

**Testimony to Massachusetts Health Policy Commission  
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Lachlan Forrow, MD

Chair, Massachusetts DPH Interdisciplinary Advisory Council on Palliative Care and Quality of Life  
Chair (2008-2011) Massachusetts Expert Panel on End-of-Life Care

Director of Ethics Programs and Palliative Care Physician, BIDMC  
Associate Professor of Medicine, Harvard Medical School

Good afternoon. My name is Dr. Lachlan Forrow. I am a palliative care physician at Beth Israel Deaconess Medical Center and past Chair of the Massachusetts Expert Panel on End-of-Life Care. I currently serve as Chair of the DPH Interdisciplinary Advisory Council on Palliative Care and Quality of Life. I am here to update you on efforts to improve end-of-life care in the Commonwealth, and to stress one specific thing you can do to contribute to those.

To give a very brief overview – the Massachusetts Expert Panel on End of Life Care identified end-of-life care as the only issue in all of healthcare that affects every single one of us, and everyone we care about, with 100% certainty. It is also an issue everybody cares deeply about. When it goes well, in addition to the patient benefitting enormously, surviving family and friends look back, however sad they are at their loss, with gratitude and often deeply-loving memories. But when it goes badly, as happens far too frequently, people are left angry, confused, guilty, and sometimes even deeply scarred. So it really, really matters, to every single person in the Commonwealth, whether or not we do this well.

In addition, we are spending vast resources in caring for people in the last year of life – as Stuart Altman has said in his book, up to 25% of all healthcare spending in this country occurs in the last year of life. For that amount of money, we all have a right to expect, and we all deserve, truly superb results.



The most important finding of our state Expert Panel, utterly contrary to the deeply-polarizing national “death panel” controversies that took place during our work, was that everyone in the Commonwealth actually agrees on this topic. Specifically, everybody agrees that: ***Each one of us should always be cared for in the way that we would want, supported in our choices from among the full range of available options for our care.*** But our Expert Panel found that our health care system today has not even been trying to make sure that that is true. So we have in the Commonwealth not only a truly serious problem; we also have an extraordinary opportunity to unite everyone – patients, families, clinicians, health systems, payers, faith communities, government, truly everyone -- in statewide efforts to achieve an important goal that every one of us cares deeply about.



Since I spoke to you last year, there has been exciting progress in uniting the Commonwealth to work in this area. In May an extraordinary statewide grassroots coalition was launched -- the Massachusetts Coalition for Serious Illness Care. Under the visionary leadership of Andrew Dreyfus, Atul Gawande, and Maureen Bisognano, the Coalition’s inaugural event at the John F. Kennedy Library was attended by an overflow audience of over 400 people, joined by Governor Charlie Baker and many other health and civic leaders. The Coalition now engages and supports a rapidly-growing statewide network of health and civic organizations, representing thousands of highly-motivated individuals, committed to making measurable progress toward a single shared goal: ***“Health care for everyone in Massachusetts is in accordance with their goals, values and preferences.”*** Generously coordinated, in the best “servant leadership” tradition, by Blue Cross/Blue Shield of Massachusetts, Coalition partners range from the Massachusetts Hospital Association, the Massachusetts Medical Society, the American Cancer Society, and numerous health systems, hospitals, and insurers; to grassroots organizations including The Conversation Project and Honoring Choices Massachusetts and its many Alliance Partners; to faith communities including the Archdiocese of Massachusetts, Greater Boston Interfaith Organization (GBIO) and others; to many others outside the direct health sector, including the Association of Independent Colleges and Universities in Massachusetts.

New data, however, confirms both the frequency and the severity of the shortcomings in care that we need to fix. Results from a statewide survey done by the Coalition, reported on the front page of the Boston Globe, were even worse than many of us had anticipated. Responses to two of the Coalition's survey questions provide a clear "call to urgent action" for all of us. When asked to rate the recent care of a loved one through the time of death, barely half (52%) of Massachusetts residents said that the care was very good or excellent. Fully 20% said it was either "poor" or only "fair". Since roughly 60,000 people die each year in the Commonwealth, this means that the care of more than 10,000 patients each year is severely deficient. Perhaps even worse, when asked about the extent to which their loved one's wishes were followed and honored by healthcare providers at the end of life, barely half reported "very much", with only 20% reporting "some" and fully 15% saying only a little bit or, hauntingly, "not at all". For nonwhite respondents the results were far worse. There can no longer be any doubt about the importance and the urgency of major health care reforms in this area.

Fortunately, in Massachusetts we already have every single form of expertise that we need to achieve superb results for all of the people of the Commonwealth -- leaders and staff-level experts within our healthcare systems, nationally-renowned experts in academia, and grassroots expertise through organizations such as The Conversation Project and Honoring Choices Massachusetts. And we have not just expertise, we have enormous interest and enthusiasm about doing better. Every one I have met with over the past year, in health care, in civic organizations, and others, is deeply committed to collaborating to achieve rapid improvement, many driven by their own personal experiences, too often unsatisfactory, of the care of loved ones.



But despite all of this expertise, and despite all of this interest, and despite lots of specific good work being done by so many organizations and individuals on pieces of things that we need to improve, the reality is that all of us are essentially **flying blind**. We are flying blind because none of us is working from any outcome data, data that is crucial for showing us what and where we need to improve, and how to improve it. None of us today can reliably tell whether the improvement interventions that so many are energetically undertaking -- whether training of clinicians in communication, or education of patients and families, or electronic record systems improvements -- are actually leading to better outcomes, i.e. improved patient and family experiences at the end of life. And flying blind makes it almost impossible to learn from each other -- we have no way to identify, compare, and share "best practices" that have been shown to improve actual outcomes.

Fortunately, having the outcome data we need is also within our grasp. Nationally, CMS-approved [Hospice CAHPS measures](#) now provide a steady stream of data from post-death surveys of family members for patients enrolled in hospice. The [VA's PROMISE program](#) is learning from over 30,000 completed post-death surveys of family members of veterans how to make improvements in the care of our veterans. All it will take to adapt their instruments and experiences to learn about, and learn from, the experiences of the nearly 60,000 people who die each year in the Commonwealth is a commitment to do so. Yes, it will take a one-time investment of resources to adapt, pilot, and validate a statewide survey applicable to all deaths. Health systems also need to ensure they have identified health care proxies or other family members for all patients with serious illness, including contact information. But the ongoing streams of outcome data that this will provide is absolutely essential for us to know the quality of care currently being provided for the many billions of dollars we are spending each year in the last phase of life, and for us to achieve the improvements that every single person in the Commonwealth wants and deserves.



I will leave you with one final thought. It was particularly appropriate that the Massachusetts Coalition for Serious Illness Care was launched in May from the John F. Kennedy Library, near the 55<sup>th</sup> anniversary of President Kennedy's call for a nationwide effort to land a man on the moon, and return him safely, by the end of the decade. Achieving excellence in care through the end of life for everyone in Commonwealth will be far easier than that daunting challenge, but the two essential ingredients for success are the same. First, President Kennedy offered a clear, concrete, and obviously easily-measurable goal. For us, however, the absence of outcome data makes it virtually impossible to set clear, measurable "outcome goals" for our efforts to improve care through the end of life. Second, perhaps even more important, is what President Kennedy learned in answers to his question to experts: *What Will It Take to Succeed?* Some mentioned the need for unprecedented advances in rocket technology; others mentioned major financial investments; others mentioned advances in medical support for astronauts in space; But the crucial answer came from rocket scientist Werner von Braun, who said he could explain in five words the one and only thing that was needed: *"The Will to Do It."*

For us, the road to success is clear, individuals and organizations across the Commonwealth are ready to do whatever work success will require, and if the Health Policy Commission and others can ensure that we will soon have the outcome data systems we need, I truly believe success will become inevitable. Thank you for your support.