

Statement of

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Before the

U.S. Senate Special Committee on Aging

Concerning

Being Mortal:

*Assuring Care That Honors One's Goals
and Priorities Beyond Just Living Longer*

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Executive Summary

People with serious, potentially life-limiting illnesses face substantial and increasing suffering, particularly during the last year of life. Medical care today typically exacerbates this suffering, often without any benefit of lengthened life. We have a major opportunity to change this, however.

People have priorities in their lives besides just living longer. These priorities are individual and change over time. The most effective and important way to learn these priorities is to ask people. But we ask less than one-third of the time before people die. When we don't ask, the result is suffering, for care and treatment often ends up out of alignment with what matters most to individuals. When we do ask, and align our care with their priorities, the results are remarkable. People experience more control over their care, less anxiety and depression, more time at home and with family, and lower costs, and they do not have shorter lives. On average, in fact, they live longer.

Our goal therefore must be to assure all Americans that when they face a serious illness, their care will honor their personal goals and priorities. Achieving this requires ensuring that:

1. *Everyone 18 or older has designated a health care decision-maker (health care proxy);*
2. *Everyone 18 or older has had a conversation (and continues to have conversations) with their proxy to communicate their goals, values, and preferences for care at the end of life;*
3. *All clinicians have appropriate training to facilitate high-quality communication with patients on advance care planning and serious illness;*
4. *Everyone facing a serious illness has had a high-quality, informed goals and values conversation with their care team;*
5. *All health care providers have systems in place to elicit and document goals, values, and preferences for patients with serious illness;*
6. *All health care providers have systems in place to share patient goals, values, and preferences across care settings, to ensure they are accessible regardless of place of care.*

To achieve these goals, we need a concerted campaign and federal support to assure:

1. That we track progress on these goals, and on the outcome of improving the wellbeing of people with serious illness.
2. That we have a clinical and elder care community with better systems and skills for discussing serious illness care goals and priorities with individuals and their families.
3. That we devote research resources to science that improves our therapies and our systems for increasing the quality of life, and not just the quantity of life, of the seriously ill.

Formal Statement

Good morning, Senator Collins, Ranking Member McCaskill, and members of the Committee. My name is Atul Gawande. I am a surgeon, public health researcher, and a writer, and I thank you for the opportunity to provide testimony on the critical subject of improving our often inadequate and inhumane system of care for people with serious, life-limiting illness.

I did not come to this issue as an expert in improving serious illness care. I came to this issue out of my own experiences as a general surgeon at Brigham and Women's Hospital in Boston. After more than a decade in practice, I realized that although I was competent and often effective at taking care of people with fixable problems, I wasn't sure what being competent and effective at taking care of people with unfixable problems even meant. We are lucky to live in a time when the vast majority of us will live long enough to grow old. But although medical capabilities allow people to live both longer and better lives, nearly all of us will also face serious illness and impairment along the way. During the last phase of their lives, the average American experiences eight years of significant disability due to age or illness.¹ As people become weaker and sicker--whether from end-stage organ failure, terminal cancer, dementia, or the mounting infirmities of old age--they and their families ask doctors a seemingly simple question, "Isn't there anything you can do?"

The thing is, there is always something we can do. We can operate, provide chemotherapy, put in tubes, insert devices, and attach machines, carrying on this way right to the very end. And I saw, over and over again, how much suffering we caused, and how much we even shortened people's lives, out of a desire to keep doing something, anything, no matter what. But it can be difficult for clinicians, patients, and families not to regard any other choice as, essentially, "doing nothing." I wanted to understand how to do better, but I didn't know how.

That was the genesis for my book, *Being Mortal*. I interviewed more than 200 patients and their families about their experiences with serious illness or frailty from aging. I also talked to and observed scores of experts--hospice nurses, palliative care specialists, geriatricians, nursing home directors, and the like.

I took away a few simple lessons. People have priorities in their lives besides just living longer. These priorities are individual and change over time. The most effective and important way to learn these priorities is to ask people about them. The overwhelming majority of time, however, we don't ask, whether as clinicians or as family members. When we don't ask, the care and treatments we provide usually fall out of alignment with people's priorities. And the result is suffering. But when we do ask, and work to align our care with their priorities, the results are extraordinary.

¹ Chernew M, Cutler DM, Ghosh K, Landrum MB. "Understanding the Improvement in Disability-Free Life Expectancy in the U.S. Elderly Population." *Insights in the Economics of Aging*. Ed. Wise DA. Cambridge, MA: National Bureau of Economic Research, (Forthcoming).
<<http://www.nber.org/chapters/c13631>> Accessed June 20, 2016.

The Current Situation

In studies of people with terminal cancer, clinicians ask about their goals for the last phase of their lives less than one-third of the time before they die.² Families appear to do little better. And when we do ask, it is generally not until close to the very end.

Partly, this is because we clinicians are uncomfortable having these conversations until all uncertainty is removed about what is happening and when. Partly, we often fail to recognize that the amount of suffering that people endure in their last year of life, even well before the end, is considerable. Surveys reveal, however, that during their last year of life, half of patients are often in moderate to severe pain and experience at least a month of depression, periodic confusion, difficulty breathing, and incontinence. Worse, between 1998 and 2010, the percentage of people experiencing pain, depression, and periodic confusion actually increased.³ Medical care for the symptoms people experience at the end of life does not seem to have gotten better; it may have gotten worse.

These findings do not simply reflect patient preferences to trade the quality of life for therapies that extend life. According to a study by the Institute of Medicine, when care is provided with a narrow focus on disease control, without efforts to elicit and tailor care to include broader goals for the quality of life, the evidence is that patients do not survive longer; they just suffer more, experiencing more pain, more anxiety, more family exhaustion, while receiving more non-beneficial care and more hospitalization, even to the very end of life.⁴

What Is Needed: More, Earlier, and Better Goals Conversations

By contrast, a number of studies have demonstrated that when people with serious illness have discussed their goals and wishes for their care with their clinician, the outcome is far better. They suffer less, they are more physically capable, and they are better able, for a longer period, to interact with others; their family members were also markedly less likely to experience depression. They enroll in hospice sooner,⁵ but they do not die sooner--on average, in fact, they live longer.⁶

The best done study on this issue was a landmark 2010 Massachusetts General Hospital randomized trial with stage IV lung cancer patients. Their average survival was just eleven

² Wright, Alexi A., et al. "Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment." *JAMA* 300.14 (2008): 1665-1673.

³ Singer, Adam E., et al. "Symptom Trends in the Last Year of Life From 1998 to 2010: A Cohort Study." *Annals of Internal Medicine* 162.3 (2015): 175-183.

⁴ Institute of Medicine (US). Committee on Approaching Death: Addressing Key End-of-Life Issues. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: National Academy Press, 2014.

⁵ Wright et al, 2008.

⁶ Connor, Stephen R., et al. "Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window." *Journal of Pain and Symptom Management* 33.3 (2007): 238-246.

months. Half received usual oncology care. The other half also received early consultation with a palliative care specialist.

Palliative care provides expertise in working with seriously ill patients to identify their goals for quality of life, not just quantity of life, and to tailor care to support those goals. It is appropriate at any stage in a serious illness and at any age, and it can be provided together with curative treatment. It is not exclusively for people who have reached the end of life.

Nonetheless, in oncology, we usually don't involve palliative care specialists until the end of life is imminent. There is a common perception among both the medical profession and the public at large that seeking palliative care consultation amounts to "giving up," and is only relevant when people no longer have options for disease-based therapy. But the MGH study found that when the specialists were involved early after diagnosis, patients stopped their chemotherapy sooner, entered hospice earlier, spent fewer days in the hospital and ICU, experienced less suffering at the end of their lives, and--here was the kicker--*they lived 25 percent longer*.⁷ In other words, our decision making in medicine has failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of mortality. If a serious illness discussion were an experimental drug, the FDA would approve it.

There is increasing evidence about what the content of these discussions should be. At Ariadne Labs, our research center at Brigham and Women's Hospital and the Harvard Chan School of Public Health, we have developed a serious illness conversation guide for clinicians based on the evidence. It identifies critical questions for clinicians and families to discuss in order to identify one's goals and priorities for care:⁸

1. What is your understanding now of where you are with your illness?
2. How much information about what is likely to be ahead with your illness would you like from your doctor?
3. If your health situation worsens, what are your most important goals?
4. What are your biggest fears and worries about the future with your health?
5. What is the minimum quality of life you'd find acceptable?
6. If you become sicker, what are you willing to go through, and what are you not willing to go through, for the possibility of gaining more time?
7. How much does your family know about your priorities and wishes?

We recently deployed this approach in a randomized trial at the Dana Farber Cancer Institute that aims to assure patients that their care is matched to their goals and priorities. The program involved training clinicians in using the Critical Questions approach, providing a system to identify patients at highest risk of death, mailing a guide to patients with suggestions to help them discuss preferences about care with their families, and creating a system for documenting personalized patient goals and priorities in the electronic health record.

⁷ Temel, Jennifer S., et al. "Early Palliative Care for Patients With Metastatic Non-Small-Cell Lung Cancer." *New England Journal of Medicine* 363.8 (2010): 733-742.

⁸ Bernacki, Rachelle E., and Susan D. Block. "Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices." *JAMA Internal Medicine* 174.12 (2014): 1994-2003.

Our preliminary data have been encouraging. Thus far, 92% of patients with clinicians who were trained in the program had an advanced care planning conversation. It happened earlier--five months before death instead of just a few weeks. The conversations were higher quality. And the patients experienced markedly lower levels of anxiety and depression before they died.^{9 10} In other words, we found that it is possible to bring the benefits of high-quality serious illness care conversations to entire health systems.

The Gap: People Don't Identify Their Health Care Agent Or Have Serious Illness Care Discussions

In my state, we recently launched the Massachusetts Coalition for Serious Illness Care with the mission of ensuring that every resident receives health care that honors their goals, values, and preferences. Achieving this requires that people across the state have critical conversations about their goals and wishes in the event of serious illness long before crisis comes. After all, seventy percent of those who require end-of-life care decision making will be unable to make those decisions for themselves.¹¹ If someone else is to make these decisions, they have to know how to be faithful to our wishes.

We have recognized **six measurable goals** required to achieve this. We must as a state--and in fact, as a country--ensure that:

1. *Everyone 18 or older has designated a health care decision-maker (health care proxy);*
2. *Everyone 18 or older has had a conversation (and continues to have conversations) with their proxy to communicate their goals, values, and preferences for care at the end of life;*
3. *All clinicians have appropriate training to facilitate high-quality communication with patients on advance care planning and serious illness;*
4. *Everyone facing a serious illness has had a high-quality, informed goals and values conversation with their care team;*
5. *All health care providers have systems in place to elicit and document goals, values, and preferences for patients with serious illness;*
6. *All health care providers have systems in place to share patient goals, values, and preferences across care settings, to ensure they are accessible regardless of place of care.*

⁹ Bernacki, Rachele, et al. "Delivering More, Earlier, and Better Goals-of-Care Conversations to Seriously Ill Oncology Patients." *Journal of Clinical Oncology* 33.29-Supplement (2015): 39.

¹⁰ Paladino Joanna, et al. "Effect of Conversations About Values and Goals on Anxiety in Patients." *Journal of Clinical Oncology* 33.29-Supplement (2015): 9.

¹¹ Silveira MJ, Kim SYH, Langa KM. "Advance Directives and Outcomes of Surrogate Decision Making Before Death." *New England Journal of Medicine* 362 (2010): 1211-1218.

We are an alarmingly long way from achieving these goals. In order to track our state's progress, the Coalition has planned an annual statewide survey of people's attitudes and experiences related to serious illness and end-of-life care. Results from our initial (March 2016) baseline survey reflect what national surveys have indicated--we have a lot of work to do:¹²

- 85% of respondents believe that doctors should discuss end-of-life matters with patients, yet only 15% have ever had such a discussion.
- Only 25% of those facing a serious illness have had a goals conversation with their doctor.
- More than half have not named a health care agent to make decisions when they can't.
- Men, minorities, and those with less than a college education were significantly less likely to have named a health care agent or discussed their end-of-life care wishes.
- Almost one-third of those surveyed had lost a loved one in the past 12 months, and of those, more than one third felt that their family member's wishes were only partly followed, or not at all.

Barriers and Opportunities for Action

Our coalition has gathered more than 60 organizations across the state, all committed to improving planning and care for people facing serious, life-limiting illness. We have a multi-pronged, multi-year strategy. We will work with nursing schools, medical schools, and residency training programs to insure clinicians are exposed to palliative, geriatric, and hospice care and taught serious illness communication skills. We will work with provider organizations and payers--from the state hospital and medical associations, insurers, and state government to organizations nursing home, assisted living communities, home care services, and other elder care providers--to increase opportunities for people to identify a health care agent and communicate the goals and priorities they most want their caregivers to serve. And we will work with advocacy groups--religious organizations, consumer groups, and others--to increase awareness and progress on these issues.

However, there remain significant barriers to making progress toward assuring that every Americans receive health care that honors and supports their goals, values and preferences, including for the quality of their life. You, as Senators, can help to address these barriers.

1. Our quality measures for hospitals, nursing homes, elder care, and hospice are narrowly focused on safety and health and exclude other critical domains of wellbeing.

If there is any single, consistent lesson that I learned in my research for my book *Being Mortal*, it was that people who face serious illness or infirmity fear more than anything losing their autonomy--their ability to control the purposes and parameters of the care that they receive. Care plans and quality measures for nursing homes and other settings, however, focus almost exclusively on narrow issues of health and safety like fall prevention, management of feeding tubes, nutrition, pressure ulcers, and so on. These are important. But just as, if not more important to people who need help with their needs for day-to-day living is the ability to have a

¹² "End-of-life care: New MA Survey Shows Deep Chasm Between What We Know and What We Do." May 12, 2016. <<http://prn.to/1rvYvet>> Accessed June 20, 2016.

say over matters like privacy, the risks they are permitted to take, when they go to bed and when they wake up, how they furnish and decorate their rooms, opportunities to pursue purposes larger than just mere existence, and who will make decisions when they cannot.

Similarly, in acute care settings, there is little recognition that care should focus not only on improving survival but also on supporting the ability to pursue those purposes and aims that matter most to individuals. We publicly report survival rates for particular conditions and measures for preservation of health and safety, but we do not have measures that ask how effectively care supports wellbeing. People have reasons they wish to be alive, but in our incentives and expectations for health care and elder care, we don't seem to acknowledge that at all.

Regulations for particular care settings sometimes indicate that care plans should specify the plans to support "psychosocial wellbeing." But that directive has not remotely incorporated the basic expectation that people have an effective opportunity to state their most important goals and preferences for their care besides just living longer, and that care be aligned accordingly.

We need a commitment that includes resources to develop, track, and prioritize quality measures for serious illness care planning and for wellbeing. Similarly we must track our progress toward achieving those six measurable goals that were articulated by the MA Coalition, including whether people have named their health care agent and discussed their goals and priorities for serious illness care with them, and whether clinicians are providing more, earlier, and better serious illness care conversations.

2. The clinical community lacks adequate skills in serious illness communication and palliative care.

The current supply of skilled clinicians in palliative care and in geriatrics is severely inadequate to serve even a small percentage of the more than two million people per year in the United States who die from cancer, heart disease, chronic respiratory illness, cerebrovascular disease, Alzheimer disease, or end-stage renal disease, let alone the even larger population that faces prolonged serious illness or frailty.¹³ More generally, there is a need for all clinicians to be equipped with the basic skills of palliative care and geriatrics--including the ability to have high-quality serious illness care conversations and to align treatment plans with individual patient's goals for quality of life. However, the vast majority do not have these skills.

Federal policies and funding need to focus on training more palliative care specialists and geriatricians *and* on enabling and scaling programs that foster the ability of these specialists to teach non-palliative care clinicians to do this work as well. Furthermore, federal policy must also enable and incentivize health systems to incorporate serious illness care discussions and planning as a routine and expected part of care.

¹³ Institute of Medicine, 2014.

The Serious Illness Care Program at Ariadne Labs shows that training for clinicians in these skills is both possible and effective. We are now scaling up work through partnerships with individual health systems across the country, but we have nowhere near the resources to provide our program nationwide. Investment in a national demonstration program to produce measurable increases in serious illness care planning would markedly accelerate the development and deployment of effective programs.

The other avenue for people to gain access to palliative care is through hospice. However, Medicare and private insurers have codified benefit limits that require patients to give up on curative therapy in order to receive the intensive palliative services and management that hospice care provides.¹⁴ This has been a major contributor to the underuse of hospice, the underrecognition of the value of palliative care, and the resulting poor quality of life experienced by patients with advanced disease and limited life expectancy. This needs to change.

The recent Medicare Care Choices Model demonstration is a welcome initiative, testing the lifting of those limits with 141 hospice organizations across the country.¹⁵ The evaluation, however, runs the danger of continuing to treat support of quality of life differently from support of extension of life. Adoption as a national policy should not depend merely on whether the change reduces overall health care costs. It may well do so, based on the experience of private insurers who have tested the idea. Nonetheless, just as with any other medical intervention, the key measure of effectiveness is how much it improves patients' health and wellbeing.

3. Research funding has largely ignored quality of life in serious illness.

There are two major areas of research opportunity: discovery of new treatments and development of systems innovation. The vast majority of federal research funding is oriented toward a single dimension of life: survival. This is despite the fact that twenty-five percent of Medicare spending occurs in the last year of life,¹⁶ with considerable and increasing levels of suffering that people face during that time. Recent studies also show that therapies commonly given for people with serious illness--for example, palliative chemotherapy for patients with end-stage cancer--improves neither survival nor quality of life, and frequently worsens quality of life.¹⁷ Research to develop therapies in cancer, organ failure, and other conditions should include funding for science aimed at the development of palliative therapies that improve quality of life. People deserve better options than the ones we have.

¹⁴ Odejide, Oreofe O. "A Policy Prescription for Hospice Care." *JAMA* 315.3 (2016): 257-258.

¹⁵ "Medicare Care Choices Model." *Center for Medicare and Medicaid Services*. Center for Medicare and Medicaid Services, May 6, 2016. <<https://innovation.cms.gov/initiatives/Medicare-care-Choices/>> Accessed December 27, 2015.

¹⁶ Riley, Gerald F., and James D. Lubitz. "Long Life." *Health Services Research* 45.2 (2010): 565-576.

¹⁷ Prigerson, Holly G., et al. "Chemotherapy Use, Performance Status, and Quality of Life at the End of Life." *JAMA Oncology* 1.6 (2015): 778-784.

Research investment, both through AHRQ and the NIH, should also support science and innovation that produces breakthroughs in the development of tools and programs that strengthen serious illness care, including through:

- Improving provider skills in serious illness care planning (e.g., through software);
- Improving the ability of people with serious illnesses to articulate and track their highest priorities and goals for acceptable quality of life;
- Better prognostication (including not only about survival but also about impairment of function in different conditions);
- Greater ability to track quality of life and changes in patients' priorities and preferences for their care;
- Greater ability to detect mismatches between care provided and patients' preferences for their care.

Proposed bills like the Care Planning Act of 2015 (S. 1549) and the Palliative Care and Hospice Education and Training Act (S. 2748) would address a few of these goals (S. 1549 would strengthen quality measures in some settings; S. 2748 would invest in palliative care specialty training) but not all. There is a significant need for concerted federal effort to improve serious illness care discussions and planning across the board--through better quality measures, professional and public education, and research investment. Because the most important thing we can do is widen our intentions in health care and elder care to recognize that wellbeing for people, especially those facing serious illness, is larger than merely survival.

Conclusion

My investigations made clear to me that we've been unclear about the goal of good care for people with unfixable problems. It is not mere bodily survival. Nor is it a good death. The goal is to have as good a life as possible all the way to the very end.

The evidence indicates that we in the medical profession harm vast numbers of people by neglecting this goal. People with serious illness have essential needs aside from just living longer. Medical practices, research, and policies must ensure that clinicians have the skills to understand those needs and the ability to serve them.

Because death is not an inherent failure. Neglect, however, is.

I thank you for this opportunity to appear before you, and look forward to answering your questions.