

**THE RIGHT CARE AT THE RIGHT TIME:
ENSURING PERSON-CENTERED CARE FOR
INDIVIDUALS WITH SERIOUS ILLNESS**

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THURSDAY, JUNE 23, 2016

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice, at 11:01 a.m., in Room 562, Dirksen Senate Office Building, Hon. Susan M. Collins, Chairman of the Committee, presiding.

Present: Senators Collins, Heller, Casey, Whitehouse, Blumenthal, Donnelly, Warren, and Kaine.

**OPENING STATEMENT OF SENATOR
SUSAN M. COLLINS, CHAIRMAN**

The CHAIRMAN. Good morning. Not long ago one of my dear friends was a patient at the Gosnell Memorial Hospice House in Scarborough, Maine. Despite her serious illness, her days were filled with visits from friends and families and many joyful moments. She was surrounded by her family when she died peacefully.

In many cases hospice care enables dying patients to remain in the comfort of their own homes, free from unnecessary pain, and surrounded by family and friends. The Gosnell Memorial Hospice House provides an alternative when care in the home is no longer possible or sufficient. It provides a comfortable, attractive, home-like setting for hospice patients and their families, where they can receive patient-centered care. From pain and symptom management to psychological and spiritual support, and even to delivering longed-for scones to go with my friend's tea, the care at the Gosnell Memorial Hospice House is first-rate. Such compassionate, high-quality, and seamlessly coordinated care can make a tremendous difference for seriously ill patients such as my friend and their families.

Advances in medicine, public health, and technology are helping more and more of us live longer and healthier lives, but when medical treatment can no longer promise a continuation of life, patients and their families should not have to fear preventable pain, avoidable distress, or care that is not consistent with their values or needs.

A majority of Americans say that they would prefer to die at home. Yet, most people die in the hospital. Fewer than 45 percent of Americans receive hospice care at home during their last stages

of life, and nearly half of those receive hospice care in the final weeks or even days of their lives.

Federal policies must support efforts to relieve suffering, respect personal choice, provide opportunities for people to find meaning and comfort during serious illness, and most important, remain in control of their own care.

We know that hospice care can benefit both the patient and the family, so why aren't people accessing this service sooner?

I am concerned that this may be a result of a restriction in Medicare that requires beneficiaries to stop conventional curative care for their terminal diagnosis in order to elect hospice care. It is encouraging that CMS and organizations such as BlueCross BlueShield of Massachusetts are beginning to evaluate the benefits of allowing beneficiaries to receive curative and palliative care concurrently.

As the Senate Co-Chair of the congressional Task Force on Alzheimer's Disease, I am also particularly aware of the needs of Alzheimer's patients and their families. Although it is the fifth leading cause of death for seniors, Alzheimer's is not always viewed as a terminal illness, and too little attention is paid to the special end-of-life needs of Alzheimer's patients and their families.

While strides are being made in improving care, people with dementia often die without the benefit of hospice care. Medicare's eligibility requirements for hospice can prevent some individuals with dementia from accessing quality care. Current regulations require a physician to certify that a patient entering hospice is likely to die within 6 months. It is difficult for physicians to determine with that kind of precision how long anyone with a terminal disease will leave, and it is particularly challenging with a disease like dementia which has an unpredictable trajectory.

As a consequence, Alzheimer's patients who could benefit from the better pain control, fewer hospitalizations, and greater family satisfaction that hospice provides are under-enrolled in hospice care.

Additionally, since hospice has traditionally been used for the care of patients with cancer, hospice staff are not always sufficiently trained and prepared to meet the special needs of Alzheimer's patients and their caregivers.

Today, we will explore ways to improve the quality and availability of care and discuss models of care that are helping people with serious illnesses and their families. We are so fortunate to have an outstanding panel of witnesses, including a personal hero of mine, Dr. Atul Gawande, whose book "Being Mortal" has been a bestseller. In fact, I thought I was going to have it right here to hold up, and this book, by the way, and my ownership of it, has an interesting journey. It first was read by Jay Rockefeller, who passed it on to Angus King, who passed it on to me, and I had my husband read it first, and then I got to read it.

Now Dr. Gawande is probably not happy about what that means for book sales, that there was—there you go. I could hold that up. That there were so many readers.

Senator WHITEHOUSE. This is the iPad version.

The CHAIRMAN. I passed it on to my staff, whom I asked to bring it today, but we also have truly outstanding other witnesses, one

of whom Senator Whitehouse will introduce, and I will introduce the other, but I want to thank all of them for being here today.

Regrettably, one witness who was supposed to be here today is Dr. Katherine Pope. She was the medical director of that wonderful hospice house in southern Maine, but the thunderstorms caused her early morning plane from Maine to be canceled.

The CHAIRMAN. I know that this issue is a personal passion for my colleague from Rhode Island, Senator Whitehouse, and I so appreciate his serving as the Ranking Member at today's hearing, and I now turn to him for his opening statement. Thank you.

**OPENING STATEMENT OF SENATOR
SHELDON WHITEHOUSE, MEMBER OF THE COMMITTEE**

Senator WHITEHOUSE. Thank you so much, Chairman Collins.

As many people in the audience know, Senator Collins has an abiding concern for this issue. She has held hearing after hearing, and I am really grateful for her leadership and that she and Ranking Member McCaskill agreed to hold this hearing, and I welcome Senator Heller as well. This is a really, really important issue.

I first became engaged with it as our State's Attorney General and, for years, worked with our medical professionals and faith leaders and advocates for seniors, particularly those engaged with care for the terminally ill: to first, improve our policies for assessing and managing pain; second, to look at the different socioeconomic factors that often intruded on a patient's ability to get the decisions that they wanted to make about care to be what happened; and then to simplify and clarify the legal standards and protections so that it was easier for people to make decisions about their care that would hold up later on when the pressures of an emergency tended to foul things up.

Like many of us here, I also had the experience of loved ones who have died with and without their wishes for their care at the end of life being respected, and it is certainly very clear to me that when a patient's wishes are respected it not only changes things at that particularly intimate and important time for the patient but also for all of the family. It adds a whole added dimension to the natural grief if you cannot do anything about helping your loved one get the kind of care at the end of their life that they wanted.

In 1997, the Institute of Medicine described a human care system as one that—and I will quote them here—“people can trust to serve them well as they die, even if their needs and beliefs call for a departure from typical practices, yet honors and protects those who are dying, conveys by word and action that dignity resides in people, and helps people to preserve their integrity while coping with unavoidable physical insults and losses.”

As we know, too often our system fails to meet this standard. As Senator Collins pointed out, most everybody would prefer to die at home, and yet, most die in an acute care hospital or a nursing home. We can do better.

Part of it is cultural. Part of it is not having organized ourselves as a society to have the conversation and to get people to make the decision and put it on record, but an unfortunate piece of it is tied to the payment structure, so we need to design our payment sys-

tems so that they will yield to the desires of patients and families, so today, I am introducing the Removing Barriers to Person-Centered Care Act, which stems from a series of roundtable discussions with Rhode Island stakeholders and with the Coalition to Transform Advanced Care. The common theme that emerged was that providers are really frustrated with Medicare rules and regulations that prevent them from coordinating care for individuals who have serious advanced illness and get these patients the right care and in the right setting, so this would simply open up pilots and allow CMS to say, bring us your ideas, and we will give waivers where necessary so that you can do what you want.

One of the things that inspired me in this, Senator Collins, was a hearing witness that you brought from Maine who described the way in which she had had to work through a whole array of difficult procedures in order to deliver the care that she felt her patients deserved, so I am hoping that we can get this done:

Allowing Medicare patients to receive hospice care and curative treatment at the same time ought to be a sensible solution.

Allow patients to receive Medicare coverage in skilled nursing and without these 3-day inpatient hospital stay rules ought to be something that we can work through, and allowing Medicare patients to receive home health services before they are finally home-bound, but when it is cheaper and better to serve them at home, ought to be another restriction we can work around, so there are a lot of issues on which we can make progress.

I join Chairman Collins in welcoming the witnesses. Dr. Gawande is a nationally renowned expert in this area, who also brings an extraordinarily humane point of view that shines through his expertise, but my personal hero here today is Kate Lally, and if I could just take a minute to introduce her now, then we can go on through that.

The CHAIRMAN. Yes.

Senator WHITEHOUSE. Kate wears a lot of hats in my home State. Our second largest hospital chain is Care New England, and she is the Chief of Palliative Care at the Care New England Health System. Care New England also has an accountable care organization that tries to improve care and lower costs and work through the ACO model. She is the medical director for that ACO model, and finally, she is the Hospice Medical Director for Care New England VNA Hospice.

She spearheaded the hospital system's role as a pioneer sponsor in the Institute for Health Care Improvement's "Conversation Ready" initiative. She is a graduate of Yale's School of Medicine and post-graduate training in internal medicine at the Hospital of the University of Pennsylvania.

She is an outstanding doctor, but also really a remarkable leader on this in Rhode Island, and somebody who I count on a lot. Her judgment and her humaneness are really paragon, so delighted that she should be here.

The CHAIRMAN. Thank you very much, Senator.

I, too, want to welcome Senator Heller and Senator Casey for being with us today.

Now we will turn to our panel. As I said, I am absolutely thrilled that Dr. Atul Gawande is here today, and I now have my copy of

his book to hold up, and he is a surgeon and a best-selling author. He is the Executive Director of the Ariadne Labs and a professor at both Harvard School of Public Health and Harvard Medical School.

His most recent book, “Being Mortal: Medicine and What Matters in the End,” has been on the “New York Times Bestseller List” for more than a year and a half, and to me, that indicates the hunger in this country for guidance and a dialog on these important issues of caring for people with serious illnesses.

Senator Whitehouse has introduced our second witness, but I also want to extend my welcome to Dr. Kate Lally.

Our final witness this morning is going to be Amy Berman. She is a Senior Program Officer at the John Hartford Foundation in New York City. She has a wide range of experience as a researcher and as a cancer survivor herself. She has a unique perspective from all different angles on the issues surrounding care for individuals with serious illnesses.

Thank you all for joining us today, and we will start with Dr. Gawande.

**STATEMENT OF ATUL GAWANDE, M.D., M.P.H.,
EXECUTIVE DIRECTOR, ARIADNE LABS; PROFESSOR,
DEPARTMENT OF HEALTH POLICY AND MANAGEMENT,
HARVARD T.H. CHAN SCHOOL OF PUBLIC HEALTH;
SAMUEL O. THIER PROFESSOR OF SURGERY, HARVARD
MEDICAL SCHOOL; STAFF WRITER FOR “THE NEW YORKER,”
BOSTON, MASSACHUSETTS**

Dr. GAWANDE. Thank you, Chairman Collins, and thank you, Ranking Member Whitehouse and the members of the Committee, for the chance to provide some testimony on ways to improve what is too often an inhumane system of care for people with serious and life-limiting illness.

Now I just want to start out by saying I do not come to this issue as an expert. I came to this issue as a practicing surgeon at the Brigham Women’s Hospital in Boston, where midway through my career (I am a little over a decade now in practice) what I had come to recognize was that my training as a clinician had helped me understand and feel quite competent and capable in taking care of people when they come to me with fixable problems—a cancer I can remove. I would primarily practice cancer surgery, but I did not find over and over again that I was all that prepared or all that clear about what it meant to be competent and excellent at taking care of people who were bringing unfixable problems how to manage the consequences of an incurable cancer, worsening organ failure, frailties of aging, and I can tell you many, many cases, but I will just pick out one, where a neighbor called—my daughter’s piano teacher. Her name was Peg Bachelder, and she was 62 years old.

She had had a cancer. It had been treated a couple years before, and it came back. It came back in her pelvis. It had spread to her liver. She had undergone chemotherapy. She was admitted to the hospital with fevers and pain and findings that the chemotherapy that she was on had not produced a response to—the cancer had not responded.

At that point the team did not have any conventional options to offer, and the debate was what should she do. Should she try for something, anything, experimental therapy, something to attack this problem? Or, should she just be comfortable, as the doctor said? Should we try something to be comfortable? The way she heard it is: Should she do something, or should she do nothing? She called and wanted to know: What should we do?

This is the moment that we are debating. This is the moment that we are having a national debate and have been having this national debate for a while now.

We break the bad news, and then what? What do we think it means to be great at care?

I honestly did not have good answers. I did not have the training, and I did not have the background, and so what I did was I got to pick up my writer's pen and go as a journalist to say let me talk to a whole bunch of folks and see what I should be doing different.

I ended up interviewing more than 200 patients and families about their experiences with serious illness and serious infirmities, more than scores of experts, including folks like in Dr. Lally's profession of palliative care hospice nurses, nursing home workers, critical care doctors, you name it, and what came out of that were a couple simple lessons: Medicine and society have failed to recognize that people have priorities in their life besides just living longer. Those priorities, the quality of life they want, varies from individual to individual and over time.

The most reliable way to learn what people's priorities are for their care is to ask them, and we do not ask. We ask less than a third of the time.

The result is that for the majority of people their care, at some point along the way, becomes out of alignment with what their deepest wishes are for what matters to them besides just surviving, and we are seeing it now play out on a national level. We have—since 1988, we have had measures every year of some of the aspects of quality of life, and the data has been that now today for people in the last year of life they spend—more than half spend—are often in moderate to severe pain. More than half have more than a month of depression, periodic confusion, incontinence, shortness of breath, but the treatments they are receiving are entirely focused on solely the question of: Do you survive, or do you not survive? And that is where you get suffering.

Now when we do ask, when care is not narrowly focused on just the control of the disease but on the wider range of priorities, on both quality and quantity, the experience is stunningly different. The result is that when people are asked and receive options of palliative care, which includes—which is focused on quality of life: People choose less toxic care. They enter hospice sooner. They suffer less. They are more physically capable. They are better able to interact with others and for longer in their life. Their family suffers less depression. They spend fewer days in the hospital and in the ICU, and as a result, they have lower costs, and they do not die sooner; they live longer, if anything else, and what we have tried to understand then in the research center where I work—at Ariadne Labs, what we try and understand is: How do we take that knowledge that palliative care doctors create and bring it to ordi-

nary doctors like me? What am I supposed to do differently next time I am with a patient? That is what I did not understand, and the few critical questions—they are good at understanding how to ask the questions that help you understand what matters in people's lives, and so you ask questions like:

What is your understanding of where you are with your illness at this time?

What are your fears if your health worsens?

What are your goals if time should be short?

What are you willing to go through and not willing to go through for the sake of more time?

What is the minimum quality of life you would find acceptable?

When I listen to people who were asked these kinds of questions, they answer them in ways—they say, you know, things like: “I would like to get to a family wedding. That is a really important thing to me.” “I want to be at home.” Or, as one—the father of one of my colleagues told her, “If I can eat chocolate ice cream and watch football on television, that is good enough for me. Keep me going. If I cannot, let me go.” It was like the best living will ever.

Now Peg Bachelder, my neighbor and the piano teacher of my daughter, when I asked her these questions, it came down to one thing; she wanted to be home, she wanted to be comfortable, and she wanted to teach. She wanted to teach her students.

She went home on hospice, and that is what they managed. They provided medical capabilities so she was not only not in pain, but she could teach again, and my daughter got 4 weeks of lessons from Peg. She had the last—she lived 6 weeks. In the last 2 weeks of her life, she had a recital with all the children and my daughter playing there, and it is the reason that now, 4 years later, music is the career she wants in her life.

What it made clear is that we have had a 50-year experiment in medicalizing mortality, treating it as purely a problem of the disease and how we focus our treatment on it, and that has failed because we failed to recognize that our goal is not merely survival, and often we respond by saying that the goal—well, our goal must be a good death, and that is wrong either—it actually disturbs me that we think that that is the goal.

The goal is a good life, as good a life as possible all the way to the very end.

Recent data came out just last week from researchers at Harvard, showing that if you reach age 65 we will get to live, on average, at least 20 more years of our life. We live better and with less disability, but we are still going to have 8 years of our life with disability, with significant disability, and that is a prison if no one asks you what the quality choices are you want in your life and matches care to it, or that is incredible freedom in that we get to be lucky enough to live to be old and sometimes frail but get to do the things that matter to us, and it is achieved by making these conversations normal, the conversations about what your priorities are.

The gaps are large. We have a long way to go. In the education of clinicians, we have gaps. We have gaps in the availability of palliative and geriatric expertise. We have gaps in the systems to ensure people have health care proxies and discuss their priorities.

We have gaps in research, but with just some tiny efforts underway—my own research center’s work; as Senator Warren knows, a coalition also that we have launched in Massachusetts involving the payers, involving the State government, involving health care organizations, consumers, medical schools, and a public campaign—we are showing that better is possible, and I look forward to discussing how.

Thank you.

The CHAIRMAN. Thank you very much, Doctor.

Dr. Lally.

**STATEMENT OF KATE LALLY, M.D.,
CHIEF OF PALLIATIVE CARE, CARE NEW
ENGLAND HEALTH SYSTEM, PROVIDENCE, RHODE ISLAND**

Dr. LALLY. Thank you, Chairman Collins, Senator Whitehouse, and members of the Senate Special Committee on Aging. Thank you so much for having me here today.

As Senator Whitehouse, I do serve as Chief of Palliative Care at Care New England, but I am also a practicing hospice and palliative care physician, much as Dr. Gawande mentioned.

I want to talk with you a little bit today about our work in palliative care and the program we have developed in our hospitals and in the community, and I want to tell you about it in terms of how it affected one of our patients, Mr. L., and the barriers that he faced as he approached the end of life.

Our program started in 2012 when we joined forces with the Institute for Health Care Improvement and their work on the Conversation Project and becoming “Conversation Ready.” It was through that work that we learned statistics, as have been mentioned here today, that while 70 percent of us say we want to die at home, 70 percent of us will die in a hospital, nursing home, or other long-term care facility, so in order for our patients to live and die in ways of their choosing, and not in ways that are put upon them by the medical system, we developed a palliative care program, first in one of our hospitals and then in all four, and we treated a lot of patients. We treated 1,400 patients in our hospital alone last year.

One of those patients early on was Mr. L. He was a man with pancreatic cancer that I met in one of our hospitals. His oncologist asked me to meet with him to manage pain but also to have the kind of conversation Dr. Gawande just mentioned about his understanding of his disease and the treatment options in front of him.

When I met with him, he told me that he understood that he would die from his cancer, he understood he had a terminal diagnosis, but until that day he wanted to live with his cancer, and what mattered most to him was spending time with his family, spending time with his grandchildren, and being home, but he said his quality of life at the moment was so poor due to pain and anxiety, so over the next few days I worked with him. We adjusted his medications, and we made him comfortable, and he was discharged home.

Not long after, though, his oncologist called me. He had failed his first line of chemotherapy. His cancer was progressing. Now she was looking at a second line, but she was not optimistic, and his

pain was getting worse with his disease, so she wanted me to meet with him and talk about those symptoms and talk about what options lie ahead when chemotherapy was no longer available.

Unfortunately, for Mr. L, at that time we were like most health systems in this country, and we did not have community-based palliative care, but we quickly developed it. We hired nurse practitioners who go into patients' homes, like Mr. L. They can adjust pain medication, and they can continue those conversations because they are not one-time conversations.

We also integrated into our new accountable care organization because when you look at those highest risk patients many of them are approaching end of life and we need that basic skill set on symptom management and goals of care, so we work with our nurses, our nurse practitioners, our social workers in our ACO to help them have those conversations.

Recently, a patient said to one of our nurses, I feel like I am dying and everybody is afraid to tell me. She did not know what to say. What do you say? We have done some training on conversation tips and techniques to help our team with that.

We have also applied for and received a Hartford Foundation grant, and we have worked with Ms. Berman on improving transitions of care for palliative care patients out of the hospital and into the community, and we send nurses into our area skilled nursing facilities, again, to continue those conversations about what matters most to patients and help transition them to services like hospice when it becomes appropriate, but even with all that specialized care, we knew we could not make a dent in things for exactly the reasons Dr. Gawande mentioned. All of our providers, all of our nurses need the skill set, so we applied for and received a Geriatric Workforce Enhancement Program grant from HRSA, where we are working with our PCPs.

Myself and a geriatrician are going into their practices and asking them those questions, as Dr. Gawande just discussed—what are the barriers? What are you struggling with—and having these conversations. We are giving them tips, techniques, and tools to do this better.

We are starting with our young physicians, our medical students, our residents. We are having them go through a month-long training in geriatrics and palliative care, and many of them go through a simulation experience where they meet with patients, or actors who play patients and family members, to have those difficult conversations in a safe space, but even with all of this, there are still barriers that excellent care alone cannot overcome. There are legislative barriers.

For example, Mr. L was lucky. He went home, but if he had gone to a skilled nursing facility, he would have had to make a choice. He could have gone for rehabilitation and care focused on getting stronger, but given his advanced cancer that would have been unlikely.

If he chose hospice, that would have been the right care for him, but he would have been stuck paying for his room and board fee in the nursing home, which would have been covered if he had chose more rehabilitative-focused care.

Senator Whitehouse, as he mentioned, is addressing many of these issues with his Removing Barriers to Patient-Centered Care Act of 2016. There are other legislative opportunities—the Palliative Care and Hospice Education and Training Act, which really focuses on educating doctors on these issues, as Dr. Gawande focused on the need to do. In addition, there is the Care Planning Act of 2015 looking at how we can pay in better ways for patients as they approach the end of life and the specialized care that they need.

It is an incredibly exciting time to be in health care, and many of these issues we are talking about today most of us will face at one point in our lives.

I thank you for the opportunity to be here.

The CHAIRMAN. Thank you very much.

Ms. Berman.

**STATEMENT OF AMY BERMAN, SENIOR
PROGRAM OFFICER, THE JOHN A. HARTFORD
FOUNDATION, NEW YORK, NEW YORK**

Ms. BERMAN. Thank you Madam Chair, Ranking Member Whitehouse, and illustrious members of the Special Committee on Aging.

I am delighted to be here. My name is Amy Berman, and I am a nurse and the Senior Program Officer at the John A. Hartford Foundation in New York. Our sole mission is to improve the care of older adults.

I am here because I am terminally ill. This is the face of somebody who lives with life-limiting illness. I want you to remember that. Five and a half years ago I was diagnosed with stage four cancer, inflammatory breast cancer that spread to my lower spine. The cancer is progressing and this particular kind of cancer has the worst prognosis, so for most people with breast cancer, 90 percent survive 5 years or more. Mine, the prognosis, the likely course of the disease, 11 to 20 percent survive to 5 years. That means it is not just unlikely, it is highly unlikely, that I would live to 5 years.

I am at five and a half years, and I am not just here; I am doing great. I feel well. I work full-time. I get to play and travel, walk my puppy, do all of the good things that we get to do in life. I enjoy, but the reason is because I get the care that most people cannot get, the care that is not yet available. I get access to the workforce that is not broadly out there, and so I am going to talk a little bit about that.

When I was first diagnosed, I went to two doctors. It is not uncommon you go for a second opinion.

One doctor wanted to throw everything at the disease, just as Gawande was talking about. No conversation. Never asked me what it is I was hoping to accomplish. Knowing that there is no cure for the illness, he wanted to do the most intense chemotherapy, mastectomy, radiation, and more of the most intense chemotherapy. He was ready to fight, fight, fight, but, unfortunately, there is absolutely nothing that he would have been doing in his Hail Mary pass that would have gotten me to a better place, and in fact, it would have gotten me to a worse place.

I went to another oncologist, and this oncologist explained information in the way in which we talk about care planning should be, talked openly with me about treatment options, and she said, what is it that you would like to accomplish?

I said, well, you know, I kind of like the Niagara Falls trajectory, so I start here feeling really good, and I end at the universal “We all end here.” I want to go good, good, good, and drop off the cliff. Give me more of the good days and try to limit the bad days. That is all that I ask for. You know, there is no cure. There is no cure on the horizon, so just give me as good of a life as possible.

Now that first doctor, who never asked me a question, who suggested what he was going to do to me, not for me, he was going to drop me off the cliff with burdensome treatment, and I was going to go out to the same end point.

It was the complete opposite of the trajectory that I wanted. It would have been harmful. It would have been costly. I would have been hospitalized multiple times.

I refer to myself as a walking triple aim. I have the good fortune of having better health, better care, and I have saved about a million dollars to date. A million dollars. I am one person. One. An “N of 1,” a million dollars, and the benefit is not the cost savings. I mean, yes, that is a benefit to society, but the benefit to me is that I get to continue living a good life. I get treatment, but the treatment that I get I choose those treatments that have the least amount of side effect, the least amount of burden, so that I can continue to feel as well as possible and get that Niagara Falls.

I also have a professional life, and professional and personal have certainly converged for me. I lead the John A. Hartford Foundation’s investments in models of care that improve health cost and quality for older adults. We have invested roughly a half a billion dollars since 1982 in efforts, including things like: The Center to Advance Palliative Care, which is a major resource to this field. National POLST, Physician Orders for Life-Sustaining Treatment. Respecting Choices, one of those models that we talk about. The Conversation Project, you know, how do you have conversations at the kitchen table, and they have a wonderful starter kit. Vital Talk. Training for health care professionals to be more engaged in the conversation. Home-based primary and palliative care. The work of the Independence at Home demonstration, and Dr. Gawande’s work. My dear Kate Lally’s work.

You know, we have the good fortune of getting to, you know, select the best, most promising, evidence-based things in the country, and they are all represented in these discussions.

As a person who gets the kind of care that is the happy story, the right way of getting care, I want to tell you my care is the exception. I pay for my care. I organize my care.

People who have money would not know to have this care. It is truly the exception, and yet, it is the thing that makes everyone succeed in life. It makes my family happy as well, by the way, so there are a few things that I would recommend.

The first, you know, regarding the workforce, we do not have enough experts in palliative care, and we do not have enough broad-based competence for the rest of the workforce that cares for seriously ill people and the skills around palliative care, so they call that primary palliative care, so you need both primary and the experts.

In graduate medical education, it is shocking to me that we do not give a single slot to palliative care. Cardiologists, neurologists,

plastic surgeons, but not a single slot to palliative care. I really think this needs a relook, and nurse practitioners, so some of the things that are before you that—some of the pieces of legislation that Dr. Lally talked about address these kinds of issues. Models of care: There are a number of outstanding models. Evidence-based, but the bottom line is putting palliative care along with the treatment that one gets from their regular provider, so as an extra layer of support. As Dr. Gawande mentioned, there are improvements, reduction in hospitalization, nursing home placement, people live better, and the savings are tremendous. It is all of those things that you want. Research: I just need to mention that the NIH has doubled their funding in this area. It has gone from 0.2 percent to 0.4 percent. It still rounds to zero; it should not. As we do a moonshot and try to find cures, we need to be attentive to care because the death rate still hovers at 100 percent and will continue to do so.

The last thing that I would like to say to this wonderful Committee is I want to see the actions happen. I have a life-limiting illness. I would like to see legislation passed that furthers these kinds of things that we are talking about, and I would like to be there to witness that signature.

I thank you so much.

The CHAIRMAN. Thank you very much, Ms. Berman. I cannot imagine more eloquent testimony for our Committee to hear, and I just wish every member of the Senate could be here to have heard your plea for action at the end of your statement but also your extraordinary story.

As I listened to you, I thought you epitomize what is the theme of our hearing, which is you received the right care at the right time, but I cannot help but wonder; if you had not had a medical background and been a researcher who was so familiar with this area, would you have been able to get the kind of care that is consistent with your wishes?

Would you have even known, particularly after going to the first oncologist, if you had stopped with him? Do you think that most people realize that there are alternatives to the Hail Mary approach that you described that your first oncologist wanted to pursue?

Ms. BERMAN. I think not. I think you are right. If I did not know about the field of palliative care and had not been one of the supporters of that for the past 11 years, long before I was ever diagnosed, perhaps I would not have known to access the kinds of services that help me feel great today, but even when you think about having these kinds of discussions, I think a lot of people go to the doctor and they say, treat me, and it is kind of like getting in a cab and saying, take me to the airport, except you end up at DCA Reagan and you meant to go to Dulles. You know.

We go in assuming that people are going to do the right thing, but without having that deeper-dive conversation we are not going to get to the right place.

I am reminded of a person who was the head of a health system, a chief nurse officer, a very, very accomplished woman, and her husband got sick and had care and later died, and she was as ex-

pert as expert could be, but she said to me, I never thought to question the doctor.

When we are in these situations, I think a lot of people—if we do not structure the kind of encounter in a way that really engages people, if we do not intentionally do these things, you know, the way that both of my esteemed colleagues on the panel do so well, if we do not structure them well, they are not going to naturally happen that way, and people are going to be taken down a path that may not be the right path.

The CHAIRMAN. Thank you.

Dr. Gawande and Dr. Lally, one of my favorite expressions is from Uwe Reinhardt, the Princeton economist, and he says that Americans are the only people on earth who think that death is negotiable, and I have always felt that that sums up our reluctance to have these kinds of conversations.

As you said, Dr. Gawande, the goal is not a good death; it is a good life. I love that phrase, and as both of you have pointed out, many physicians, unless they are experts in this area, and that is very rare, particularly in a rural State like mine—we do not ask the majority of people if their care is consistent with their wishes, but there is another situation that I think is even more difficult, and that is when a patient is no longer able to articulate his or her wishes because those conversations which should occur when people are younger and healthy have never occurred, and they should, in my judgment, occur more than once during a person's life because people change as far as what their goals may be.

What do we do in situations where the patient has no advance directives, no indication of their wishes, and is unable to articulate what a good life would mean to them?

The family members do not always agree, I have seen this, on what should be done.

Dr. Gawande and then Dr. Lally.

Dr. GAWANDE. Well, I am partly going to have—you know, Dr. Lally, this is the common thing she does every week, and I will be very interested to hear how she talks about it, but the two things that are fundamentally important here: Number one is that often even when people have not had the direct conversation, you can find ways to trace back and understand the values they have expressed in their life. I will give you one example.

I did a number of interview with people in their first month of being in a nursing home and then met people along the way, and even very—and this was a place where 70 to 80 percent had advanced dementia, and one of the people that I met along the way was a woman who was 85 years old, had Alzheimer's disease, and she had started to develop the advanced form that includes sometimes having difficulty with swallowing, and so she was put on a pureed food only diet, and she was caught over and over again hoarding cookies. She would steal cookies from neighbors, eat them, and the staff would find them, take away her cookies, and write her up, and they would call the family. You know, she is breaking the rules. This is not safe, and understanding that—I think there is one level of recognition about the discussion with the families. The assumption is that safety and health are the only thing that matters, but here she was expressing what her one joy

was in life, that she wanted to eat, and you want to just say, let her have the damn cookies, and that ability to say it is okay to take risks that are consistent with what the person is voicing as what matters to them, whether it is what mattered before or what matters now, and how they are expressing it along the way, and for me that was a revelation, that you could ask what else matters to a person besides just their survival. Tell me what their joys are in life. Tell me what their joys were in life. Tell me how that I would understand how to do this, and I will just say this week I was in the operating room with a patient where they had not had the discussion, and I discovered surprisingly extensive cancer, and I had to make a decision about whether we would have to sacrifice her ability to talk and leave her with a permanent tracheotomy or not. She was only in her 50's, and I went to the family to discuss it, and they had not discussed this before, and we had not recognized going in that this might be the kind of thing that I would even need to have discussed.

If I just put in front of them, so what do you want to do, they were completely lost, but I could say to them, do you think that she would want to sacrifice—would she be willing to live—would she consider a minimum quality of life acceptable to live with a tracheotomy?

They said, no. They could not imagine it, that she would take some risks. We could try radiation. We could try other things that we could potentially address, and it was not the end of the conversation, but it let me make a decision that we did not push forward at the end of that time. We would wake her up. We would have ongoing conversations and then come back to decide if we would go back and go from there, but I think that even when on one level it is too—it is always too early to have these conversations, people feel, until it is too late, but then it is also always possible to be able to have these conversations even after the person is not expressing for themselves and bring people together.

The CHAIRMAN. Thank you.

Dr. GAWANDE. Dr. Lally, you see the conflict yourself.

The CHAIRMAN. Dr. Lally, I am going to ask you to be brief in your response because I have gone over my time, or if it is okay, and I am also going to turn the gavel over to Senator Whitehouse, something that rarely happens in a Senate committee, because I have an amendment on the Senate floor and did not anticipate the timing here, but please, if you do not mind, I will have your Rhode Island witness begin a response. Thank you.

Senator WHITEHOUSE. Thank you for your amendment on the Senate floor.

The CHAIRMAN. Thank you.

Dr. LALLY. Thank you.

I agree with Dr. Gawande. In his description of that patient with the tracheotomy, what he asked was not do you want a tracheotomy or do you not? He said, what is a good quality of life to you, and would having this tracheotomy be a good quality of life?

When I talk with patient and families, when there is a family member who cannot speak, I ask that family, tell me about your loved one. Tell me about the kind of life they led. Tell me about the types of values that they had, and if I hear this person was so

active, they were always out and about, the idea of being bed bound would be very difficult to them, then I may talk about options for treatment one way.

If I hear, as Dr. Gawande mentioned earlier, sitting and watching football and having a little bit of Jello, that is a good quality of life, I may guide my treatment options another way, but I think you can often talk with patients and families and really get a sense of that person. Clearly, it is ideal to get it from the patient themselves, but if they cannot speak, the people who love them often know well, and there are tools now. We have talked—all of us have talked—about the Conversation Project, and they have recently put out a tool targeted at patients with advanced dementia to help families really think about what the person would value and what they want most.

The CHAIRMAN. Thank you very much, and I do turn it over.

Senator WHITEHOUSE. Thank you, Chairman.

When we are dealing with this patient group—people who are usually elderly, often very, very ill, and at least in contemplation of their mortality—and we are trying to develop care plans for them that meet their wishes and their family's wishes, I want to ask you how three specific Medicare payment rules affect getting a good outcome.

One is the Medicare payment rule that forbids Medicare patients to receive hospice care and curative care at the same time. Does that help in any way?

Another is the Medicare rule that forbids patients to receive Medicare coverage in a skilled nursing home without having had the two-night rule, the consecutive 3-day inpatient hospital stay first, which often forces, everybody winks, and you get a phony hospital stay in order to open up the skilled nursing home aspect, and the third is forbidding Medicare patients to receive home health care until they are completely homebound, even if they are terribly ill and it would be appropriate to deliver home health care.

Those are three rules we would like to find workarounds for. Could you, just from your own practical experience—let me go across this way this time and ask for your comment on any or all of how those rules affect getting the care that we are trying to aim at here.

Ms. BERMAN. Senator Whitehouse, you have named three things that are real barriers to good care.

You are correct that for people who are seriously ill they may not be homebound and they may have an unsteady trajectory. There may be periods of time that they need to access this care, and they are not permanently homebound, and so you are right; that is a major barrier.

Each one of these things stand in the way of good care.

I think, you know, what you are really talking about is opening up a set of services that really can be life-changing, life-enhancing for not only the person but also their family, and allow them to be supported and stay at home.

Senator WHITEHOUSE. These rules, in your view, are obstacles?

Ms. BERMAN. They are obstacles. If I have to go into a hospital in order to enter hospice, that is a tragedy. It is not what it is that I would think that I would want.

My hope is that, like 70 percent of people surveyed in America, I want to die at home, and for me to have to go through a hospitalization that has all of the potential harms and costs, it is not what I want, and it is not hopefully what I will ever need.

Senator WHITEHOUSE. Dr. Lally.

Dr. LALLY. I would agree absolutely. These are huge barriers to how we deliver care to our patients.

Just yesterday I met with a woman who has a uterine cancer which is very advanced, and chemo is much more likely to cause harm than to benefit her, so I had had a big meeting with her family and her, and we talked about that, and her wishes were not to go through with chemotherapy, but then as we talked about hospice, and she and her family saw very well the benefits hospice would bring—being able to call someone 24 hours a day, having the nurses come into your home when needed—they saw that that was a huge benefit, but her son said, what if there is a clinical trial? What if she needs a blood transfusion? What do we do?

Then we start the dance. Well, then we could take her off of hospice and talk about these options, but would anything really change with that? No. She needs that person-centered care coming in, talking with her and her family as she gets sicker and weaker about what to expect as her disease progresses, and to put up these barriers where we cannot—she cannot get that blood transfusion, she could not get one round of chemotherapy, if it were felt to benefit her, as a barrier to hospice, is a huge barrier that our patients face, and they have to acknowledge I am going to die within 6 months. That is something we say to them right out front. That is a big thing to ask a patient to acknowledge, so I think that is a huge barrier.

Senator WHITEHOUSE. Just one additional point—presumably, these rules were all put in place with a good intention.

Dr. LALLY. Yes.

Senator WHITEHOUSE. To try to control costs and so forth, but when you are dealing with this particular population that we are talking about today, is it your experience that if we were to waive those rules so that people could go through a more patient-centered health program, that that would drive costs up?

Dr. LALLY. It is not. You know, this particular patient I think is a good example. She was very clear in her wishes not to pursue chemotherapy, but her family was not so clear on those wishes, and that was a lot of our discussion.

I would worry with her that, let's say, her son went out and said: You know what? We are not going to do hospice because we may pursue chemotherapy down the road, and many of my patients make that choice.

I would think then without having that expert care coming in and saying the fact that you are getting weaker, the fact that you are having trouble swallowing, that is disease progression, that is going to bring her back to the hospital, and then we are going to do all of these medical things that we do to try and prolong her life, which are not going to help her very much and probably are not consistent with her wishes, which is going to end up having us have a much higher cost rather than that one round of chemo.

I know some private insurers will carve out occasional curative treatments because they know that the overall cost will still be lower, so no, I do not think this will lead to an increase in costs. I think it may lower them.

Senator WHITEHOUSE. My time has run out. Let me turn next to Senator Casey.

Senator CASEY. Thanks very much. I appreciate Senator Whitehouse and Senator Collins convening this hearing.

What a panel. We often come to hearings on a whole range of subject areas in different committees, and often you are informed after that hearing or leading up to it. Sometimes you are inspired, and that happens more often than you would think, but rarely have I been to a hearing where we are both informed, inspired, and moved by your testimony.

I wanted to start with Ms. Berman. I guess it was—I am not certain of the year—1997 or 1998 the “Philadelphia Enquirer” did a series on long-term care. Three parts or five parts, I cannot remember, but it was a remarkable series focusing on one topic, and their writer, his name is Michael Vitez, in one of the stories, said—quoting experts and advocates, he said, life can have quality and meaning even until the very last breath.

I have never forgotten that line. It has been kind of a touchstone for me on a whole range of issues, but I have never, I do not think, met the personification of that, and you seem to personify that, the spirit of that assertion, so we are grateful that you brought that to us today.

How do we bring this not only to more—not just more families but even to the younger people so they can begin to think about the end, their end of life, or at least begin to think about planning?

The focus of my question would be young people but in addition to that, obviously, physicians. It is, in a sense, a culture change as much as anything, and what would you encourage us to do by way of policy of advocacy or otherwise to move in the direction you hope we can move in so that more people have the experience that you are currently enjoying?

Ms. BERMAN. Thank you so much, Senator Casey.

I would say that there needs to be greater public awareness, and this is awareness at all ages. There needs to be a campaign of sorts so that people understand what is at stake, so that people understand that they have an opportunity to do advance care planning sooner. Seventy–5 percent of people are unable to make some or all decisions at the end of life.

If we do not think about these things early, the decisions are left in the hands of family members who have no understanding of what somebody wants, and I can tell you that will rip apart a person’s soul—making decisions and not knowing whether they are making the right decision. It is a horrible thing, not just for the person who is receiving the care but for the family.

I think also, you know, in terms of the young people, just kind of normalizing an understanding of what end-of-life is. You know, a public campaign would do that as well.

I think we have to think about a greater awareness about palliative care, so palliative care, many people view this as turning off care or giving up care, or they conflate it with end-of-life.

If you look at me, and I am seriously ill, palliative care is really about keeping your life, and it goes along with curative care or it goes along with the care that keeps you going, so I receive treatment, and I have palliative care, and that has helped me avoid at least one hospitalization. It has helped me proactively manage pain and symptoms. They have had conversation with my family. It has been helpful on so many different levels to avoid a lot of the care that I do not want, but for people to access it, it has to be something that is a conversation started much earlier, that people become aware of what it is and what it means, and I would say it is the best friend of the seriously ill.

Senator CASEY. I appreciate that.

I guess I will be running out of time, but I did want to ask, I guess, one or both of the doctors. Kaiser Family Foundation tells us that 14 percent of primary care providers are offering advance care planning to help patients better navigate advanced illness and end-of-life, so obviously, this is for the health care practitioners in the system a huge change that we have to confront, and I have only got about 10 seconds, but let me go a little over. Any advice you have for us just in terms of those kinds of structural changes?

Dr. GAWANDE. I will jump in with a couple of things. Number one is that we are demonstrating models now for being able to bring the skills that palliative care doctors have to nonpalliative care clinicians.

We just ran a trial, or just finished a trial, where we are having results come out from taking the whole Dana-Farber Cancer Institute. We randomized, so half of the clinicians we provided a two-and-a-half-hour training in asking the kinds of questions that palliative care doctors ask: What is your understanding of where you are with your illness? What are you willing to go through and not willing to go through for the sake of more time? Those kinds of things, and the clinicians—you know, even very experienced clinicians—talking to people with advanced disease, changed how they went about their conversations, and we took it to primary care clinicians as well.

We were able to—by supporting them, not just with training but also identifying the patients at highest risk of dying, and notifying them when they have not had these conversations with the system. We got from less than a third having these conversations to over 90 percent.

They also had them earlier, at 5 months before deaths instead of just in the last few weeks, and the result was—that we made public with a scientific presentation at the Society for Clinical Oncology—we have cut their likelihood of depression during their last period of life by 50 percent, from 20 percent to 10 percent, and also cut their rate of anxiety, so we now know there are models, and ours is not the only one, for how to take it to change clinician training, and I would say there are a couple policy points of view here. Number one, our quality measures for hospitals, for health systems, nursing homes, elder care, hospice care, they are narrowly focused on just safety and health, which are just measures of survival.

They do not include well-being. They do not include questions like: Are you able to—are you suffering during the course of your care? What is the likelihood you are suffering along the way?

Developing those measures and having them incorporated so that well-being is considered, and not just quantity of life, is reflected in our policy.

Second, I think we have been doing this work of learning how to teach and actually measuring whether we have these impacts, doing it on tiny funds and with little significant effort at demonstration projects and making them work, and so that is an opportunity.

Then, third, our research funding is aiming—

Senator CASEY. We may have to wrap up only because we are out of time.

Dr. Lally, I may ask you to submit it in writing if you can do that.

Dr. GAWANDE. Okay. Just the third one is that our research funding has almost its entire budget focused on survival without asking whether we have therapies and whether we have implementation programs that are able to improve the quality of life. Our therapies are not even designed to improve the quality of life along the way, purely focused on survival often.

Senator CASEY. Great. Thanks very much.

Senator WHITEHOUSE. Senator Warren. Just so my colleagues know, then Senator Kaine and Donnelly is the order we have.

Senator WARREN. Thank you, Mr. Chairman.

Thank you all for being here, and I want to say thank you especially for your being here, Ms. Berman.

I was very close to my father, and my mother had already passed away when he was diagnosed with advanced stage cancer, and we went through the same thing about in and out of the hospital, and I remember when my daddy took me aside and said, baby, I am just asking you for one last gift. Let me die at home with you and my brothers there, and we did. We made that happen, and I remember a few hours before he died he said, this has been a great gift, and he held my hand, and I thought, no, Daddy, you are the one who gave us the great gift.

We knew we were doing the right thing. My brothers and I were all there, and we could give him the best possible days that were left to him, so I know those are hard, hard subjects for families to talk about, but you have given us a chance to talk about it and to urge other families to talk about it.

Now I want to go back to your work, Dr. Gawande. According to a recent survey from the University of Massachusetts Medical School, 85 percent of respondents believe that patients should discuss end-of-life concerns with their physicians; only 15 percent have actually had the conversation about their own wishes. That is a giant disconnect.

Now, Dr. Gawande, you have identified in this two key problems. First, for many people these are very hard conversations to have, and second, there are tangible barriers in the system that prevent an individual's wishes from being followed, like the lack of widespread reimbursement for providers' time to help patients and their families make these plans, lack of physician training at the end-

of-life and palliative care, and the overall lack of coordinated person-centered care.

I am not the only family member who has had to argue with doctors, with other hospital personnel, about end-of-life treatments, even when I had a fistful of papers that my father had filled out, and, frankly, I am no retiring violet on such things, of fighting for people I love, but the tilt for more care no matter what was palpable.

Let me ask you about this, Dr. Gawande. How is the Massachusetts Coalition for Serious Illness Care, which was organized in part by BlueCross and BlueShield and has a partnership with Ariadne Labs, which you are the executive director for—how are you working to address that part of the disconnect?

Dr. GAWANDE. We have—thank you for asking that, Senator.

We just launched a couple months ago a coalition, a statewide initiative, first to measure the gaps, and the University of Massachusetts survey has been crucial. It showed how few people and where we are, but we are going to make that measure every year and watch and drive those numbers down.

The way that the coalition is working is by bringing payers, health systems, the consumer groups, and others together, groups like the Conversation Project based out of Massachusetts, to foster the consumer conversation, the public conversation, working with the medical schools at the very beginning.

You know, I had no exposure to geriatrics, to palliative care skills, or to what a hospice was. I did not ever walk or set foot in a hospice until I did the research for writing my book, and being able to work with the medical schools, we are the first State where the medical schools are all teaching these as basic skills, and then teaching at the higher levels, all the way up the chain, and getting the commitment of the health systems, and then the payers. We have BlueCross-BlueShield that agreed this year that they would cover hospice without requiring you to give up curative care. It was based on Aetna findings that when they randomized that, that they had 70 percent who chose hospice, that they ended up being able to save money, and that they had much better quality of life for people without harming survival, so we are aiming to see if we can bring all of the payers in the State aboard with doing that, and I agree with Senator Whitehouse and the legislation that aims to do that here at a national level as well.

Senator WARREN. Good. Well, I just want to say thank you because what Massachusetts has begun with the Coalition for Serious Illness Care is potentially transformative here, both in how we deliver health care and how people can have their wishes respected at the ends of our lives.

There are lots of options on the table to advance these goals, including pilot projects for Medicare beneficiaries with advanced illnesses. This is the program proposed—I will quit. I am giving you a plug here, Senator Whitehouse.

Proposed by Senator Whitehouse, better to test ways that we can manage this at the end of life, so I just want to say thank you. Thank you all for your work.

Thank you for your bill, and thank you for holding this hearing. Senator WHITEHOUSE. Thank you, Senator Warren.

Senator Kaine.

Senator KAINE. Thank you, Mr. Chairman.

Thanks to the witnesses.

What a wonderful hearing, and the title. You know, I think we have a system that is really institution-centered, not person-centered, and you can see this replicated in a lot of areas of policy. Juvenile justice. There is a whole lot of areas, you know, where we will put money into institutions, and when you have to get a waiver for somebody to be treated in their home and they do not need a waiver to be treated in the institution, it just tells you we have got the whole thing flipped around. You should not need a waiver to be treated in your home. If we are going to have to have waivers, you should get a waiver to have to go to an institution, but the bias is moneys to institutions, not moneys to persons, and that is why I am so happy to have you here today.

Senator Warren told a moving story about her dad. Now I am fortunate enough that my parents and my wife's parents are still alive, but one of my best friends—I am going to tell the reverse of the story. One of my best friends' father-in-law was slipped very quickly into a position where he was not able to make his health care decisions for himself, and my friend watched his wife and the siblings have the battle about what should be done, and here is a family dynamic that is common to a lot of families. They were not all on the same page, and in fact, one of the siblings had frankly been kind of persona non grata in the family and been estranged from his father and kind of battled with his father over his lifetime, and now with his father not able to make decisions this was his moment in his own odd way—no, I am going to battle for Dad. We need to do everything for Dad—when the other siblings had reached the position: We think we know what Dad would have wanted, and it would not have been to use extraordinary measures, and so in this painful moment of losing their dad, they are also ripping the Band-Aid off this family dynamic of the differences among the siblings that went back, and the father, who is there in this precarious State, is kind of almost just like a suffering innocent and silent bystander to a family dynamic that is exacerbated because of the fact that the family had not come together and reached conclusions before, and so many families go through this, so many families go through this, and you know, the death is hard enough without the dynamic.

I am intrigued by, Doctor, as you discussed the Massachusetts example, and I think we really want best practices, and I am enough of just kind of an incentive thinker that, you know, what about a reimbursement under Medicare or Medicaid or even under Social security for people hitting that age and a joint reimbursement to both the physician and the individual for doing an end-of-life plan?

That plan does not have to be submitted to anybody other than the individual's physician, but if it is done and if a physician says it has been done, then have an incentive in place so that people, you know, will not just shy away from something, "Oh, I do not want to talk about that," but will say, "Hey, there is really a reason to do that." I think that could take that gap between the 85 percent and the 15 percent that Senator Warren was talking and start to

close it, but we really need to learn from you, and I will just open it up and see if you have additional. We really need to learn from you about what are the incentives that would help us close that gap and enable us to get over the hump and have these discussions which, though painful, are certainly necessary and avert all these kinds of later challenges, and I would bet to say if you did an incentive program like that and paid for it and it worked, the financial savings, payment notwithstanding, would be enormous. Anyway, whatever your thoughts, I would appreciate hearing them.

Dr. LALLY. Senator Kaine, you have described a day in my life. That is what I do every day as I work with families and patients, and very often there is exactly what you beautifully described—years and years of infighting in families that really comes to a head at this very emotional moment, and of course, when families are losing a loved one, there is grief. There will be grief, but then on top of it there is that stressor of: What did Dad want?

I find what I often do is I try to, as you again beautifully described, bring the patient back to the center and really try to put aside a lot of the infighting and think not “Could we do X, Y, and Z,” but “Tell me about your father and what his wishes would have been,” and then really reframing some of the language.

As you mentioned, there is always the child from out of State, who comes in and says, you know, I am going to save Dad.

We talk about what everything means to that person, and everything should be consistent with their goal. It shouldn’t necessarily be everything to keep you alive as long as possible because that may not have been his wish, but what is everything that we can do to meet this person’s goal, so that is a very common conversation that I have, and it is also a very common thing I talk with patients about.

When I am saying, we need to come up with a plan, I will say to them: Your family, of course, they will be sad when it is your time, but if you can stop that fighting, if they can hear your voice, of course, they will grieve, but there will not be anger. There will not be stress, and you can take that stress off of them.

I often use that incentive, but clearly, there could be other incentives as well.

Ms. BERMAN. Senator Kaine, it is an excellent question.

I would say that if we had access to palliative care in the community, if there were a consultation with individuals, one of the things that they do, as Dr. Lally is describing, this is part of the process of their care. It is not just about managing pain and symptoms, and care coordination, and addressing spiritual needs. It is a team-based care but also very much is about understanding goals of care and have advance care planning done, but right now palliative care is largely available in hospitals. It is in about 90 percent of large hospitals. We do not really have a payment mechanism to cover palliative care in the community, so the care that I get—I do get palliative care, and I am not in the hospital, which is great—I pay for that, so I get the care that is not available. I seek it out very intentionally, but I am not sure whether or not we need incentives other than some way to be able to incorporate this into the usual part of care, as the Institute of Medicine has recommended in their oncology report and their end-of-life report, as Dr.

Gawande talked about in terms of the research findings on cost and quality, and as Dr. Lally described in her everyday life, and as I stand before you saying, this is exactly what other people should have, but they will not get unless we all do something.

Senator WHITEHOUSE. Senator Donnelly.

Senator DONNELLY. Thank you, Mr. Chairman, and thanks to the entire panel.

Ms. Berman, I just wanted to ask you: You had to make some really tough decisions. You do not know if the decision you are making is going to shorten your life or is going to take away a chance or make a chance better. Tell us a little bit about how you worked through all that, if you would not mind.

Ms. BERMAN. Thank you, Senator Donnelly.

When I first diagnosed, I think I was just shocked. It was not something that I expected to hear because I felt too good. I had a spot on my breast, and that is how we started figuring it out, but I felt great, and I then had to go for a full body scan, and when they did the scan they saw a spot light up on my lower spine, and the only way to figure out whether that was cancer and not wrenching my back—I happen to like surfing in the ocean. I could have wrenched my back, so the only way to find out was to remove a piece of bone from the lower spine, and I agreed to do that because I needed to know was this early or was this late because I thought it would be a very different set of choices, so I did have that piece of bone removed, and it did confirm the cancer, and then I knew I was stage four. I felt great, and I am stage four, so you know, making these kinds of decisions, I think it is important to know that most people know their diagnosis, but they actually do not know where they are in terms of their care. They do not have a good sense of, you know, what people in the medical profession call a prognosis, the likely course of the disease.

There was a piece written in “Health Affairs” that said 60—basically, two-thirds of physicians who were surveyed, their own self-report, two-thirds of them said they either gave a rosier prognosis or lied outright, so they are not telling people, and people cannot be part of that decision without that good information. That is a problem.

Senator DONNELLY. Yes.

Ms. BERMAN. We need to have care planning, which of course, Ranking Member Whitehouse, you know, this is incorporated into your efforts. You know, the notion of doing good care planning is more than just advance care planning.

Senator DONNELLY. Right.

Ms. BERMAN. You know. I am not at the end of life, so it is not just about those decisions at the end. It is about understanding kind of where we are and then what are the options so we know which way to move forward.

Senator DONNELLY. Well, I think you are incredibly brave, and we are really, really proud of you.

Dr. Gawande, I want to ask you about trying to help the medical community make better decisions.

I remember a very, very close relative of mine who was elderly and did not have any kids, so we were trying to help with the decisions that were made, and they lived in another part of the coun-

try, so I went down to try to help, and he had just come out of a colonoscopy surgery, and he was like in his last week of life, and I thought to myself, this is crazy, but nobody had said this is not going to make his last week better, no prognosis showed him with a long-term prognosis, and my relatives were following the course of care that was recommended to them, so they are doing everything they can for him, and I am sitting here looking, going, this makes no sense at all, and I am not a medical professional, but I hope I have a little common sense, and so how do we help the medical community? Everybody surrounding these kinds of decisions, how do we help them to take a breath and just say, "You know what? This may not add up right now?"

Dr. GAWANDE. For me, as a surgeon who made those choices all the time and felt like I was doing badly, I did not know a way out of that box. The family is in front of you, you have got a bad situation, and the only way I understood how to frame it was to say, "Do we do something, or are we just going to 'keep you comfortable?'"

That was about the extent of what I had learned about how to think about it, and what it seemed to me and to the families was: Do we fight, or do we do nothing? If that is the only way you understand the options, then it is not surprising everybody says, well, let's try that colon surgery as a last-ditch effort because you would not do nothing for somebody, would you?

When we have changed it—and this was the paradigm shift for me—to ask: What are we fighting for? What matters to you besides just surviving? What matters to you about why you want to survive? What is it you want to be capable of doing? What would happen?

It ties into what Amy had to say, that when those tough choices came, now I was on the son side. My father, himself a surgeon, had a brain tumor that was in his spinal cord and brain stem, and he had made clear from our conversations that for him priority one was he wanted to keep doing surgery as long as he could, and then when that is not possible that he could be at the family dinner table, having conversations with his family and friends because he is an incredibly social person, and that was the definition of life for him.

Now with his clinician, with his surgeon, radiologist, radiation therapist, oncologist, our goal was what can we do that he can still have his shot at being at the table however long as possible, but do not take away his ability to eat, his ability to be at home, do things that would take that away.

Now they could offer guidance. We had three doctors in my family, and we did not understand the options they were putting in front of us, but they could give us guidance and say, this is the option that you have your best chance to achieve that with, and that divided family is often divided because the unwritten and the undiscussed concept was you understood there was something more than survival to be fighting for. It was what mattered to him about a good life all the way to the very end, and what that looked like, and then asking the clinicians and the family, what do we do to give him that best good life?

It is not either/or. It is not quantity versus quality. When we think about how to have those best possible days, people do not live shorter and often live longer.

Senator DONNELLY. Thank you.

Thank you, Mr. Chairman.

Senator WHITEHOUSE. Thank you very much. This has been a memorable and remarkable panel hearing, and I am immensely grateful to the witnesses for their participation in it.

Committee members have until Friday, July 1st to submit questions for the record.

I know that my question with regard to the no hospice care and curative care together rule, the no nursing home care without a 3-day hospital stay rule, and the no home health care until you are fully homebound rule only got answered by Ms. Berman and Dr. Lally. If I could invite you, Dr. Gawande, to do a response for the record on those questions, that would be, I think, really helpful to us.

This concludes the hearing, with my very grateful thanks to all three of you. You are remarkable.

[Whereupon, at 12:26 p.m., the Committee was adjourned.]

APPENDIX

Prepared Witness Statements

Statement of

Atul Gawande, MD, MPH

Executive Director, Ariadne Labs; Surgeon, Brigham and Women's Hospital;
Professor, Department of Health Policy and Management, Harvard T.H. Chan School of
Public Health; Samuel O. Thier Professor of Surgery, Harvard Medical School; staff
writer for *The New Yorker*; Co-Chair, Massachusetts Coalition for Serious Illness Care

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*

June 23, 2016

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, Rachelle, 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-Term Trends in 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.

**Testimony Before the
Special Commission on Aging
United States Senate**

June 23, 2016

Statement of Kate M. Lally, MD, FACP

Chief of Palliative Care

Care New England Health System

 **Palliative Care**
at Care New England

 **Care New England**

Chairman Collins, Senator Whitehouse, and members of the Senate Special Committee on Aging, my name is Dr. Kate Lally and I am Chief of Palliative Care and Hospice Medical Director for Care New England Health System, Medical Director of the Integra Accountable Care Organization and Assistant Professor of Medicine at Alpert Medical School. I work as a hospice and palliative medicine physician and have the honor of providing care to patients in the last months and years of their lives. I feel blessed to do this work, and to be able to reflect with my patients on the life they have lived, their joys and regrets. I feel I am able to share some of the most sacred moments of their life, and be at their side as they consider what is most important to them in their limited time. It is through this lens that I view the American health care system, and the gaps that our sickest patients often fall through. I would like to share our work at Care New England to provide palliative care both in our hospitals and the community as well as our efforts to educate health care providers in how to provide the highly skilled, complex medical care that our sickest patients need.

Care New England (CNE) Health System is comprised of four hospitals - two community, and two specialty hospitals - a home health and hospice agency, the Visiting Nurses Association of CNE, and a community behavioral health organization in Rhode Island. In 2015, the system partnered with a large independent practice association, Rhode Island Primary Care Physician Corporation, which consists of approximately 150 primary care practices, to create an accountable care organization (ACO), Integra Community Care Network.

Palliative Care at Care New England

Our palliative care program has only been in existence for a few years, but has grown rapidly during that time. In August 2012, Care New England began our palliative care program with a goal of improving the care of patients with advanced illness and helping them manage the symptoms associated with their disease. Like many other programs across the country, palliative care at Care New England started where the need was most acute, inside of one of our community hospitals. We identified that many of our patients were living and dying in ways that were not consistent with their wishes, and that as health care providers, we often had no idea what mattered most to our patients as they approached the end of their life. This often resulted in care that was unwanted, potentially harmful, and expensive.

Care New England is not alone in this - a California study showed that while 70 percent of us say we want to die at home, 70 percent of us will die in a hospital, nursing home or other long-term care facility. Also, while 90 percent of us say it is important to talk about our end-of-life wishes, less than 30 percent of us have talked to our loved ones and less than 10 percent have talked to our doctor.^{1,2}

Care New England looked to the field of palliative care to help provide high quality care that is focused on the patient's goals and encouraged our patients to have a voice in developing a treatment plan that centered on what mattered most to them. Palliative care is defined by the Center to Advance Palliative Care as symptom-focused care for patients with a serious illness. The main goal is to improve the quality of life for both the patient and their family. Palliative care is provided by a team of doctors, nurses, social workers and other specialists and can be

provided at any stage of a serious illness, regardless of prognosis. Palliative care consultations frequently consist of conversations about goals of care and “what matters most” with patients who have a serious illness, as well as helping to manage symptoms of the illness. Our palliative care program was quickly identified by both patients and providers as high value and grew rapidly, prompting us to quickly expand to see inpatient palliative care consults at all four of our hospitals.

Patients seen by palliative care often have multiple concerns that extend beyond their medical problems. One patient we saw early on was Mr. L, a 62-year-old with a new diagnosis of pancreatic cancer. He was aware that his cancer was advanced and decided to try chemotherapy. While his cancer initially responded well to the chemotherapy, further testing showed that the cancer had spread to his bones and spine, creating severe abdominal and back pain. He was admitted to the hospital for pain management, where his oncologist recommended a palliative care consultation. We met with Mr. L and his daughter and talked about what mattered most to him. He said he understood his time was limited, but felt he had a very good quality of life.

Until very recently, he had gone for a walk every day, had large Sunday dinners with his extended family, and helped his wife care for their young grandchildren. The thing that mattered most to him was controlling his pain so he could spend as much time as possible with his family. We discussed that for his quality of life to be acceptable to him, we had to manage his pain more effectively and anticipate and manage other symptoms, such as nausea and anxiety. We worked with his oncologist to start him on pain medications and, after a few days, we had his pain well controlled. In caring for Mr. L, the key to understanding him was understanding what he valued most so we could provide care in alignment with it. That’s what effective palliative care strives to do: understand what matters most to individuals at the end-of-life.

In 2012, about the same time we started our palliative care program, Care New England partnered with the Institute for Healthcare Improvement (IHI) as a Pioneer Sponsor of The Conversation Project and Conversation Ready. The Conversation Project is a nationwide campaign to make sure everyone’s end-of-life wishes are heard and respected.³ It encourages each of us to sit around the dinner table and talk about what matters most to us at the end-of-life. As a health system, if we are going to encourage our patients and families to have these conversations, we needed to be Conversation Ready and able to engage effectively with patients about their wishes when they came to us for care.

As a Pioneer Sponsor, we worked with the IHI and 10 other health systems nationwide to define what it means to be Conversation Ready. Care New England learned that many of our providers were not comfortable talking with patients and families about what matters most to them at the end-of-life, and we needed a way to expand the number of people who had those skills. Given that we had limited availability of palliative care-trained physicians, we developed the role of Conversation Nurse, a nurse who is trained to have end-of-life conversations. Initially, we used these nurses to expand the reach of our inpatient palliative care team and be a resource to physicians seeing their patients in the hospital. We eventually determined that this skill set was needed in both the hospital and the community.

Community-Based Palliative Care

As our palliative care program grew and developed within our hospitals, we were able to help many patients. However, as we cared for patients like Mr. L, we started to identify gaps in the patient-centered care we were hoping to address. Mr. L had his pain managed well in the hospital and had a good conversation about his illness, prognosis and his goals for care. He was discharged to his home with his oncologist and his primary care physician, but unfortunately he did not have access to a palliative care team in the community that was comfortable managing the significant amounts of medications he took, or trained at having conversations about what options were available for when he was at the end-of-life. For patients like Mr. L, there is a gap in community-based palliative care. There are often no providers in the community who are skilled with ongoing conversations around goals of care, or who are comfortable adjusting medications for pain, shortness of breath, or other symptoms associated with the illness.

We realized there was a significant gap in the care of patients with serious illness, not just here in Rhode Island, but on a national level. Hospice, while a wonderful service, is limited to patients with a prognosis of six months or less who choose to forgo aggressive treatments like chemotherapy or radiation. What about patients who have a serious illness, but are not quite at the end of their lives, or who have a significant symptom burden? How can we ensure that these patients can get ongoing palliative care that is consistent with what matters most to them?

To bridge this gap, Care New England expanded palliative care outside the walls of the hospital and developed a community-based program. Our initial goal was to bring the experience of highly skilled palliative care specialists to an outpatient setting. We did this in a number of ways, the first being the introduction of a nurse practitioner home visit program. When a patient like Mr. L was discharged from the hospital, he could have a nurse practitioner come to his home, assess him for symptoms, and work with his oncologist to adjust pain medications and treat other symptoms as they arose. The nurse practitioner was also skilled in talking about disease progression and prognosis and could help a patient like Mr. L and his oncologist determine when he was approaching end-of-life and when hospice might be a reasonable option. Many of our physicians were already convinced of the benefits of palliative care, so they quickly referred to the home-based program and it rapidly expanded. We quickly realized that we still needed more support, as the community need was significant.

As a way to further expand specialist palliative care, in 2015 we integrated palliative care into our newly-formed ACO, Integra Community Care Network. A major focus of an ACO is to achieve the IHI Triple Aim for health care, the simultaneous goal of improving the health of populations, improving the patient experience of care, and reducing the per-capita cost of health care. ACOs are an alternative payment model that focuses on high quality care and allows for interventions to improve care that might not be reimbursed under traditional fee-for service models. We identified that many of our highest need Integra patients would benefit from palliative care and conversations about what matters most to them. We developed a Complex Care Management program of nurse care managers, nurse practitioners, and social workers who operate under physician oversight and collaborate with the primary care providers to provide in-home care for our highest need patients. In addition to this basic team, we brought in specialist expertise in geriatrics, palliative care, and behavioral health.

Our Complex Care Management team would provide home visits to see where the patient lived, meet their family, and assess support structures. Seeing patients at home often allows them to open up about their hopes and fears as their disease progresses. During one home visit, a woman with advanced lung disease told her nurse, “I feel like I am dying but everyone is afraid to tell me.” The nurse felt at a loss for how to respond to the patient. To improve the skill of our Complex Care Management team, palliative care providers and geriatricians offer a series of training sessions on conversation skills and the unique management skills required to take care of patients with an advanced illness. In addition, geriatricians and palliative care specialists meet with health care providers on the Complex Care Management team weekly to review patients and provide opinions on care management.

Finally, this past January, as a way to continue to expand specialist palliative care into our community and particularly into our area skilled nursing facilities and Visiting Nurse Association, a member of the Care New England palliative care team obtained a Practice Change Leader grant from the John A. Hartford Foundation to improve transitions of care for palliative care patients and continue end-of-life conversations into the community.

We realized that while we were starting conversations inside the hospital, they were often not being transmitted when our patients were cared for at a skilled nursing facility or by a visiting nurse. A preliminary review of the readmission rates of patients seen by a palliative care team in one of our community hospitals showed that for our sickest patients, there was a reduction in readmissions compared to similar patients not seen by palliative care. Our initial data was not sophisticated enough to identify what intervention caused the reduction in readmissions; however, we speculated that linking our sickest patients more effectively to community-based resources, particularly hospice and our community-based palliative care programs, made a difference.

The goal of the Hartford Foundation grant was to follow each patient seen by inpatient palliative care for 30 days after discharge to identify what level of care they transitioned to and if they were readmitted to the hospital. We quickly identified that very few of our patients that were sent to hospice were being readmitted to a hospital. This was due in part to the high mortality of patients sent to hospice, but on a larger level, we felt it was due to the intense support patients get on hospice. A patient on hospice knows their prognosis is terminal and they often have a clearly stated goal of being at home. They have access to specialized nurses, who are focused on meeting that goal of staying at home and who can come to their home 24 hours a day to help. We felt this clear goal of care and specialized nursing helped prevent hospital readmissions.

However, when we looked at other discharge dispositions for our palliative care patients, such as a skilled nursing facility or home with therapeutic VNA, they were frequently readmitted. We speculated the reason for the hospital readmission was that goals of care were not clear, nursing staff was not trained in managing palliative care patients, and adequate supports were not in place. These were often patients with a serious illness who were being discharged to a facility of skilled nursing with a goal of “getting stronger.” As could be predicted based on their advanced illness, they did not get stronger, but in fact got weaker. As their illness advanced, instead of having a conversation about their goals and the fact that their illness was progressing, they were often sent back to the hospital.

To improve the care of our palliative care patients who are transitioning out of the hospital, we started a pilot project in local skilled nursing facilities and our health system VNA to continue highly skilled conversations about goals of care and what matters most in the community. When we identify a patient who has been seen in the hospital by our palliative care team, and who is being transitioned to one of the pilot skilled nursing facilities or VNA for therapeutic nursing services, we send one of our Conversation Nurses to continue the palliative care relationship with the patient and their care team in the community. We are using Conversation Nurses to have ongoing conversations and identify when a palliative care nurse practitioner from our home-based palliative care program is needed to assist in symptom management. We hope that by using Conversation Nurses in this manner, we will reduce readmissions, improve communication from the acute to the post-acute setting, and help design ongoing treatment plans that accommodate the patient's serious illness.

Health Care Provider Education

As we have done this work, we realized that there is a need, and desire, on the part of health care providers to understand how to more effectively manage complex patients with serious illness. As we work in the community, we are frequently approached by health care providers asking for resources to better manage patients who could benefit from palliative care. To meet this need, the University of Rhode Island, in collaboration with Care New England, was awarded a Geriatric Workforce Enhancement Program (GWEP) grant from the Health Resources and Services Administration. The objective of this grant is to increase the skills, on a statewide level, of health care providers who care for older adults and to develop training materials for managing older adults with serious illness. As a result of this grant, we are developing a series of didactics for health care providers from such disciplines as physicians, nursing, and social work. We are also sending palliative care and geriatric specialists into primary care offices to discuss difficult cases, evaluate the training needed to improve the care of these patients, and provide targeted education on advance directives, billing for advance care planning conversations, and managing patients with serious illness.

Beyond our work with the GWEP grant, Care New England is an academic institution. We believe the best way to ensure that future patients can get the type of care they need is by training the doctors of tomorrow. As a result, all internal medicine and family practice residents at Care New England spend a month in a geriatrics and palliative care rotation. We also provide a series of didactics, shadowing opportunities, and exercises in our simulation center. In this experience, residents experience difficult conversations around end-of-life and prognostication with actors playing the patient and family. The residents describe this as very realistic and, at times, very stressful. However, it allows them to have difficult conversations in a safe space and debrief after about what went well and what didn't. The residents describe this as an excellent way to prepare them for having these conversations on their own.

Looking to the Future

Our health care system is rapidly changing and there are amazing opportunities to change how we care for our patients while acknowledging the complexities of caring for people with serious illness. Excellent care involves listening to our patients' voices as they review what they understand about their illness and what they hope for the future. It is by listening that we can help understand what they value and help orchestrate medical care consistent with those values. Excellent care involves using a team of providers from different professions and understanding how the strengths of each team member can help provide a better understanding of our patients and what matters most to them.

While we are working to overcome many of the challenges patients face as they struggle with a life-limiting illness, there are some barriers, such as regulatory requirements, that we cannot overcome. I mentioned previously that many of our patients who go to a skilled nursing facility after the hospital are readmitted. One such patient was Mr. S, an 82 year-old patient I recently met with bladder cancer. After beginning chemotherapy, he developed multiple complications from both his cancer and its treatment, including pneumonia and a urinary tract infection, as well as significant pain and nausea. He asked his oncologist for an honest assessment of prognosis, and his oncologist felt he had a couple of months to live at most. Given how weak he was, he needed to go to a skilled nursing facility for 24-hour care and wanted to start hospice there. Unfortunately, Mr. S discovered that Medicare will only pay for his room and board at the skilled nursing facility if he went for rehabilitation; it would not if he went for hospice care.

Mr. S and his physicians knew that by going for rehabilitation, he was likely to be readmitted to the hospital, since he was unlikely to meet his goals and would likely get sicker and weaker. However, it was important to him that he not put a financial burden on his wife, so he made the choice to go for rehabilitation to avoid the room and board fee, and as a result was readmitted to the hospital. He is one of many patients we care for who make similar choices. This choice between financial incentives and the best level of care is a barrier to providing the patient-centered care that we strive for.

To address this and other barriers that patients face at the end of their lives, Senator Whitehouse is introducing a bill called "Removing Barriers to Person-Centered Care Act of 2016". This work was begun as a result of multiple meetings with various stakeholders in the state of Rhode Island, to help improve the care our patients receive.

The population of Americans who are living with advanced illness continues to grow and healthcare needs to adapt. We need ways to both train healthcare providers in the management of these complex patients and identify better ways to pay for this highly complex care.

One current legislative effort to improve palliative care in the community is S.2748/H.R. 3119, named The Palliative Care Hospice Education and Training Act. This legislation would establish education centers and career incentive awards to improve the training of health care professionals in palliative care. In addition to this training, the act would expand research funding for palliative care and pain and symptom management, and require a national education and awareness campaign. These programs would allow doctors to be prepared for difficult conversations and operate more effectively when they arise in the work place.

A second legislative opportunity to expand the idea of community-coordinated care is the Care Planning Act of 2015. The proposed legislation, S.1549, would provide Medicare coverage for advanced illness care coordination services, develop quality metrics for the services, and require education about the availability of these services. Educating patients about these services and providing them on a more common basis would allow patients like Mr. L to receive the care they need, in a high quality manner that satisfies both the patient as well as the care provider.

As we look at a national level toward what can benefit our patients with advanced illness, we need to focus on expanding the number of trained palliative care specialists, improving the skills of all providers in caring for patients with serious illness and finding ways to pay for that care than doesn't force patients to choose between aggressive rehabilitation focused care and comfort care. As our population ages, this will only become more critical.

Thank you for your time and support.

References:

1. National Survey by The Conversation Project 2013
2. Survey of Californians by the California Health Care Foundation 2012
3. TheConversationProject.org.

Testimony to the Senate Special Committee on Aging
 "The Right Care at the Right Time: Ensuring Person-Centered Care for Individuals with
 Serious Illness."
 June 23, 2016
 Amy Berman, BSN, LHD
 Senior Program Officer
 The John A. Hartford Foundation

My name is Amy Berman and I am terminally ill. I was diagnosed five and a half years ago with stage IV inflammatory breast cancer, a rare form of cancer that has the worst prognosis. My cancer is not a lump that can be found on a monthly self-exam. By the time a red spot appeared on my breast it had already spread to my lower spine. It is incurable cancer.

Roughly 90% of people diagnosed with breast cancer survive five or more years, unfortunately the likely course of the disease according to the National Cancer Institute, is an 11-20% chance of survival to five years. This means it is highly unlikely that I would survive five years.

Yet I sit before you five and a half years following the diagnosis. I feel like I look great. I work full time. I travel and enjoy my family and friends. I haven't been hospitalized once. I am a walking triple aim of better health, better care, and I have saved more than a million dollars to date. But the care that I receive is the exception.

At the beginning, I went to see two very different oncologists. One oncologist wanted to throw everything at the cancer. He heroically suggested the most intense chemotherapy, followed by a mastectomy, many courses of radiation, then more intense chemotherapy. He admitted that it would not cure the disease but said, "This is what I do for all my patients." He never asked me a single question about what I was hoping for. He never discussed the futility of his approach or other treatment options. He wanted to do a "Hail Mary" pass on my body. He wasn't going to live with the consequences of the care. I was.

I went to another oncologist who talked to me about my diagnosis, the likely course of the disease, and treatment options. She shared openly what she knew and asked me what I hoped for. I told her that I wanted the Niagara Falls trajectory. I wanted to feel good and then drop off the cliff. I told her that I wanted to maximize my good days and not aggressively push for more bad days. She said I could opt for treatment (medication) that had the least amount of side effects which could help to hold back the cancer and allow me to continue to feel well. My doctor said I didn't need to have a mastectomy because the cancer was already floating throughout my body. The mastectomy wouldn't get rid of the cancer. It would work against my goal of holding onto the life that I have. The surgery would be debilitating, make me miss work, cause pain and possibly swelling of the arm. This is everything I told her I wanted to avoid.

My mother was with me as I went on these visits. She participated in the conversations with me and my care team. She fully understands and supports my choices. She is my health care proxy and I am hers. I completed my proxy with a social worker at my medical center just after diagnosis.

But perhaps the most important aspect of my care, reason that I am doing so well despite being seriously ill, is palliative care. Palliative care is the best friend of the seriously ill. It is an extra layer of support that goes along with the care provided by my oncologist. Studies have shown that when palliative care is added at the beginning of a serious illness that people feel better and live longer (<http://www.nejm.org/doi/pdf/10.1056/NEJMoa1000678>). My palliative care provider has helped me determine what care to opt for and addressed my pain and symptoms. The team-based care also addresses the needs of the family, care coordination, and even spiritual needs.

I am terminally ill. But I also have a professional role as senior program officer at The John A. Hartford Foundation in NYC (www.jhartfound.org) where I lead efforts to develop, test and spread of evidence-based models of care that improve the care of older adults. The majority of those with serious illness are older adults.

The John A. Hartford Foundation is a national health care foundation focused on improving the care of older adults. The Foundation was founded in 1929 by John A. Hartford. He was the son of the founder, and a former CEO, of the Great Atlantic and Pacific Tea Company, later known as the A&P grocery store chain. We have funded efforts to improve the care of older adults since 1982 and have invested roughly half a billion dollars in the development, testing and spread of models of care and training of the health care workforce.

We are longtime funders of palliative care supporting the Center to Advance Palliative Care, the leading national resource for the field of Palliative Care, for more than a decade. We also fund the leading efforts in care, training and public engagement. These efforts include Atul Gawande and Susan Block's Serious Illness model, Respecting Choices, Home-Based Primary Care (Independence at Home), National POLST (Physician Orders for Life Sustaining Treatment), Vital Talk, The Conversation Project, and the Coalition to Transform Advanced Care also known as C-TAC.

I am here to speak about the importance of care planning, the workforce, models of care including community-based palliative care.

Care planning is key to providing the right care and avoiding the wrong care for the seriously ill person. It is more than just advance care planning and the end of life. Care plans include goals of care conversations over time and specifically before critical choices about treatment need to be made. The seriously ill very often aren't told their prognosis. You can only make reasonable decisions and plan for the future when you know how ill you are and the likely course of the disease. A survey of 2000 physicians

published in Health Affairs (<http://content.healthaffairs.org/content/31/2/383.full>) found that a startling two-thirds of the physicians reported that they either gave a rosier prognosis or were not truthful with their patients. Similarly, less than 50% of people living with Alzheimer's Disease or their family caregivers are informed of the diagnosis (<http://www.usnews.com/news/articles/2015/03/24/most-alzheimers-patients-not-told-about-their-diagnosis>). Understanding where you are in terms of your overall health is one of the key components to a person's participation in decisions about one's care. It astounds me that we have more protections around full disclosure when buy a home than when we are treated for serious illness.

Our workforce needs experts to support the care of the seriously ill and competence in others that care for this population. We do not have a sufficient number of palliative care physicians and nurse practitioners to care for the seriously ill demographic. Did you know that we pay for graduate medical education slots for cardiologists, neurologists, even plastic surgeons, but not one slot for palliative care? We have a rapidly aging society with an older demographic that is doubling. Yet we have not dedicated a single slot to train our palliative care workforce, a workforce that decreases unnecessary high cost care such as hospitalization and nursing home placement, and improves the quality of life for seriously ill.

There are a number of models that address the complex needs of people battling serious illness and approaching the end of life. The John A. Hartford Foundation investigated these care models for years before determining what efforts showed the greatest efficacy and evidence. I mentioned Dr. Gawande's Serious Illness work, Respecting Choices (advance care planning), Independence at Home (comprehensive primary and palliative care of the homebound) and others. The most important thing you could do is to create a mechanism to cover community-based palliative care. This proactive care is the kind of high value care we all desire. Yet palliative care remains largely only available in the hospital, an essential part of good inpatient care. It is care you need when everything goes wrong. But we need a proactive approach to care that avoids unnecessarily high cost care that people want to avoid.

I am reminded of the charge of the Campaign to End Unwanted Medical Treatment (<http://endumt.org/>), a coalition of 19 national organizations such as the Gerontological Society of America, the society for people doing research in the field of Aging. They summed it up for me with their mission. "Patients, families and their advocates deserve and demand all the information necessary to make informed choices about their treatment preferences and expect that healthcare professionals and institutions honor their wishes."

My one request is that, should you pass legislation to further these aims and improve the care of the seriously ill, I would like to be there at the signing of that legislation. I ask that you move quickly and make this happen in my lifetime.

Statements for the Record

The New York Times

<http://nyti.ms/1n6EHLS>

SundayReview | OPINION

The Best Possible Day

By ATUL GAWANDE OCT. 5, 2014

A COUPLE of years ago, I got a call from the husband of Peg Bachelder, my daughter Hunter's piano teacher. "Peg's in the hospital," Martin said.

She'd been treated in 2010 for a rare pelvic cancer requiring chemotherapy, radiation and radical surgery.

She returned to teaching and refilled her student roster in no time. She was in her early 60s, tall, with a lovely, gentle way that made her immensely popular. Two years later, however, she developed a leukemia-like malignancy caused by her treatment. She went back on chemotherapy but somehow kept teaching. Then for two straight weeks, Peg postponed Hunter's lessons. That was when I got Martin's call from the hospital.

He put his cell on speaker for Peg. She sounded weak and spoke in long pauses. She said the leukemia treatment was not working. It had impaired her immune system, however, making her sick with fevers and an infection. Imaging also showed that her original cancer had come back in her hip and liver. The recurrent disease caused immobilizing hip pain and made her incontinent. That was when she checked into the hospital. She didn't know

<http://www.nytimes.com/2014/10/05/opinion/sunday/the-best-possible-day.html>

what to do.

What had the doctors said they could do? I asked.

“Not much,” she said. She sounded utterly hopeless. They were giving her blood transfusions, pain medications and steroids for the fevers caused by her tumor. They’d stopped giving her chemotherapy.

This is the moment we continue to debate in our country. What is it we think should happen now? Her condition was incurable by established means. So should she press the doctors for other treatments, experimental therapies, anything with even a remote chance of keeping her going, no matter what? Or should she “give up”?

Neither seemed right. But for more than a decade in medical practice, I had not really understood what other choices might exist. I wasn’t effective in these situations. And it bothered me — as a surgeon caring for patients with problems I often could not fix and then as a son with a father in his 70s experiencing mounting difficulties in his life. So for three years, I researched a book on what has gone wrong with the way we manage mortality and how we could do better.

I spoke with more than 200 people about their experiences with aging or serious illness, or dealing with a family member’s — many of them my own patients, some in my own family. I interviewed and shadowed front-line staff members in old age homes, palliative-care specialists, hospice workers, geriatricians, nursing home reformers, pioneers, and contrarians. And among the many things I learned, here are the two most fundamental.

First, in medicine and society, we have failed to recognize that people have priorities that they need us to serve besides just living longer. Second, the best way to learn those priorities is to ask about them. Hence the wide expert agreement that payment systems should enable health professionals to take sufficient time to have such discussions and tune care accordingly.

I also discovered that the discussions most successful clinicians had with patients involved just a few important questions that often unlocked transformative possibilities: (1) What is their understanding of their health or condition? (2) What are their goals if their health worsens? (3) What are their fears? and (4) What are the trade-offs they are willing to make and not willing to make? These discussions must be repeated over time, because people's answers change. But people can and should insist that others know and respect their priorities.

Not everyone will feel ready to discuss such subjects, to be sure. But I decided to try the questions with Peg. I asked her what her understanding of her condition was. She said flat out that she knew she was going to die. There's nothing more they can do, she said, an edge of anger in her voice.

I asked what her goals were. She didn't have any that she could see were possible. Then I asked what her fears for the future were, and she named a litany: facing more pain, suffering the humiliation of losing more of her bodily control, being unable to leave the hospital. She choked up as she spoke. She'd been there for days just getting worse, and she feared she didn't have many more. They'd talked to her about stopping life-prolonging therapy and going on hospice, but she didn't see how that could help her.

Someone in her position who was offered "death with dignity" — assisted death — might have taken it as the only chance for control in the absence of other options. But hearing her fears, I suggested that Peg try hospice. It'd at least let her get home, I said, and might help her more than she knew. Hospice's aim, at least in theory, I explained, is to give people their best possible day, however they might define it under the circumstances. It seemed as if it had been a while since she'd had a good day.

"Yes, it has — a long while," she said.

That seemed worth hoping for, I said. Just one good day.

With her husband's encouragement, she went home on hospice less than 48 hours later. We broke the news to Hunter, then just 13 years old, that Peg could not teach her anymore, that she was dying. Hunter was struck low. She asked if she could see Peg one more time. We didn't think so, we said.

A few days later, however, we got a surprising call from Peg. She wanted to resume teaching. She'd understand if Hunter didn't want to come. She didn't know how many more lessons she could manage, but she wanted to try.

That hospice could make teaching possible for her again was more than I'd imagined. But when her hospice nurse arrived, she asked Peg what she cared most about in her life, what having the best day possible meant to her. Then they worked together to make it happen.

Her first goal was just managing her daily difficulties. The hospice team put a hospital bed on the first floor so she wouldn't have to navigate the stairs, organized a plan for bathing and dressing, adjusted her pain medications until they were right. Her anxieties plummeted as the challenges came under control. She raised her sights.

"She was focused on the main chance," Martin later said. "She came to a clear view of how she wanted to live the rest of her days. She was going to be home, and she was going to teach."

It took planning and great expertise to make each lesson possible. The nurse helped her learn how to calibrate her medications. "Before she would teach, she would take some additional morphine. The trick was to give her enough to be comfortable to teach and not so much that she would be groggy," Martin recalled.

Nonetheless, he said, "She was more alive running up to a lesson and for the days after." She'd had no children; her students filled that place for her. And she still had some things she wanted them to know before she went. "It was important to her to be able to say her goodbyes to her dear friends, to give

her parting advice to her students.”

Medicine has forgotten how vital such matters are to people as they approach life’s end. People want to share memories, pass on wisdoms and keepsakes, connect with loved ones, and to make some last contributions to the world. These moments are among life’s most important, for both the dying and those left behind. And the way we in medicine deny people these moments, out of obtuseness and neglect, should be cause for our unending shame.

Peg, however, got to fulfill her final role. She lived six weeks after going on hospice. Hunter had lessons for four of those weeks, and two final concerts were played. One featured Peg’s current students, all younger children; the other, her former students from around the country. Gathered in her living room, they played Brahms, Chopin and Beethoven for their adored teacher. A week later, she fell into delirium and, a short time after that, died peacefully in her bed.

My final remembrance of Peg is from the end of her last recital with the children. She’d taken each student away from the crowd to give a personal gift and say a few words. When it was Hunter’s turn, Peg gave her a book of music. Then she put her arm around her.

“You’re special,” she whispered to her. It was something she never wanted her students to forget.

A surgeon at Brigham and Women’s Hospital, a professor at Harvard, and a staff writer for The New Yorker. His newest book is “Being Mortal: Medicine and What Matters in the End,” from which this essay is adapted.

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Living Life In My Own Way—And Dying That Way As Well

A health foundation executive receives a diagnosis of terminal breast cancer and, with the help of a doctor who respects her goals, forgoes aggressive treatment in favor of palliative care.

BY AMY BERMAN

The day I found out that I was terminally ill, it was misty, just barely raining, appropriately gray and damp. It was November 2010; I was fifty-one years old. My life was normal—wonderful, in fact.

My mother and I, both in our raincoats, both carrying umbrellas, were walking down a city sidewalk miles from home when my cell phone rang. It was my oncologist calling to give me test results; she knew I'd want them before

a medical appointment the next day. She told me gently. I hung up.

"It's stage IV," I told my mother. "The bone biopsy showed that the cancer has spread. It's in my lower spine." I paused. "This is the worst case—it's bad." The diagnosis seemed to drop from the sky, rain clouds turned to lead, crashing down on us. We hugged, crying, rain and salty tears mixing. My tiny mother. Her tall daughter. One wet, raincoated shape as we held one another, our umbrellas forgotten.

"Take three deep breaths," I finally managed to say to her. We tried. But as we inhaled, suddenly both of us began laughing, uncontrolled belly laughs, despite—and in defiance of—the damp death sentence that had just fallen from the sky.

That was eighteen months ago. Now, in April 2012, the medical countdown toward the end of my life continues. And I've done a lot thinking about how best to live the limited time I have left.

From Feeling Fine To Cancer

Earlier, even as I was being diagnosed, I felt fine. I looked the same, too—with one exception: A small, red, rough-textured spot (not a lump) about the size of a pea had appeared on my right breast. I was educated as a registered nurse and led quality improvement efforts as a health care administrator, and now I am at a foundation focused on improving the health of our nation's older adults. But even without that background, I'd have known something was wrong. Anyone would.

My primary care physician quickly arranged for me to have scans and a biopsy at a local hospital. Both of us were aware that the red spot might be cancerous.

The night before my hospital appointment, I was wide awake, reading. Today, breast cancer, in general, has a five-year survival rate nearing 90 percent. But inflammatory breast cancer, which I suspected the spot might be, is different. It's an especially aggressive form of breast cancer where the breast itself eventually can become red and swollen ("inflamed"), and even develop a diseased open wound. But most frightening is that it tends to spread to other parts of the body. Of those who are diagnosed with inflammatory breast cancer, at which point it's usually stage III or IV cancer, only 40 percent live five more years.

By midnight, my research had revealed that despite all the funding going toward curing breast cancer, what seemed to me an insignificant amount

Illustration By Brett Ryder

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goes toward finding a cure for inflammatory breast cancer. By 2 a.m., I knew who was involved in inflammatory breast cancer research, what kinds of clinical trials were happening, and where. The next morning, before most people had sipped their first cup of coffee, I was in the hospital, watching as a radiologist extracted "core samples" of my breast tissue. In a clear, informational way, she explained what she was doing and what she was seeing. She noted eventually that the samples appeared to be malignant. I appreciated her honesty.

When the biopsy results were back, I met with an oncologist in New York City, where I work. She had been recommended by a leading geriatric oncologist I knew through my foundation activities. After she gave me a physical exam, we sat quietly in her office lined with its reassuring books and diplomas. She looked me in the eye and in a soft voice told me the diagnosis: inflammatory breast cancer.

I didn't flinch. Hearing it said out loud was almost anticlimactic. I'd thought so. And the radiologist who'd taken the biopsy had gently helped prepare me for the news.

I told the oncologist that I knew inflammatory breast cancer was incurable, and that there was no cure in the offing. She confirmed what I'd read about the survival odds. My oncologist told me she didn't like the word "terminal," but I knew that's what she meant. I might have far less than five years to live. "Not...five...years." How simple it sounded. How final.

She asked me how I wanted to move forward and what my goals were. My thoughts drifted to my grandmother, who'd had Alzheimer's disease. I remembered how she disappeared into the illness, frail, sad, and frightened. "I want to feel good for as long as possible," I told the oncologist. "Don't push to extend my time if I'm not able to have that." She nodded and put her hand on mine.

"Here are my suggestions, then," she said. "I'll arrange a body scan to see if the cancer has spread." If the disease was still confined to the breast, she said, "I think we should be aggressive. That could give you a better chance at a longer, better life. But, if the cancer



has spread far beyond the breast, we can talk about less aggressive approaches that could slow the cancer but have fewer side effects for you."

The body scan showed a "hot" spot in my lower back, an area that the injected irradiated glucose had been drawn to. It could mean cancer, or something as benign as a minor back injury that was healing. The only way to know was to remove a small piece of bone from the spine—so I underwent the surgical procedure. When I awoke, my back felt bruised. I had to sit down quite carefully for the next week.

A Newer Treatment?

It can take years before scientific breakthroughs and innovations become common medical practice. Although no cures were on the horizon for my disease, I figured some newer ways to treat this kind of cancer might exist.

I'd come across information about an oncologist, a specialist in inflammatory breast cancer, at a respected cancer center in a nearby state. Might he be able to help me? My New York oncologist assured me that if the specialist could suggest a treatment, she'd work with him on my care. She sent me off to an appointment with him, and she gave me her blessings and slides of my cancer cells packed in a Styrofoam box.

It was that rainy afternoon when I was walking with my mother when my cell phone rang, with my oncologist explaining that the breast cancer had spread to

my spine. It meant that I'd be telling the specialist the next day that I had the worst possible diagnosis.

That day came, and as we walked into the lobby of the top-notch cancer center, we saw that contemporary art graced the airy space. The aroma of freshly brewed coffee from a café mingled with the scent of flowering bouquets. An attentive nurse directed me into the office of the preeminent inflammatory breast cancer expert.

He wore a tepid smile and a dark moustache, and he greeted me with little fanfare. His eyes eagerly focused on the slides prepared by my oncologist in New York City. After a perfunctory hello, review of papers, and a brief physical exam, he outlined his recommendations. He advised intensive chemotherapy, radiation, and a mastectomy, followed by more chemotherapy.

Why? I knew there was no cure for stage IV inflammatory breast cancer.

"This is not a cure," he told me. "But if you respond to the treatment, you might live a little longer—although there are no guarantees. All of my patients use this protocol."

I asked why he wanted to remove my breast when the cancer had already spread to my spine. "You don't want to see the cancer. Do you?" he answered, looking annoyed.

I was stunned—then angry.

The specialist never asked me what I wanted. He didn't mention my needs or treatment goals. He didn't know—or seem to care—that my hope was to extend my quality time on this planet rather than merely linger. He didn't care about the toll of the treatments on my body and my remaining days.

Were I to choose his one-size-fits-all approach, I'd strip myself of the very type of life I'm pleased to have now, probably without gaining any benefit. If I'd detected even a whiff of caring about me as a person or as a patient, I'd have explained, "No, that's totally wrong for me. I want to work, enjoy family and friends, do things that are important to me—while feeling good—for as long as possible. Once I can't, I'm not interested in aggressively extending the length of my life." But it didn't seem worth it with a doctor who used the same protocol with every patient.

My mother and I left quickly.

Patient-Centered And Palliative Care

Thank goodness my oncologist wasn't like that specialist. Instead of ignoring my wishes and goals, my doctor was embracing them and keeping me as informed as possible. She'd discussed the diagnosis, prognosis, and possible treatments, and she'd asked me about how I wanted to proceed. Together, the two of us chose a treatment regimen that would slow tumor growth, while protecting what was precious to me: my quality of life.

Too many other patients have doctors like that specialist. A cancer-survivor friend told me that her oncologist once said, "I wish I could just treat the cancer; patients get in the way." Another friend, with stage IV cancer, was advised by her oncologist to skip a three-hour car ride to visit her new granddaughter because she'd miss a chemo appointment—one that would do nothing to change the fatal nature of her advanced disease.

Why do these and so many other doctors miss that patients have their own needs and desires? William Osler, who's been called the founder of modern medicine, understood. As he put it, "The good physician treats the disease. The great physician treats the patient who has the disease."

I realize that doctors want to cure, to save lives, to instill hope. Perhaps that also makes it difficult for them to tell patients they're dying. Maybe, hoping that each terminally ill patient will be that one-in-a-million miracle outlier who lives, doctors temper their words. "Terminal" becomes "advanced illness." The words "we're going to treat this aggressively" are uttered even though *treatment* isn't *cure*. Patients like the sound of "treat aggressively." It seems as if doctors are fighting for us, but few truly understand what the phrase means. Because of my nursing background, I know all too well.

Is there a downside to aggressive treatment? You bet. In the case of incurable cancer, it can mean rounds of radiation or chemotherapy, or both, with side effects of crushing fatigue, overwhelming nausea, burned and peeling skin, permanent pain or numbness of fingers and toes, and the cognitive impairment known commonly as "chemo brain." The "treat aggressively" approach can leave

It's outrageous that we're more likely to receive full disclosure when buying a house than when seeking medical care.

patients bruised and battered, wishing they were dead.

Yes, perhaps, a few months of added life come with it—but at what cost? Furthermore, recent evidence suggests that people with certain cancers might actually live longer—and better—using a palliative approach, such as the one I'm taking.

For many patients, especially in the United States, "palliative" is, alas, a vague term, a word and medical approach they've heard of but don't understand. If patients knew what it entailed, I bet many more would opt for it—precisely as I did.

To be clear: It's *not* hospice care, although palliative care and hospice care often occur in tandem. Rather, the focus of a palliative approach is to prevent patients from suffering. If, in the course of an illness, suffering and pain become inevitable, then a palliative approach provides relief. It can be used at the same time as cures are being put in place—going hand-in-hand, for instance, to relieve side effects, such as nausea. It can be used with chronic conditions, such as back pain.

A palliative approach often is medically multidisciplinary, focusing on pain, symptoms, the needs of the family, and the ability to function at all ages and all stages of life. Palliative care can also provide comfort and symptom management at the end of life, which is why it's frequently used even during hospice. It's about providing the best possible quality of life, whether that means offering a cure; minimizing the burden of a chronic disease; or, as in my situation, focusing on maximizing comfort.

In my case, because my progressing illness is incurable, I've chosen a solely palliative approach. Instead of waging war with a disease that can't be cured, my doctors and I are focusing on treatment that optimizes how I function and addresses my symptoms, including com-

fort care for pain symptoms, for when I'll need it.

I've been fortunate so far, in that my pain isn't bad. I get twinges in my right breast. If at some point it is overtaken by disease, I'll probably have it surgically removed as a comfort measure. I also have a dull ache in my lower spine that I notice primarily if I stand too long or carry a heavy bag. As more serious problems arise, my doctors and I—eventually with the help of a palliative care physician—will address them.

But our nation's health care delivery system still defaults to aggressive treatment for all illnesses. If patients knew the true benefits—and true drawbacks—would that be their choice? Or would they go the palliative route instead?

Recent studies suggest that fully informed patients nearing the end of their lives are less likely to choose aggressive care when they understand what they can realistically expect. They also are less anxious, and they rarely end up in intensive care units or on ventilators.

The "triple aim" of American health care, according to Don Berwick and colleagues, should be better health, better care, and lower costs. Palliative care for inflammatory breast cancer? Check. Check. Check.

It's outrageous that we're more likely to receive full disclosure when buying a house than when seeking medical care. An overhaul of consumer protection in health care is long overdue.

Creating A Better Way

There are things we can do today that would be game changing for patients, providers, and payers in this country. And for people like me, who are struggling with a serious illness, these would just plain be the right things to do.

Providing information about the benefits of a palliative approach to medical care is high on this to-do list. It's a kinder, gentler approach to care that many people don't know exists but would surely embrace if they knew about it and it were made available to them.

I'm still on the young side, but for older Americans, who are the focus of my professional life, gaining this kind of knowledge goes hand-in-glove with requiring conversations about goals of care during the annual Medicare

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checkup. In fact, palliative care should be available across the life span; should be part of discussions with patients who need help with symptoms and pain; and, if patients aren't yet enrolled in Medicare, should be covered by private insurance.

Some people have voiced concern that creating a Medicare benefit that paid physicians or other primary care providers to have end-of-life discussions with their patients might somehow lead down a slippery path to government control over health care decisions and "care rationing." That makes absolutely no sense. Such conversations are essential. Without them, patients have no control over crucial decisions that deeply affect their lives.

What patients really need to be wary of are rationed information and rationed decisions, meaning any attempt for their quality of life to be decided—rationed—by someone else. Whenever doctors fail to ask what patients and families think, what it is they want, that's actually what's happening.

I want every patient facing end-of-life decisions—which, when you think about it, eventually will be all of us—to have access to the kind of open communication I'm receiving. Each patient deserves to understand the diagnosis, the probable course of his or her disease, and the likely timetable. Each deserves to be asked about personal goals. Each deserves to be an informed participant and help decide about treatment options. Otherwise, it means that somebody else decides how we live and how we die. Doctor-patient conversations of this sort are a fundamental right and a basic element of good care.

Furthermore, it's not enough to simply say these conversations should happen. Money talks—and talk costs money. Doctor-patient conversations during annual Medicare checkups must be reimbursed, and preferences should

It's the ultimate win-win to allow patients some control about how their lives will end, just as patients are able to choose how they live them.

be carefully documented in a way that can be shared with other members of the health care team.

As the federal government enhances so-called meaningful-use guidelines for electronic health records, these systems should be required to include patients' goals, because it doesn't get more "meaningful" than these. One-quarter of all Medicare spending occurs during the final year of people's lives. If even a small percentage of patients at the end of life rightfully and knowingly opted for a less-is-more approach—as I am—it would more than offset the modest Medicare reimbursement costs for conversation time.

Additionally, we as a nation need to understand and use the Medicare hospice benefit more fully—not just in the last week, or month, of a patient's life. The benefit was designed to help patients and their loved ones get the support they need in the final months of life, eventually shifting the priority from the person's treatment to the person's comfort.

Families often say they wish they'd known about the services earlier. Much more information should be made available to patients and their families about the high-quality, low-cost care provided by hospice so that people know about it well before the final weeks. We can improve quality and lower costs by initiating hospice care earlier. And I sincerely hope that a demonstration project mandated by the Affordable Care Act—one

that allows patients in certain hospices to receive disease treatment while in hospice—becomes the norm for the land.

Some patients don't want to take part in their own end-of-life decisions, or any medical decisions, for that matter. Some want to be sure aggressive means are used until the end. That is their right—their decision.

Others, like me, want to be fully involved, to have detailed conversations. That's my right, and I think many patients would want it too, if given the option. No matter the decisions that are made, we need to have a health care process that supports patients' rights in the way in which they want to be supported. We also need a process that helps doctors, in the midst of their dedication to extending our lives, to learn that the length of patients' lives isn't the sole consideration. It's the ultimate win-win to allow patients some control about how their lives will end, just as patients are able to choose how they live them.

As you read this piece, I'm getting close to two years into a terminal diagnosis. I have the most deadly form of breast cancer, and it will eventually kill me. So far the disease seems to be held at bay by one small yellow pill each night, some extra vitamins and minerals, and a monthly infusion to stave off problems like spontaneous fractures because of the cancer eating at my spine. No treatment will work forever, though. I know that. But however my story evolves—then ends—I'm at peace. And I'm living just the way I want to. ■

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