Medicare hospice benefit was created in 1982 and made permanent in 1986. In 1995, the Massachusetts Legislature passed a Mandated Hospice Benefit, which requires that payers subject to Massachusetts health insurance regulations provide a hospice benefit. (Self-insured group health plans, including virtually all plans offered by large employers, are not subject to state-mandated benefits, including hospice. However, many plan sponsors have voluntarily included this benefit.)

Most frequently delivered in the patient's home, but also in nursing facilities, hospice residences, and hospitals, hospice services include medical, social, emotional and spiritual support tailored to the

patient's needs and wishes. Support is provided to family members and loved ones as well, including bereavement care for 13 months after a patient's death. Under Medicare and most insurers, eligibility for hospice requires a patient's physician to document that the patient has a terminal illness with a typical life expectancy of six months or less, and covered treatments include those designed to optimize quality of life.

In Massachusetts, the average length of stay in hospice care is 51 days; the median is 25 days.¹⁵ Hospice patients are served by one of Massachusetts' 67 licensed hospices—either freestanding or affiliated with health care systems, visiting nurse associations, or extended care facilities—that together provide care in the Commonwealth. There is no community in Massachusetts that does not have access to hospice services, and residents are increasingly turning to them for their services. Since 1996 the number of Massachusetts residents receiving hospice care each year has more than doubled, from 9,400 individuals (<20 percent of all deaths) to more than 21,000 (40 percent of all deaths).

Family members of patients who died at home with hospice services report a more favorable experience—including emotional support for both the patient and family—than those whose loved ones died in institutional settings such as hospitals or nursing homes.¹⁶

Not every patient with a terminal illness will choose hospice, even when death appears imminent. Some will want to continue to pursue all available life-prolonging efforts, including in a hospital or ICU if necessary, to the very end. But for choices to be well-informed, all patients and families making decisions about serious, ultimately fatal illnesses must understand what hospice offers.

2. End-of-Life Care in Massachusetts: Progress, Problems, and Potential

Our Successes

Massachusetts policymakers have a historical commitment to improving end-of-life care for patients and families. In recent years, Massachusetts residents have benefited from the creation of:

- A **health care proxy law** (1990) authorizing individuals to appoint a health care agent to make decisions in the event they become incapacitated;
- A **hospice benefit** for MassHealth (Medicaid) enrollees (1990);
- A **mandated hospice benefit law** (1995) that gives members of Massachusetts public and private health plans insurance coverage for hospice services;
- An **out-of-hospital Comfort Care/Do Not Resuscitate Verification Protocol** (2000) that allows emergency medical services personnel to honor the existence of a Do Not Resuscitate order and instead provide comfort measures;
- **Creation of the Massachusetts Commission on End of Life Care** to promote improvements in care near the end of life in the Commonwealth (2001);
- **Print and online resources** cataloging available services and information about end-of-life care, developed by the Massachusetts Commission on End of Life Care (2002);
- A **joint research survey** of Commonwealth residents regarding their end-of-life preferences and needs, conducted by the Massachusetts Commission on End of Life Care and Massachusetts AARP (2005); and
- A **funded pediatric palliative care program** (2006) that removed existing barriers and provides high-quality care for children with life-limiting illness and their families, including care at home.

Where We Fall Short

“Failure” is a strong and disturbing word. Massachusetts is home to some of the finest health care institutions in the world, with physicians, nurses, and other health care professionals who are extraordinarily dedicated to providing the best care possible to each and every patient. Every day in the Commonwealth, compassionate and skilled caregivers ensure that their patients receive excellent end-of-life care, contributing to lasting positive memories for family members after their loved ones have died.

Certainly there are many patients in Massachusetts who receive excellent end-of-life care. But for many, if not most, care during a final illness is a mix of successes and failures. This list highlights common failings—not for every patient, and not every time, but often enough to demand action.

Too often in Massachusetts, the health care system is **failing to**:

- **Elicit and document patients' wishes about care near the end of life**
Only 17 percent of respondents to a Massachusetts Commission on End of Life Care /MA AARP survey have even spoken with their physicians about their end-of-life preferences.¹⁷
- **Alleviate patients' pain and suffering**
45 percent of Massachusetts nursing home residents surveyed say they are in persistent pain.¹⁸
- **Fulfill patient's preferences for dying at home**
The percent of Massachusetts deaths that take place at home has held steady between 22 and 24 percent for more than six years.
- **Support families as caregivers**
Many families struggle under the financial and personal burden of caring for a loved one at the end of life, and too often receive little if any support.¹⁹
- **Ensure an adequately trained and supported workforce**
Even though 100 percent of patients will one day die, health professional schools, training programs, and certifying bodies place limited emphasis on the knowledge and skills needed to achieve excellence in end-of-life care.
- **Ensure that treatment decisions are made, and resources allocated, based on patient-centered priorities**
There are no publicly accountable systems in place to ensure that health care providers elicit effectively and then respect the treatment preferences of patients with serious advancing illness.
- **Provide a hospice benefit to all patients under MA public plans**
Patients covered under Mass Health Basic, Mass Health Essential, and Mass Health Limited currently do not have a hospice benefit.
- **Monitor and ensure progress in improving end-of-life care in the Commonwealth**
In the late 1990s, the Massachusetts Commission on End-of-Life Care was formed to lead state improvement efforts, but it was not provided with either the resources or the authority to drive system-wide change and accountability. Today, wide variation exists across the 50 states in the provision of end-of-life care, with Massachusetts lagging. In a 2008 study grading access to palliative care, Massachusetts received a "C."²⁰

These failures cannot be blamed on shortcomings of individual health care professionals. Efforts to improve end-of-life care must target the structures and processes in the health care system that currently too often prevent individual caregivers from providing the care patients want and need at this most vulnerable stage of their lives. Even the most skilled, dedicated and compassionate professionals cannot provide the highest quality care if the system in which they work does not support them in doing so.

The good news is that examples exist in the Commonwealth and across the nation of health systems

successfully addressing each problem identified above. Truly transformational change in the quality of care we provide to patients with serious advancing illness is within reach.

A New Call to Action

Understanding that past efforts to improve end-of-life care in the Commonwealth had fallen seriously short, in 2008 the Massachusetts legislature (Chapter 305 of the Acts of 2008, Sections 41–43) called for:

- *Creation of an Expert Panel on End-Of-Life Care to recommend public policy and best practices for the delivery of such care to patients with serious chronic illness;*
- *Initiation of a public awareness campaign to highlight the importance of end-of-life care planning; and*
- *Establishment of a demonstration program for communicating Medical Orders for Life-Sustaining Treatment across health care settings (MOLST).*

The Expert Panel’s charge was to “identify best practices for end-of-life care, including those that minimize disparities in care delivery and variations in practice or spending among geographic regions and hospitals, and [to] present recommendations for any legislative, regulatory, or other policy changes necessary to implement its recommendations.”

From the Spring through the Fall of 2009, the Panel held four full-panel meetings to review the state of end-of-life care both nationally and in the Commonwealth. Additional meetings and considerable work were divided among three Work Groups, and coordinated by a Core Group and the panel’s leadership (chair and two vice-chairs).

This report and the recommendations it contains are the result of the extensive work done by the Panel, which believes that by taking bold and urgently needed steps to improve end-of-life care, Massachusetts can lead the nation in this important area, as it has already done in health insurance reform.

The urgency is clear: nearly 1,000 people in the Commonwealth are dying each week in a health system that too often fails them and their families.

3. The Context of Reform: Myths and Realities

Perhaps because it is laden with emotional triggers, the phrase “end-of-life care” engenders serious misunderstanding and misconceptions. Efforts to reform end-of-life care are set against this backdrop of confusion, sometimes exacerbated by inflammatory political rhetoric. Improving care must include improving public understanding about many aspects of caring for patients with serious life-limiting illness.

The Panel is eager to dispel multiple myths that are major impediments to the progress we need, and promote the realities that make possible the improvement efforts we envision.

Myth: There Is No Consensus About End-of-Life Care Standards

Reality: A Strong National Consensus on End-of-Life Care Standards Already Exists

There is widespread agreement among palliative and hospice professionals regarding standards of care. The Framework and Standards of the National Priorities Partnership-National Quality Forum and the emerging standards of the Joint Commission on Accreditation of Health Care Organizations are critical initiatives that define the frame and scope of end-of-life care.^{21,22}

Much of our current understanding of the shortcomings in access, quality, and effectiveness of end-of-life care stems from the 1997 Institute of Medicine report, *Approaching Death: Improving Care At The End Of Life*. This seminal work sought to build understanding of quality care for the dying and offered many recommendations that still require attention in addressing barriers to achieving that care. This profile of how, when, and where Americans die examined determination of diagnoses and prognoses, communication, establishing goals, and respecting the patient’s values and circumstances in a broad range of settings.²³

Since *Approaching Death* was published, important progress has been made nationally in the areas of palliative care, advance care planning, and hospice. Leading works and initiatives include the Robert Wood Johnson Foundation’s *Last Acts* program; the development of the Center to Advance Palliative Care (CAPC); increased professional support, legislative outreach, and public education through the American Academy of Hospice and Palliative Medicine and the National Hospice and Palliative Care Organization; quality improvement initiatives through the Institute for Healthcare Improvement’s Breakthrough Series; as well as innumerable advances in the development of palliative care training programs and improvements in medical and nursing textbooks and other educational resources.^{24, 25, 26, 27}

Myth: End-Of-Life Care Is Primarily About Death and Dying

Reality: Improving End-Of-Life Care is a Life-Affirming Endeavor

Dr. Albert Schweitzer taught that awareness of our shared mortality, and the fact that we will one day lose each other, should be the basis for a heightened appreciation of the miracle of life, for a sense of the sacred value of each day we share together. Honest acknowledgment that an illness will one day be fatal is therefore most fundamentally about living as well as possible in the face of approaching mortality, not about “dying.” From the time of diagnosis of an ultimately-fatal illness, the central

responsibility of health care providers and the health care system is to help ensure that patients and their loved ones are able to make the most of whatever amount of time it is possible for them to have together.

In fact, it is often not even possible to predict when a patient with a “terminal illness” is likely to die. The largest study ever undertaken of the care of patients with serious advancing illness—nearly 10,000 patients hospitalized with advanced heart disease, lung disease, and various types of cancer across the U.S.—revealed a startling fact: just days before most patients died, the patient’s own physician frequently believed that there was a reasonable likelihood (50 percent chance or higher) that the patient would live additional months.²⁸ Simply put, it is not possible to improve care in the last phase of many patients’ lives by targeting efforts only on patients who are identifiably “dying” soon. And recent evidence that “early” palliative care can help *prolong* survival in patients with advanced cancer should dispel once and for all the myth that palliative care is about dying, rather than about living as well as possible.²⁹

Myth: Hospice Care is Primarily For Patients in Their Last Days of Life

Reality: Hospice Care Often Helps Patients and Their Families Most When It Is Begun Months Before the Terminal Phase of Illness

For many patients, the multi-dimensional nature of hospice care, which includes care for physical, psychological, emotional, and spiritual needs, makes it not just appropriate, but highly valuable, throughout their last months of life. Experts agree that patients who receive hospice care for at least 60 days benefit the most in terms of pain and symptom management and emotional support.³⁰

Myth: Patients Need to Choose Between Life-Prolonging Care and a Focus on Quality of Life

Reality: Patients With Life-Threatening Illness Can Choose Simultaneous Life-Prolonging Treatments and Palliative Care Efforts to Promote Quality of Life

New models of care reject categorically the idea that options for care should be divided into mutually exclusive life-prolonging versus quality-of-life-enhancing efforts. From a patient-centered perspective this dichotomy makes no sense. For example, if an acceptable quality of life can be achieved, most patients will then of course want longer life in that condition.

Increasingly, palliative care—designed to maximize comfort and the ability to live well—is provided alongside curative treatments. One palliative care physician puts it this way to cancer patients: “Your oncology team is in charge of helping you live as long as possible. I am in charge of helping you live as well as possible. And we are working together.” Figure 3 below illustrates the changes in how and when palliative care is provided.

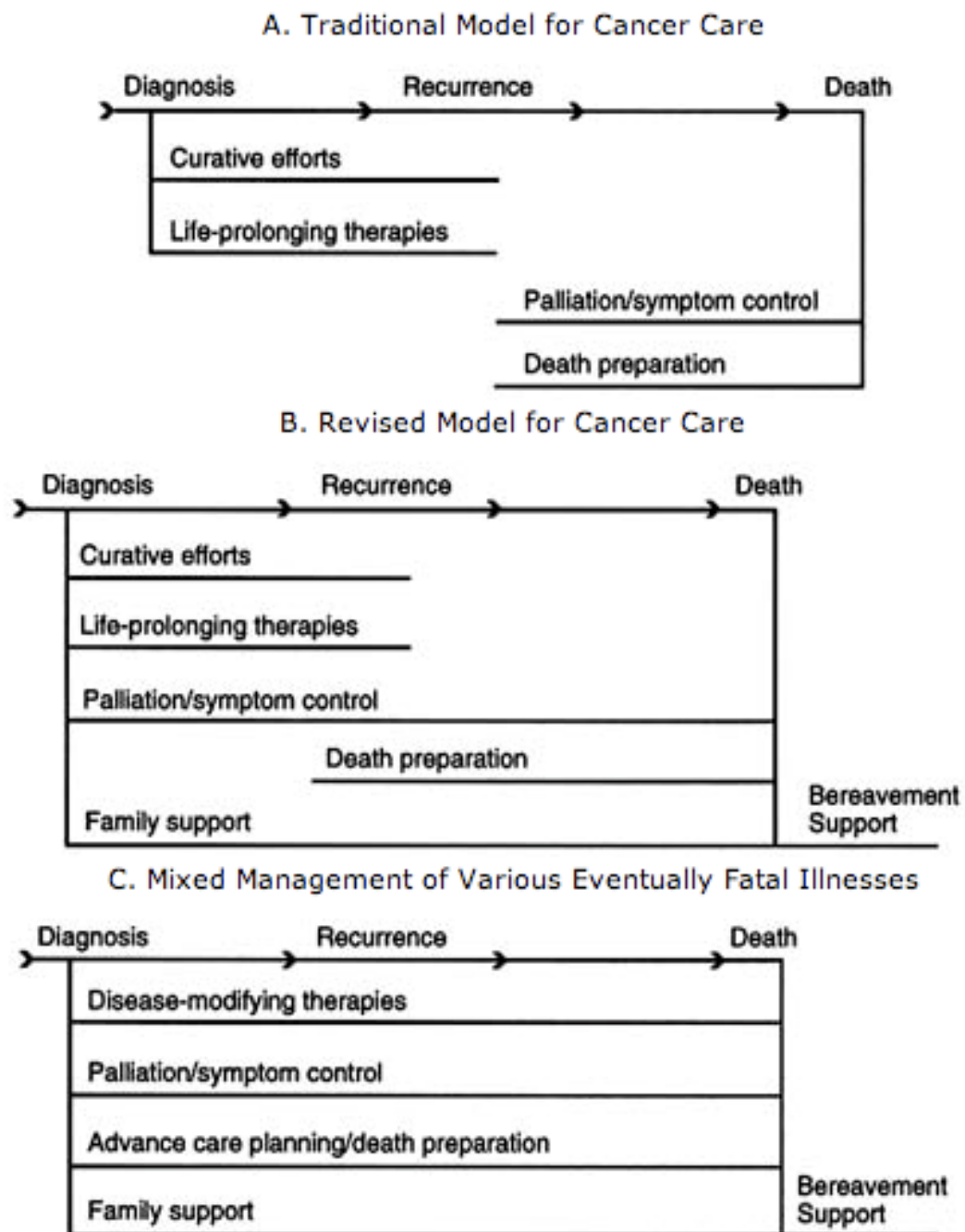


FIGURE 3: Alternative models of end-of-life care. *Source:* Institute of Medicine, *Approaching Death: Improving Care at the End of Life* (1997).

Myth: Improving Quality Means Increasing Costs

Reality: Providing Patients With the Care They Want and Need Through the End of Life is Affordable

In health care there is often no consistent correlation between cost and quality. There is, for example, increasing evidence that expanded access to palliative care and hospice services is associated not only with improved quality of life and high rates of patient and family satisfaction,³¹ but also reduced total use of health care resources.³²

For more than 20 years, the Dartmouth Atlas Project has documented significant variations in medical practices and spending across the nation. Among the project's findings is this: "...studies comparing similar patients have found that those in higher-spending regions are more likely to be admitted to the hospital, spend more time in the hospital, receive more discretionary tests, see more medical specialists, and have many more different physicians involved in their care. The extra care does not produce better outcomes overall or result in better quality of care, whether one looks at measures of technical quality (such as providing appropriate medication to heart attack patients), or survival following such serious conditions as a heart attack or hip fracture. Higher spending also does not result in improved patient perceptions of the accessibility or quality of medical care."³³

Massachusetts spends twice as much as Minnesota on health care during the last two years of life, and yet Minnesota gets better "grades" on quality of care. Massachusetts is among the top ten states in the nation for percentage of patients seeing ten or more different doctors in their last six months of life, widely considered an important sign of highly fragmented care. If the nation practiced end-of-life care like Massachusetts, Medicare spending on the last two years of life would increase by \$55 billion. If Massachusetts practiced end-of-life care like Minnesota, Dartmouth Atlas experts have estimated that the result could be as much as a \$2.3 billion reduction in Medicare spending in the Commonwealth in the last two years of life.³⁴

Myth: Improving End-of-Life Care is Unrealistic in Today's Political Climate

Reality: Transformational Change in Improving End-of-Life Care is Possible

Just a short time ago, few people would have believed that uniting political, health care, civic, and business leaders across the Commonwealth to achieve near-universal access to health insurance in Massachusetts was realistic. Today it is a reality. Transformational improvements in end-of-life care in Massachusetts will require similar unity and determination, with all stakeholders at the table.

4. Recommendations: From Vision to Reality

In this section we offer six elements that together form a vision of what end-of-life care could be like, and recommended actions that will begin to transform that vision to reality.

Recommendation #1: Inform and Empower Residents of Massachusetts

Our Vision:

Massachusetts residents are aware of and understand their options in the event that they or a loved one must make choices because of a serious advancing illness.

- Individuals know where to find information about end-of-life choices and resources.
- All individuals appoint a health care proxy and through discussions of personal values and preferences, empower the agent to carry out the person's end-of-life wishes.
- Individuals engage in conversation about choices at the end of life with family members and friends.
- Civic organizations, and allied professional groups such as estate lawyers, financial planners, funeral directors, and clergy engage in raising community awareness about choices at the end of life.

Specific Recommendations:

1. The Commonwealth should launch a vigorous, high-visibility, and ongoing public awareness campaign about the value of advance care planning by January 1, 2012, in accordance with Massachusetts Acts of 2008, Chapter 305, Section 42, with four goals:

- a. Foster statewide understanding of the importance of appointing health care agents and engaging in advance care planning;
- b. Mobilize and empower individuals and other stakeholders to demand and drive improvements in end-of-life care;
- c. Educate individuals about the role and process of Medical Orders for Life Sustaining Treatment (MOLST); and
- d. Encourage participation in national initiatives to promote advance care planning, such as National Health Care Decisions Day (NHDD).

2. Full statewide implementation of MOLST should be achieved no later than January 1, 2014.

- a. The MOLST process and forms should be made available for use beyond the Greater Worcester demonstration area by January 1, 2011.

- b. MOLST implementation should include support for a full-time project manager to oversee the statewide expansion of MOLST in accordance with the MOLST Steering Committee recommendations (final report available January 1, 2011), to ensure recognition and acceptance by hospitals, nursing facilities and other organizations statewide.

Recommendation #2: Support A Health Care System that Ensures High-Quality, Patient-Centered Care

Our Vision:

Health care providers and systems reliably identify needs and preferences of all patients with serious advancing illness, and support them in living well.

- Protocols routinely identify patients who may benefit from palliative or hospice care.
- Physicians support patients in end-of-life decision-making by helping them understand their prognosis, explore options and evaluate the risks and burdens of their choices.
- Patients are able to discuss, define and document their preferences, and have access to high-quality services across the health care continuum.
- Policies and evidence-based best practices support effective care that meets the medical, psychosocial, and spiritual needs in all care settings.
- Palliative and hospice care programs meet recognized national standards for quality, and incorporate:
 - An **interdisciplinary model** of comprehensive, coordinated care that, at a minimum, includes a physician, a registered nurse and a social worker;
 - The **time required** to provide coordinated, interdisciplinary care planning and services;
 - **Equal access** to these services among *all* patient populations, especially those with known disparities in accessing end-of-life care; and
 - **Data** on clinical outcomes and patient/family experiences that drive improvements in quality of care at the end of life.

Specific Recommendations:

- 1. All health care organizations (hospitals, nursing homes, home health agencies and others) involved in caring for patients with serious advancing illness should be required by January 1, 2014 to document to the MA Department of Public Health that they:**

- a. Identify patients with life-limiting conditions who may benefit from hospice or palliative care, with mechanisms for referral to appropriate caregivers if desired by the patient;
 - b. Demonstrate that these protocols are being systematically used; and
 - c. Have a systematic way of helping patients designate a health care agent and elicit goals of care.
- 2. By January 1, 2014, all health care organizations that care for patients with serious advancing illness should be required to provide access to palliative care and hospice services—in-house, by contract, or by referral—that meet national standards for quality.**
- 3. The Commonwealth should consider regulatory and/or legislative steps to ensure adherence to these requirements, including reviewing the successful passage in New York State of the Palliative Care Information Act [A07617], which requires health care practitioners to provide palliative care information and end-of-life care options to patients diagnosed with a terminal illness or condition.³⁵**
- 4. Providers and health plans should develop models of clinical care that integrate both palliative and life-prolonging or curative interventions.**
 - a. In light of the growing evidence about the positive impacts of the integration of palliative and life prolonging care, the Commonwealth should work with health plans to identify at least one health plan in Massachusetts willing to conduct a demonstration program expanding eligibility and services for palliative care or hospice care.
- 5. Future evolution of the Commonwealth’s Strategic Plan for Care Transitions, already highly consistent with many of the recommendations in this Report, should include explicit steps to ensure that transferred patients with identified palliative or hospice care needs experience seamless, high-quality care across settings.**

Recommendation #3: Ensure A Knowledgeable, Competent, and Compassionate Workforce

Our Vision:

Skilled professionals who are knowledgeable, competent and compassionate are available to meet patients' and families' end-of-life care needs, working in partnership with family members who are supported in their roles as daily caregivers.

Specific Recommendations:

- 1. The Commonwealth should actively promote increased palliative care training of health care professionals by:**
 - a. Requiring by January 1, 2014 that all state-financed medical schools, nursing schools, and social work programs should teach basic competencies in generalist palliative care within their undergraduate and graduate curricula.
 - b. Advocating with organizations representing the non-licensed direct care workers—including personal care assistants, certified nursing assistants, and hospice and home health aides—to include a minimum of one to two hours of education in palliative care for initial certification and at least one hour of annual continuing education by January 1, 2014.
 - c. Advocating with the Massachusetts Office of Emergency Medical Services (OEMS) to review the role and training of EMS staff and first responders related to end-of-life care, including MOLST.
 - d. Encouraging local/state chapters of organizations of key professional disciplines—medicine, nursing, social work, physician assistants—to:
 - i. Work with their respective national organizations to ensure that basic palliative care competencies are included in curricula, training, and certification requirements for graduate and undergraduate education, as appropriate for their fields; and
 - ii. Participate in developing and offering training programs in palliative care for continuing education and other professional development.
- 2. All health care organizations caring for patients with serious advancing illness should be required by January 1, 2014 to document that their staff have training commensurate with their roles and responsibilities, including:**
 - a. Physicians, nurses, physician assistants and other advance practice clinicians,

including both generalist clinicians and certified palliative care specialists;

- b. Psychosocial professionals such as social workers, chaplains, and bereavement therapists, who provide emotional and spiritual support to patients and families; and
 - c. Non-licensed direct care workers, including personal care assistants, certified nursing assistants, hospice and home health aides, and others who provide bedside care to patients in hospitals, nursing homes, assisted living residences, hospices, and home.
- 3. Hospitals, hospices, health plans and other service providers should be encouraged to provide in-home training and supportive services (respite, care coordination) to family caregivers, who provide the majority of hands-on care and support for patients, especially for patients at home.**

Recommendation #4: Create Financing Structures That Promote Patient-Centered Care

Our Vision:

Health system financing and payment structures provide incentives and ensure accountability for patient-centered care—the right care, in the right place, at the right time.

- Patients' choices drive decisions about what care is delivered and where, and payment systems support choices that are consistent with best practices in end-of-life care.
- All health plans expand eligibility for hospice beyond the current six-month prognosis, allow for concurrent care, and provide specialized case management to patients and families.
- Family members are supported in caring for loved ones at home.

Specific Recommendations:

- 1. Any Commonwealth payment reform initiative should be designed to ensure that, for all patients with serious advancing illness:**
 - a. Discussions with their physician about their goals and wishes for care, including at the end of life, are included as covered services;
 - b. Comprehensive palliative care and hospice services, delivered by an interdisciplinary team, are covered in all health plans;
 - c. No patient is forced to decline life-prolonging measures in order to receive palliative care services that enhance quality of life; and
 - d. Payment for medical services requires adequate documentation that they are based on the well-informed wishes of patients (or appropriate surrogates), including understanding of life-prolonging and palliative care or hospice alternatives.
- 2. Under state law (Mandated Hospice Benefit 1994), health plans in Massachusetts are required to provide a hospice benefit. Three MassHealth plans (MassHealth Basic, MassHealth Limited, and MassHealth Essential) currently do not, and should be changed to include hospice coverage.**
- 3. The Executive Office of Elder Affairs, the Department of Public Health, the Department**

of Mental Health, the Department of Developmental Services, the Massachusetts Rehabilitation Commission, the Department of Children and Families, and other appropriate state agencies should explore ways to increase support for family members choosing to care for loved ones at home.

Recommendation #5: Create a Responsible Entity to Ensure Excellence and Accountability

Our Vision:

A responsible entity has the resources and authority to ensure implementation of these recommendations for excellence in end-of-life care, with measurable quality indicators and public accountability.

- This entity includes representatives of the four domains addressed in the Panel's report: informed and empowered patients and families; an effective health care system; a competent and compassionate workforce; and financial systems that support care.
- The entity is responsible for promoting the implementation of the Panel's recommendations; examining and reporting on best practices; supporting efforts to measure and report performance improvement initiatives; recommending financing strategies that support the delivery of high-quality palliative care; partnering with stakeholders to improve end-of-life care; and improving communication among all caregivers about end-of-life preferences, especially during transitions in care.
- The entity further supports and analyzes implementation of end-of-life provisions within the Patient Protection and Affordable Care Act.

Specific Recommendations:

- 1. The Executive Office of Health and Human Services, the Health Care Quality and Cost Council, the Executive Office of Elder Affairs, and the Department of Public Health, and their internal bodies whose work relates to the care of patients with serious advancing illness should:**
 - a. Review the Recommendations of the Expert Panel on End-of-Life Care and determine how these recommendations can be implemented as part of their evolving work; and
 - b. Set annual goals related to implementing the recommendations, and other efforts to improve end-of-life care, and report to the Secretary of Health and Human Services on their progress.
- 2. The Governor and the Legislature, in consultation with the Secretary of Health and Human Services, should ensure that a responsible entity has the resources and authority to promote implementation of these Recommendations. This body should:**

- a. Include representatives of the four domains addressed in the Panel's report: informed and empowered patients and families; an effective health care system; a competent and compassionate workforce; and financial systems that support care.
 - b. Oversee the Commonwealth's public awareness campaign surrounding end-of-life care in accordance with Chapter 305, Acts of 2008.
 - c. Support implementation of the Massachusetts MOLST Program, Chapter 305, Acts of 2008, with full statewide implementation by January 1, 2014. (See specific recommendation 2 on pp. 17-18 for more details.)
 - d. Develop and implement additional strategies that improve end-of-life care in the Commonwealth, including:
 - 1. Ensuring that the needs of special populations, such as people with disabilities or mental illness, children, frail elders, racial and ethnic minority groups, and veterans, are being met; and
 - 2. Reviewing the size and distribution of the hospice organizations in the state and making any necessary recommendations to meet the needs of all the residents of the Commonwealth
 - e. Report at least annually on progress.
- 3. The entity should organize an annual end-of-life summit to share best practices, discuss progress, and apply lessons learned from other states.**

Recommendation #6: Employ Quality Indicators and Performance Measurement

Our Vision:

The impact of these recommendations are effectively measured and monitored over time to ensure progress in honoring patients' wishes and delivering excellence in care.

- There is transparency and accountability among all reporting entities to inform choice and drive system improvement.
- Outcome measures are developed and validated by national and state standard bearers such as The National Quality Forum, National Priorities Partnership, and the Centers for Medicaid and Medicare Services.
- All providers have appropriate measurement plans in place.
- Mechanisms for data collection and reporting are in place by providers and public agencies.

Specific Recommendations:

1. Hospitals

- a. Effective July 1, 2011, utilizing the American Hospital Association (AHA) Annual Survey, the Massachusetts Health Care Quality and Cost Council (HCQCC) will publish annually, on its website, the existence of affiliated hospice and palliative care programs (in house, by contract or referral) for all hospitals by name in Massachusetts
- b. By January 1, 2011, the HCQCC or other designated responsible body will begin discussions with the Massachusetts Hospital Association on ways to collect and publicly report the presence of palliative care training programs. The goal will be for public reporting to commence by hospitals by July 1, 2011.

2. Nursing Homes and Home Care

- a. The HCQCC will publish annually, on its website, the percent of patients with an advance directive for all nursing homes by name in Massachusetts.
- b. By January 1, 2011, the Executive Office of Elder Affairs will begin discussions with the Massachusetts Home Care Association, Massachusetts Senior Care Association, and the Massachusetts Aging Services Association (MassAging) on ways to collect and publicly report

the presence of palliative care programs (in house, by contract or referral) for all home care and nursing home organizations by name in Massachusetts. The goal will be for public reporting to commence by July 1, 2011.

- c. By January 1, 2011, the HCQCC or other designated responsible body will begin discussions with the Massachusetts Home Care and Extended Care associations on ways to collect and publicly report the presence of palliative care training programs. The goal will be for public reporting to commence by July 1, 2011.

3. Ambulatory Care Organizations

- a. By January 1, 2011, the HCQCC directly or through the designated responsible body, will begin discussions with Massachusetts Health Quality Partnership on measures to assess the palliative care programs, training, and penetration in these settings.

4. Annual Report

- a. Effective July 1, 2011 and annually thereafter, the HCQCC directly or through the designated responsible body, will publish on its website an annual progress report on palliative and end-of-life care in the Commonwealth to include, at a minimum:
 - Presence of a palliative care program (in-house or by contract or referral) by hospital, nursing home, home care agency or progress in meeting that goal;
 - Percent of patients dying in hospice, median and average length of stay, and geographic variations;
 - Location of death by community;
 - Resource use in the last six months of life by hospital;
 - Progress in the statewide implementation of MOLST;
 - Patients in extended care facilities with advance directives; and
 - Development of a measure on the degree to which the patient's wishes were honored.
- b. Effective immediately, the HCQCC Expert Panel on Performance Measurement should consider approaches to measure the degree to which a patient's wishes were honored at the end of life, drawing on the experience of the MOLST project, the prior research by Better Ending Partnership, and others. No later than July 1, 2011, the HCQCC or designated responsible body will report on a recommended measure.

5. Conclusion

Patients, Not Politics

The Expert Panel began its work in the midst of sometimes heated national debates about health care reform. Discussions about improving end-of-life care grew so politically charged that constructive debate on this topic at the national level became almost impossible. Even proposals to compensate physicians for spending time discussing end-of-life options with patients were attacked, with allegations that they would be promoted for cost-savings rather than to ensure that patients' wishes are understood and respected. It is of course crucial to ensure that discussions with patients about end-of-life care issues are driven by concern about the patient, not money; this is a uniquely vulnerable patient population. But it would be unconscionable to allow partisan politics to prevent progress in this critical area of care.

From the start, the Expert Panel explicitly rejected the idea that considerations of cost should drive its work. Improving end-of-life care is, first and foremost, about *improving care*. Just as in other areas of health care, improving care for patients near the end of life is about closing the gap between what we know, and what we do. It is about creating programs and protocols that are more patient-centered, more responsive to what patients say they want and need. It is—contrary to what some may believe—about giving patients more control, not less, over the kind of care they receive, especially as they near the end of life.

Providing care leading up to the end of life that is driven by the wishes of patients may in fact be less expensive than current patterns of care. Some patients may choose to forego more costly care once they understand all their choices. But saving money is not and must not be the focus of reforms. The reforms we need must be driven by the only legitimate goal of any health care system: providing each and every patient with the best possible care.

A Call To Action: Collaboration and Cooperation

Massachusetts proudly leads the nation in ensuring that its citizens have access to high-quality, affordable health care. Now we must build on what we have begun by ensuring that all our residents get the care they want and need throughout their lives, including as their lives draw to a close.

Massachusetts' groundbreaking expansion of health care coverage required uncommon collaboration and cooperation among all stakeholders, across the political spectrum. Extending high quality end-of-life care to all Massachusetts residents will require the same spirit of cooperation, the same willingness to put aside arguments about differences that impede progress toward the goal we all share—improved health care, more informed patients, and better value for all.

The goal of our health care system is to keep people healthy, to heal them when they are sick or injured, and—finally—to provide care and comfort to all patients and their loved ones in life's final stages. That care and comfort should be consistent with each patient's personal values, goals, and preferences, and should enable individuals to retain as much control as possible over their end-of-life experience. If the health care system succeeds in this goal, then patients, supported and surrounded by their loved ones, will experience what so many today falsely believe is an oxymoron: a good death according to their own definition, in accordance with their wishes.

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Note: Many background documents and other resources used by the Expert Panel in its work can be found at: <http://www.mass.gov/healthcare/expertpanel>

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